



Department
of Health

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



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

March 2015



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Foreword – Norman Lamb MP

We have been working together over the last two and a half years to improve the lives of people with mental health needs, learning disability and autism and realise the vision of everyone being treated with dignity and respect by health and care services and enjoying the same rights as anyone else.

A lot has been done: the Autism Strategy has been reviewed and refreshed, NHS England have ensured that more than 1300 care and treatment reviews of adults and children with learning disability or autism in inpatient settings have been carried out, a large number of groups, professional bodies, charities and agencies have produced a comprehensive suite of excellent guidance on the Mental Health Act, on commissioning, on reducing the use of restrictive interventions, on professional ethics, on advocacy, on quality of life and much more. The Care Quality Commission has transformed the way it inspects mental health and learning disability services and corporate accountability has been strengthened. The Children and Families Act and the Care Act also set an important new legal framework of support from an early age right into adulthood. We are well on the way to making step changes in the data available.

But, despite all of this, the scale or pace of change for individuals that we all wanted to see has not yet happened. In fact, in terms of admissions into inpatient units and length of stay, it appears to be business as usual. I have met many families whose stories powerfully illustrate the need for change, who have shown me how damaging it can be for people when hospitals are misused and become people's homes. While recognising the complexities, I have been disappointed that some commissioners have failed to grasp and act on the urgency of putting in place suitable community provision. We have to go further. We want to consider how we can make sure that the rights, incentives, responsibilities and duties in the system ensure that change is delivered everywhere and no-one can fall through the gaps any longer.

Above all, we want to see four things:

People in charge, supported by family and friends – not as passive patients or “prisoners” of a system, as they so often feel they are. The principle of expertise by lived experience should be absolutely core to the design of the system. People should be able to take charge of decisions about their care with personal budgets. Services must listen to the people they are there to serve. All people have a right to be in control of their own lives as far as possible.

Inclusion and independence in the community – people should not routinely be sent away from their homes and communities or to institutions which restrict access to their community or to inappropriate care. The ability to choose to live as independently as possible with support and to have access to community, to family and to opportunities like anyone else

should be embedded in the design and practice of the system. Real inclusion is an essential not an optional extra – and it should start in childhood. Patterns for exclusion can be set very early.

The right care in the right place –there should be real person centred planning with the individual themselves at the heart. The system should be designed so that the incentives, processes and rules help people received the right care for them. This means the least restrictive setting possible, including real options for treatment at home and in the community. This includes not using police cells or secure care inappropriately. Early intervention should be routine. In particular, some of the issues that people with learning disability or autism may face can become apparent very early in a child's life – sometimes as young as 18 months old. We want these children to be identified and offered support as early and effectively as possible so that no child or young adult ends up in long term inpatient or residential care because services didn't know how best to work with them. The need for crisis response should be seen as a warning about the local system's effectiveness at prevention.

Very clear accountability and responsibility throughout the system – there can be no excuses for a lack of clarity over responsibility or for people falling through the gaps between services. Integration and joint working between services are vital to giving people what they need. But this needs to go hand in hand with clear accountability – and an end to passing the buck.

This paper sets out a series of proposals on how changes might be made. We hope that this will mark a step change – and help to secure the rights for **everyone** that they deserve. We also hope that this strengthens further the drive for parity of esteem for all those with mental health needs.

Hidden impairments like autism, learning disability and mental ill health can be harder to see, and therefore easier to ignore. But, as a civilised society we simply cannot continue to ignore or tolerate people getting the wrong care or treatment any more than we would for people with heart disease or cancer.

We look forward to hearing your views.

The Rt Hon Norman Lamb MP
Minister of State for Care and Support



Foreword – Gavin Harding, MBE

As someone who has been in Assessment and Treatment Units (ATUs) as a patient – and I have experienced a few – this paper is very close to my heart. It should have been done a long time ago for people with learning disabilities. Right from the start of the *Transforming Care* programme, set up after the review into the horrific events of Winterbourne View hospital, I have been highlighting issues that are now in this paper and very much on the agenda of the Transforming Care Programme, for example restricted (Ministry of Justice) patients. But this isn't just about Winterbourne View. We must not forget the scandals and abuse cases before or since.

I hope to see this paper changing a lot of things for people with learning disabilities, mental health needs or autism about some of England's worst care.

I think it has not mattered who the Government was, this has been going on for far too long across several Governments: people not having any choice in how they are treated or supported or where they live, people being moved out of their local area to miles away, people being locked away from their families in hospital units, people, in a small minority of places, being abused by staff.

But I have seen good ATUs, including in my own area. These are often small mental health units. They are community led and meet the needs of people with learning disabilities and have good practices in place. I believe smaller units, and supporting more people in the community, as they do in places like Salford, should be possible everywhere. Larger units should be reducing or closing. I know there are some great learning disability and mental health nurses and other staff who are working at the moment in inpatient units but who could easily transfer their skills into the community to make this model happen right across the country.

We should also not forget that there are also children and young people in inpatient units too. We have to change the system for everyone from 0 to 100 years old.

Whoever is in Government needs to look at the recommendations of Sir Stephen Bubb in his report *Winterbourne View – Time for Change* and the responses from people to this consultation and use them to change how we commission services and support people in the future. We closed NHS campuses and long stay hospitals. But we now have some very large ATUs. We must not make the same mistakes again. Equally, we must not find we end up with very large organisations as providers in the community which are not responsive to individuals. Local commissioners need to start helping to make sure there are many, high quality, responsive local community providers not big institutions.

We should not allow scandals like Winterbourne View to be repeated. I, and everyone else with learning disability hope to see this end and to start to see everyone with a learning disability or autism or with mental health needs being treated with respect and dignity equal to any other human being. We have the same rights as anyone else. After all, we are not just a label. We are not someone you can treat differently. We are human beings. We have an entitlement to a life just like you. Make the lives of all people with disabilities a good life without barriers. Take this opportunity to improve our lives – whoever is in Government. Let's not continue to repeat history and make the same mistakes.

Gavin Harding, MBE
Co-Chair of the Transforming Care Assurance Board



About this consultation

This consultation seeks to explore views on a range of proposals. They are intended to strengthen or build upon existing policies, including some of those set out in:

- Valuing People, Department of Health (2001)
- Valuing People Now, Department of Health (2009)
- Fulfilling Potential, Department of Work and Pensions (2011)
- Government Response to Raising our Sights: services for adults with profound intellectual and multiple disabilities – A report by Professor Jim Mansell (2011)
- Caring for Our Future, Department of Health (2012)
- Transforming Care, the Department of Health Review into Winterbourne View Hospital, Department of Health (2012)
- Think Autism, HM Government (2014)
- Review of the Operation of Sections 135 and 136 of the Mental Health Act 1983 Report and Recommendations, Department of Health and the Home Office (2014)
- Transforming Care – Next Steps, NHS England and System Partners (2015)

It also seeks views on proposals developed in response to:

- issues raised during the 2014 consultation on the Mental Health Act Code of Practice regarding the Mental Health Act primary legislation; and
- some of the recommendations of the 2015 NAO report Care Services for People with Learning Disabilities and Challenging Behaviour.

This is a consultation. It sets out a range of potential ideas rather than a single package of measures which necessarily need to be taken together. We are therefore also seeking views on which of the measures contained in this document would be likely to have most impact.

Scope

The scope of the consultation **primarily** relates to:

- (i) assessment and treatment in mental health hospitals for people (all age) with learning disability or autism;
- (ii) 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

(iii) *all* those to whom those Mental Health Act currently applies (including children and young people);

Other elements included here, particularly, where they relate to the Care Act 2014, may be of relevance to adults in receipt of social care, including those with other disabilities.

Some of the proposals relating to possible amendments to the Mental Health Act are not intended to apply to patients under Part 3 of the Mental Health Act (those who have entered via the criminal justice system). This is because of those patients' particular needs and the important responsibility of the Secretary of State for Justice and the National Offender Management Service in relation to public protection. The scope of proposals in relation to this group of patients is set out for each relevant section.

Part three of the Children and Families Act 2014 offers a real opportunity for many of the people whose needs this document focuses on. The Act requires local authorities and clinical commissioning groups jointly to commission services, and encourages services to identify children and young people with very complex needs at a much earlier point. Through a joined up, person centred Education, Health and Care assessment and planning process, there should be a much clearer focus on helping children and young people prepare for adulthood, including employment and independent living. In combination with the Care Act 2014, the legal framework exists to support successful transition to adult services. This paper therefore does not cover any further proposals in this area.

This is a consultation by the Department of Health in England. However, the Mental Health Act applies across England and Wales and any changes to the law in Wales would have to be agreed by the National Assembly for Wales.

Who is this consultation for?

We are, in particular, seeking views from:

- People with learning disability, their families and carers;
- People with autism, their families and carers;
- People with mental health needs, their families and carers;
- Individual health and social care bodies responsible for the planning, commissioning and provision of services for people with learning disability, autism or mental health needs;
- Individual health and social care professionals;
- Representative local and national organisations for health and social care bodies or professionals;
- Individuals or organisations with evidence regarding the costs and potential impact of any of the proposed measures;
- Individuals and organisations with an interest in health and care legislation, in particular, the Mental Health Act;
- Individuals and organisations with an interest in restricted patient processes and support under the Mental Health Act;

- The police and other emergency responders who may be called on to respond to people experiencing mental health crises; and
- Any other party with an interest in improving the rights, health and wellbeing of people of all ages with disability.

New burdens

The Department of Health will work with the local government sector to assess fully the costs of any new burdens resulting from the proposals as they develop. It also undertakes to ensure that any additional costs that may arise are fully funded.

Terminology

We recognise that in many local areas, learning disability and autism are separately commissioned and provided services. One or other may, in some circumstances, be combined with mental health services. This document is not intended to impact on these arrangements.

Learning disability¹

Learning disability can be defined as a disability which includes the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills, with;
- a reduced ability to cope independently; and
- which started before adulthood, with a lasting effect on development.

Autism

Throughout this document, as in the Adult Autism Strategy for England, we use the term “autism” as an umbrella term for all autistic spectrum conditions, including Asperger Syndrome.

Consultation period

The consultation will run for 12 weeks from 6 March 2015 to 29 May 2015.

The consultation questions are summarised in **Annex A**.

An **Easy Read** version of this consultation is also available.

1 Adapted from Valuing People, DH (2001).

Getting involved: How to respond to this consultation

Timings

The consultation will run for a period of 12 weeks from 6 March 2015 to 29 May 2015.

To find out more go to: <https://www.gov.uk/government/publications>

How to respond

You can respond to the consultation in the following ways:

By e-mail to: norightignored@dh.gsi.gov.uk

Online at: <http://consultations.dh.gov.uk/>

In writing to:

Consultations Co-ordinator
No Right Ignored Consultation
Department of Health
3rd Floor Area 313A,
Richmond House
79 Whitehall
London
SW1A 2NS

To obtain a copy of the consultation in a different format, including easy read or alternative colour paper, please contact us by emailing norightignored@dh.gsi.gov.uk or by writing to the above postal address.

Remit

This is a consultation by the Department of Health in England. However, the Mental Health Act applies across England and Wales and any changes to the law in Wales would have to be agreed by the National Assembly for Wales. Although the remit of the proposals is primarily across England, this consultation may also be of interest to readers in Scotland, Wales and Northern Ireland (who have their own legislation and policies).

Summary of consultation responses

A summary of the responses to this consultation will be made available alongside any further action, such as the finalisation of this statutory guidance, and will be placed on the consultations website at www.gov.uk after the responses have been considered.

Comments on the consultation process itself

If you have concerns or comments which you would like to make relating specifically to the consultation process itself please contact:

Consultations Co-ordinator Department of Health 2E08 Quarry House Leeds LS2 7UE

email: consultations.co-ordinator@dh.gsi.gov.uk

Please do not send consultation responses to this address.

Confidentiality of information

We manage the information you provide in response to this consultation in accordance with the Department of Health's Personal Information Charter.²

Information we receive, including personal information, may be published or disclosed in accordance with access to information regimes (primarily the Freedom of Information Act 2000 (FOIA), the Data Protection Act (DPA) and the Environmental Information Regulations 2004).

If you want the information you provide to be treated as confidential, please be aware that under the FOIA, there is a statutory code of practice which public authorities must comply with and which deals, among other things, with obligations of confidence. In view of this, it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of information, we will take full account of your explanation, but we cannot give an assurance that confidentiality will be maintained in all circumstances.

An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department of Health.

The Department of Health will process your personal data in accordance with DPA and in most circumstances this will mean that your personal data will not be disclosed to third parties.

² Personal information charter <https://www.gov.uk/government/organisations/department-of-health/about/personal-information-charter>

Introduction: the same real life as any other member of the community and an end to institutional care by default

The vision:

1. The vision is clear: all disabled people, including those with learning disability, autism or mental health needs, have a right to lead their life like anyone 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.³ All services should first and foremost see the person and their potential.⁴
2. What happens as a result of this consultation will be determined by the next Government in the context of a spending review. Without committing or obligating that Government, we are setting out the case for change and seeking views on proposals for action which we are exploring in order to accelerate progress towards this vision.

The case for change:

3. We hear too often from families of a pervasive culture, just as that highlighted by Sir Robert Francis,⁵ of failures to listen to people and their families and to treat them as people who hold expertise and who have the right to be in control of their own lives. We are seeing services and systems default to what can in effect be re-institutionalisation, either through lengthy inpatient stays or residential care against people's wishes.
4. Since at least the 1950s, it has been a key goal of public policy to bring an end to institutionalisation as a model of care for disabled people. The asylum movement of the Victorian era set in place a model of care for disabled people, in particular, those with learning disability, autism and mental health needs, which meant they were set apart in physically and socially isolated settings. This institutional model excluded people and enabled poor care and sometimes abuse to flourish. There has been substantial progress in shutting down such institutions over the last 40 years which should not be forgotten:
 - The asylums have been closed: in the 1950s, there were over 150,000 residents in asylums (with a mix of physical and mental health problems and disabilities). The last asylums were closed at the end of the 1990s.

3 See, for example, the very clear principles set out in *Valuing People: A new strategy for learning disability for the 21st Century*, Department of Health (2001) which still stand.

4 See also *Fulfilling Potential*, Department of Work and Pensions (2011).

5 *The Mid-Staffordshire NHS Foundation Trust Public Inquiry* (2010).

- NHS long stay hospitals and campuses (where people with learning disability were living in NHS accommodation) have also been closed: in 2002/3, there were over 6000 NHS long stay and campus beds in England⁶ and the overwhelming majority of these have closed. All NHS long stay hospitals were closed by the end of 2010/11.

5. However, evidence suggests that, albeit in much smaller numbers, some of the same problems as identified decades ago sadly continue to exist. For example, the Care Quality Commission report into their reviews of learning disability hospitals,⁷ following the BBC Panorama exposure of events at Winterbourne View hospital, found that overall levels of compliance on care and welfare of people using services and safeguarding people from abuse were low.⁸ Lengths of stay were generally “unacceptably long, and inconsistent with the descriptions of assessment and treatment”, people and families were not involved in the design of their care and therefore were not in control of their own needs. Many people with learning disability who are not in hospitals or residential care also tell us that they also do not feel that they have enough choice and control over their own lives and how they are supported and enabled to live independently.

Hospitals are not home

6. Admissions to hospitals are there to provide assessment and clinical support that cannot be provided in community settings. Hospitals are not homes. However, from the Care Quality Commission’s work and many other recent sources we know there are still too many people with learning disability or autism, and either mental health problems or behaviour that may challenge services, who are admitted to inpatient settings and stay there for long periods of time – in some cases years – very far from home.⁹ We know that many people want to be and could be supported in their community, closer to family or friends.

7. It is, of course, essential that there should be access for people to good quality specialist services at times of crisis. There must also be alternatives for people where prison is not appropriate and, in these instances, public protection and the appropriate management of risks are important factors to consider in making any changes to the law. But we cannot allow re-institutionalisation to recur through overly long inpatient stays.

The price that individuals and families pay

8. These issues matter because individuals and families pay a heavy price when we get things wrong. Outcomes for the individual, including their quality of life, may be very poor.

6 Emerson E. An Analysis of NHS Long-Stay Beds and Residential Places for Adults with Learning Disabilities. (2003) Lancaster University.

7 Learning Disability Services Inspection programme: National Overview, Care Quality Commission (June 2012).

8 In this report 50% of facilities inspected failed some core standards on care and welfare – including protecting people from abuse. Only 14% of people were in fully compliant settings.

9 See, for example, Learning Disability census, England 2014, Health and Social Care Information Centre (Jan 2015) which showed on census day patients had an average length of stay of 547 days and were staying 34.4kms from home.

We know that in some settings levels of medication, restraint and self-harm are high. Sadly, we also know of a number of deaths.¹⁰

9. The wrong care in the wrong place can have a very significant impact on family life. When loved ones are hundreds of miles away it is not physically difficult and very costly to visit – sometimes compounded by very inflexible visiting arrangements. Family members and friends also often feel that they are not being listened to and that they are powerless to help their loved ones.

The cost to the system

10. These problems are not just costly for the individuals and their families but they can also be a poor use of taxpayer money. Many of these inpatient placements are very expensive. 2014 learning disability census data showed an average cost per person commissioned by the NHS of over £177,000 a year. In comparison, fully staffed average living costs in the community for those with higher needs¹¹ are £140,000 a year – over 20 per cent less.

11. There is growing evidence that, over time, the right care in the community can reduce incidence of behaviour that challenge services and this, in turn, reduces costs to the NHS and, sometimes, also to other parts of the public sector, such as the criminal justice system.

12. Getting services right for people now is important – and urgent. In some areas, demand is rising and the local authority spend on adults with learning disability now exceeds that on older people. By 2030 it is estimated that the number of adults aged 70+ with learning disabilities using social care services (and also very likely to be using health services) will more than double.¹² Greater life expectancy is to be celebrated but we need to ensure that services, vital processes like planning and the law – are keeping up to date with these changes. It is imperative we design the system and services which are right for this growing population now.

The case for more radical reform

13. In the *Transforming Care* programme, set in place after the scandal of Winterbourne View Hospital,¹³ we have focused on trying to bring about improvements through existing systems and legislation but, increasingly, the evidence on progress¹⁴ is suggesting that this is simply not enough. Too many commissioners 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. However, we do note that there is also considerable variability in commissioning approach and the resulting outcomes across the country.

10 On poor outcomes for individuals, see, for example, 3 Lives: What have we learned, what we need to do, CQC and Challenging Behaviour Foundation, (June 2014).

11 Sources: Learning Disability census, England 2014, Health and Social Care Information Centre (Jan 2015) and PSSRU Unit costs of Health and Social Care 2013.

12 Source: Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England, Centre for Disability Research at Lancaster University (2008).

13 Transforming Care, the Department of Health Review into Winterbourne View Hospital, Department of Health (2012).

14 See, for example, Winterbourne View: Transforming Care Two Years On, Department of Health (2015).

14. Sir Stephen Bubb's report *Winterbourne View – Time for Change*¹⁵ made a number of recommendations on the need for further reform to transform services – both to strengthen people's rights and to change the way commissioners, clinicians and providers operate. As he said:

For decades people have argued for change and described what good care looks like and how we can commission it. The Winterbourne View scandal made the need for change even clearer, and resulted in a wide range of commitments from Government and others. But the problem remains.

15. The National Audit Office in their report into *Care Services for People with Learning Disabilities and Challenging Behaviour*¹⁶ recommended that the Department of Health take stronger action in certain areas. They argue that key changes have not happened because the Department did not have the "levers to implement the necessary changes, such as... mandatory guidance, [or] pooled budgets...".

16. Most importantly, we have listened to disabled people and their families. The *Justice for LB campaign* and social movement¹⁷ driven by dedicated family carers and their supporters have also made a powerful argument on what people have a right to expect, saying they wish to:

- (i) *make it a legal reality for disabled people to be fully included in their communities*
- (ii) *make it harder for the State to force disabled people to leave their homes against their wishes, or the wishes of their families."*

A profound power shift is required to help people to move from being passive recipients to active citizens, treated with dignity and respect.

Conclusion

17. We have had a clear vision for many years that all people should have the right to the same life chances, to make choices and be in control of their own life as far as possible. It has been our goal for over 50 years to end institutionalisation.

18. But we have looked at the evidence and the data which show it is proving very hard to make this happen for everyone. Most importantly of all, we have listened to what people have told us – to their stories of feeling ignored by services, of having no say in their own or their families' care, of being cut off from family hundreds of miles away, or of a lack of effective or adequate support in the community.

19. This consultation sets out a series of measures which we think could both strengthen the rights of people to live independently and to be included in their community and to make choices about their own lives. As Sir Stephen Bubb's recent report¹⁸ stated:

We need to make it easier (or mandatory) for all these stakeholders [clinicians, providers, frontline staff, commissioners] to do what we are asking of them. We need to make it harder (or impossible) for them to settle for the status quo that we are agreed must stop.

15 *Winterbourne View – Time for Change* (2014).

16 *Care Services for People with Learning Disabilities and Challenging Behaviour*, National Audit Office (2015).

17 See <https://lbbill.wordpress.com/> and <http://justiceforlb.org/>

18 *Winterbourne View – Time for Change* (2014).

1. My right to be independent, to be part of a community and to live in a home I have chosen

Inclusion in the community

1.1 Disabled people including those with learning disability, autism or mental health needs, have the same rights as everyone else. They should have the same choices, freedoms¹⁹ and dignity as others. This means being members of their community, part of a family, having meaningful friendships and a social life, access to paid employment opportunities. We know that inclusion in family and community are very important for people – starting in childhood. There is good evidence that the family, and other social networks, are important protective factors for physical and mental health.

1.2 Real inclusion matters because the quality and quantity of social relationships have been shown to “affect mental health, health behaviour, physical health and mortality risk”.²⁰ One study indicated that the effect on health of adequate social support was comparable with quitting smoking and exceeds many well-known risk factors for mortality (e.g., obesity, physical inactivity).²¹

1.3 We know that some people are being admitted to hospitals or placed in residential settings which can be a long way from their family or from their home and which is often not their choice. This can make problems with behaviour worse, delay recovery, complicate discharge and it reduces contact with family and friends.

Individual wellbeing, independence and inclusion

What has already been done

1.4 The Care Act enshrines in law the individual wellbeing principle for care and support. It is the single unifying principle around which adult social care will in future be organised. The individual wellbeing principle incorporates key elements which are essential for inclusion in the community including social and economic wellbeing and participation in work, education, training or recreation. This means local authorities will now be under important duties in relation to these and other elements such as people’s control of their day to day life, suitability of living accommodation and contribution to society. Importantly, local authorities are required to consider each individual’s views, wishes, feelings and beliefs. This provides a focus on the outcomes that matter to people including inclusion and independence.

19 Of course, people’s choices and freedoms may be different from others’ if they have committed an offence. This includes those who are under a hospital order from the courts. All proposals in this section, need to be read with this caveat.

20 Umberson & Montez, 2010, Journal of Health and Social Behaviour.

21 Holt-Lunstad, Smith & Layton, 2010, PLoS medicine.

1.5 During the passage of the Care Act through Parliament, the issues of independent living and inclusion in the community were carefully considered. However, the Care Act does not include an explicit duty to promote independent living. The term “independent living” is usually associated with Article 19 of the UN Convention on the Rights of Persons with Disability but the term is not defined in article 19. The Law Commission explicitly looked at whether “independent living” should be included in the Care Act and they concluded that what was important was that people’s wishes and feelings about where they lived were respected. It is also important to note that, as many self-advocates tell us, this is not just about where you live but about exercising choice and control over who comes into your home and who supports you.

1.6 As the Care Act is implemented from April 2015, we will monitor its impact and explore whether guidance needs to be made clearer, for example, to underline the specific intent of the legislation for local authorities to promote independent living where this is the person’s choice. Some people will want to choose other arrangements which are appropriate to meet their needs. For some people, this might include residential care. There is no policy to prevent or deny people choosing these arrangements, including for people with a learning disability and for those with mental health needs.

1.7 The Care Act individual wellbeing principle applies only to the care and support functions of local authorities. People with more complex needs, including those who have behaviour that may challenge services, are likely to need support from both health and social care. For those individuals most at risk of inpatient admissions the level and cost of both health and social care support are likely to be high. Joint personal care planning between health and local authorities is essential for meeting people’s needs. It is important for individuals and families that there is a single shared commissioning framework across health and social care, a shared conversation with them and a shared set of person-centred outcomes for them, based on their rights, not on different agency agendas.

1.8 So, where the needs of people with learning disability and autism relate to both health and social care services and, there is a need for joint individual care planning for lifelong needs, we want to seek views on ***whether NHS commissioners should share new Local Authority duties around promoting individual wellbeing***. The aim is to ensure both local authority and NHS commissioners focus jointly on the outcomes that matter to people for their wellbeing, including inclusion in the community, and ensure they involve individuals and their families and carers in determining those outcomes.

As close to home or my community as possible

1.9 A number of measures have been put in place recently aimed at supporting people to stay closer to home, and in settings of their choice. Under the Care Act, people have a right to a choice of accommodation providing it is suitable to meet their needs.²² This includes supported living and shared lives accommodation. The Children and Families Act also requires CCGs and LAs to jointly commission services for 0-25 children and young people

22 It should be noted that certain other conditions also need to be met under the Act which we have not listed in full here.

with special educational needs and disabilities (SEND). The 0-25 SEND Code of Practice encourages commissioners to consider regional commissioning and collaboration for low incidence, high cost services so that children and young people can stay as close to home as possible. In the revised statutory guidance on the Mental Health Act, the Code of Practice, which states that under the Mental Health Act people should be “as close as reasonably possible to a location that the patient identifies they would like to be close to (e.g. their home or close to a family member or carer)”.

1.10 Some people have told us that, as well as a right to a choice of accommodation, there is a need for a specific statutory duty for local authorities and, importantly, NHS bodies, to deliver support or treatment in the least restrictive setting possible.²³ It is a guiding principle in the revised Mental Health Act Code that the least restrictive option possible should be used and people’s independence maximised. We are also therefore seeking views on whether both NHS commissioners and LAs should also have regard to the need for care to be provided for people in the way and setting that is least restrictive.²⁴

1.11 We have listened closely to stakeholders, including the *Justice for LB and LB Bill campaign*,²⁵ about strengthening people’s rights, so we want to hear your views on whether it should be more explicit, that in carrying out their functions on:

- either, in the case of LAs, decisions about individual living arrangements;
- or, in the case of NHS commissioners, arranging the provision of assessment and treatment services in hospital inpatient settings (for example lasting over 1 month);

that NHS commissioners and LAs should have regard for:²⁶

- the need to ensure people remain in or close to the community that matters to them;
- the need to maintain links with family and friends;
- the need to maintain opportunities to participate in work, education, training or recreation; and
- the principle of delivering support or treatment in the least restrictive setting possible, consistent with the wishes and choices of the individual;

The default attitude and cultural approach should be that the statutory bodies have to make efforts to do what is in line with people’s wishes and recognise the importance of people being in their own home or community or close to or with their family, if that is their choice, rather than people, supported by their families, having to fight to justify why this matters.²⁷

²³ However, do also need to ensure placements are available for certain highly specialised services or individuals with very high risks, who could only be accommodated in a very limited number of highly specialised settings.

²⁴ Where patients are Restricted under part 3 of the Mental Health Act, the Ministry of Justice (National Offender Management Service) will need to ensure that any placement is suitable.

²⁵ See <http://justiceforlb.org/> and <https://lbbill.wordpress.com/>

²⁶ The intention is that this would not apply to restricted patients’ arrangements under Part 3 of the Mental Health Act.

²⁷ In some instances, for example courts making hospital orders or for restricted patients, other factors such as public protection and the appropriate management of risk will also be important considerations which could clearly provide justification.

1.12 Our working assumption is that, for many people, particularly those with more complex needs or at particular risk of admission to mental health inpatient settings, such a duty would, at worst, result in no increase in costs across the health and social care system and could result in a reduction in costs. This assumption is based on average relative costs of more restrictive inpatient or residential settings versus less restrictive and community based settings. However, we would be interested to hear views and receive evidence on this issue.

Questions

Q1 The Care Act says that local authorities have to put individuals' wellbeing at the heart of what they do. We want to explore whether NHS commissioners should have the same duties, for example, for people with learning disability or autism who are at high risk of long stays in hospital in relation to their lifelong needs. What do you think of this idea?

Q2 In making decisions on living arrangements (whether suitable accommodation or inpatient stays both) LAs and NHS commissioner should have regard for factors which support inclusion in the community. This could include staying close to home, links with family and friends, opportunities for participation and least restriction. What do you think of this idea?

Q3 If so, what might the appropriate length of inpatient stay be where this should apply to the NHS?

Q4 What are your views on how this might impact on LAs and the NHS?

Sufficient community provision

1.13 One of the most significant challenges in some areas to making a reality of people's right to be supported in the community is the lack of effective community services. Sir Stephen Bubb wrote in his report that local commissioners should be "*more clearly incentivised to ensure there is adequate community-based provision, and admitting an individual to a secure bed is never the 'easy option' for local commissioners*".

1.14 We want to ensure there is sufficient community provision and that local commissioners in both health and care have adequate knowledge of the potential range of community providers and community options that could meet the needs of the local population of people with learning disability and autism (or mental health needs) who are at particular risk of being admitted to institutional care. This includes people of all ages – children and adults. This is not just about preventing unnecessary admission but ensuring the right capacity in the right place to enable discharge from any (necessary) inpatient stay into the community.

Closing inappropriate facilities

1.15 Expanding community provision and preventing inappropriate admissions to inpatient units means there should be a reduction in demand for inpatient beds. This means that units and beds, whether provided by NHS providers or the independent sector, which offer outdated models of care, should close down. This is not about targeting particular providers, but there is now a widely accepted view across the system that inappropriate models of care should no longer be commissioned.

1.16 It has been a clear policy position for some time that inappropriate models of care should no longer be commissioned. As stated in *Transforming Care*²⁸ “there are no excuses for continuing to commission the wrong model of care” and “the emphasis should be on designing community services in line with the best practice model. We would expect to see a dramatic and sustained reduction in the number of assessment and treatment unit beds as a result of this shift”. In line with this very clear policy expectation, NHS England have now set out in *Transforming Care for People with Learning Disabilities – Next Steps* (Jan 2015) their plans to develop a clearer service model for health and care services for people with learning disability and/or autism who have mental illness or behaviour that challenges. It will set out outcomes to be achieved, performance indicators and the kind of services that should be in place – including in the community. They also stated their intention to establish a “reconfiguration taskforce” to support local leaders in reshaping services in the North of England at pace, where commissioners who want to transform services face a particular challenge. These steps will help the NHS to ensure effective and sufficient community services. As Simon Stevens, NHS England Chief Executive said to the Public Accounts Committee on 9 February:

...the time has come to say that some of the remaining facilities are going to have to close and care will have to be re-provided in a more radical way. On the back of the report that Stephen [Bubb] has given us and the points made by the families, we must use the next 12 to 24 months to chart out what that substantial transition programme is going to look like for those facilities.

What has already been done in law to promote the right provision

1.17 The Care Act places new duties on Local Authorities which are intended to commence from April 2015 to promote an efficient and effective market for adult social care and support as a whole in relation to both diversity and quality of services. This means collaborating closely with other relevant partners, including people with care and support needs and their families and carers. This should stimulate a diverse range of high quality services. Local authorities should be looking at developing service arrangements based on outcomes for individuals rather than, for example, units of provision. Local authorities should be encouraging a wide range of services to make sure people have choice and that services are appropriate for them. Local authorities must have regard to the need for ensuring sufficiency of provision and this means planning for future needs, looking at the local population of children and young people as well as those already in adult services. These new provisions are intended to go a long way to ensuring that local authorities offer a range of community based support options for people.

1.18 The 0–25 Special Educational Needs and Disability (SEND) Code of Practice also requires Care Quality Commissions and Local Authorities to come to a joint assessment of the needs to the population of children, young people and young adults age 0–25 with SEND needs and to commission accordingly. This specifically encourages them to collaborate for groups where there may be low incidence and high cost needs. The aim was to help local areas to develop a sustainable market to exactly the group of young people who may have needs such as learning disability or autism with complex additional needs such as challenging behaviour or mental ill health.

²⁸ *Transforming care: a national response to Winterbourne View Hospital, Department of Health review: Final report*, Department of Health (2012).

What more needs to happen

1.19 We also do not yet know how the new Care Act duties will be reflected in local actions or how the provider market will respond. We propose to monitor²⁹ the impact of these market shaping requirements on community based support for people with a learning disability or mental health needs, particularly the group of people with learning disability and/or autism with particular support needs or challenging behaviour who are a low incidence and high need group and will need bespoke packages of care and support.

1.20 If someone is living in the community, (rather than as an inpatient in a hospital), it is not the case that their only support needs are adult social care. Effective professional social work, care and support for individuals and carers are very important but so are the skills of community health teams, including psychological support e.g. Positive Behaviour Support for people with learning disability who may behave in a way that can challenge services. It is also very important that community teams have access to support from forensically trained psychiatric staff (with a learning disability or autism specialism as appropriate) and expertise on working with offenders, as this will help to facilitate the safe support and treatment of restricted patients in the community rather than in inpatient settings. Effective responses for people in crisis are essential to avoid unnecessary hospital admissions. This includes from local community learning disability teams, their links with mental health crisis teams (including out of hours), access to learning disability nurses and early intervention teams that help to prevent unnecessary out of area placements. When planning and taking a view of the market Clinical Commissioning Groups and Local Authorities also need to consider the needs of both adults and children and young people, taking a whole life course approach. It is not the aim of this document to set out service specifications or models of good practice or provision. However, we have included the views of both a self-advocate with learning disability and a local professional in **Annex B** on their view of what models and elements of good community provision would look and feel like to them. Respondents might wish to consider or note these views.

1.21 However, the Care Act market shaping duties do not apply to NHS commissioners. We are therefore seeking views on whether health and social care commissioners should, in some instances (for example, those cases where complex, high cost individual health and care packages and close liaison across health and care are needed for lifelong needs), both ***have regard to the need for sufficiency of community treatment and support.***

1.22 In the light of the existing Care Act requirements on market shaping and the duties on the NHS, including those in the Health and Social Care Act to promote a comprehensive health service and arrange provision of services to deliver a comprehensive health service, we do not believe, this would be a completely new requirement. We know that some local areas have strong community services. However, we know that local arrangements are variable. We do not have systematic information at present about current community arrangements across the country. We therefore also want to hear views and receive evidence about the cost and burden of a duty to have regard to the need to secure sufficient supply of community treatment and support in certain circumstances.

29 The intention at this stage would not be to do so via any new mandatory national reporting but to use existing data collections and reporting as far as possible, if necessary supplemented by bespoke targeted evidence gathering which would not impose additional burdens on local authorities.

Questions

Q5 We think that local authorities and the NHS could have to think about how to ensure enough community based support and treatment services (for example, for people with learning disability or autism most at risk of going into hospital). What do you think if this idea?

Q6 What steps could we take to ensure such a duty is as effective as possible?

Q7 What is your view on the likely costs or impact of such a duty on the NHS? Local Authorities?

Assessment and treatment in the community and the Mental Health Act

1.23 Often, when people with learning disability or autism are sent away from home to inpatient settings, it is because they have been detained for assessment or treatment under the Mental Health Act.

1.24 The Mental Health Act enables any person who experiences “mental disorder” (which currently includes people with autism and people with learning disability in some circumstances) to be detained for *assessment* for up to 28 days (under section 2) or for treatment (under section 3) under certain specific criteria. Many stakeholders have made the case to us that many people could, in the right circumstances, be assessed (and then receive appropriate medical treatment) in the community instead without being detained in an inpatient setting.

1.25 We are therefore considering the possible benefits of requiring services and clinicians more explicitly to ***consider and record whether assessment and treatment could be provided without the person being detained***, for example, in a hospital outpatient clinic or a community setting and make clear that this is *not* necessarily about whether the right community treatment and care package is already in place for that individual at that precise moment or not, although availability of alternative options is clearly an important relevant consideration.

1.26 We think this could be achieved by amending the information required by regulations to be given in the application for detention completed by Approved Mental Health professionals (AMHPs) and the medical recommendations supporting such applications. The forms relating to these applications already require the AMHP/doctor to provide reasons why they consider it necessary for the person to be detained in hospital. We are interested in views on whether this could be amended to include more on appropriate reasons and on explaining why the person could *not* be assessed and treated in the community. This is about looking to alter some of the default assumptions – treatment at home rather than detention. Risks to family and community life could also be recognised alongside risks which are more typically noted now – as well as risks related to people’s expressed wishes and, where relevant, advance directives or decisions. If this information were required and recorded, bodies such as Care Quality Commission and the Tribunals could get a fuller picture and it should provide important evidence for local commissioners regarding sufficiency of local community based

support and treatment. The aim is that this information would be actively used, not just kept on file. This would apply for anyone for whom the Mental Health Act applies, not just those with learning disability or autism.³⁰

1.27 We would, of course, need to make sure that people and the community were kept safe and that people who do need inpatient treatment under the Mental Health Act are able to access it. But the intention is that this would support commissioners in their assessment of needs and Approved Mental Health Professionals to ensure they use their legal powers to make applications for detention under the Mental Health Act only when this is essential – not as a default in the absence of effective community based assessment and treatment options without any driver to address this underlying problem.

1.28 We assume that this would not add any cost burden and, in fact, could reduce the use of costly detentions (and related costs such as Tribunals).

Questions

Q8 What do you think about the idea to change the information which is required by Mental Health Act regulations applications for detention and supporting medical recommendations. This would mean that Approved Mental Health Professionals and doctors have to consider and record whether assessment and treatment could be provided without detention in hospital.

Q9 What is your view on the likely costs or impact of this idea?

³⁰ It is not intended that arrangements under Part 3 in relation to the decisions of the Courts will be affected.

2. My right to be listened to and have my wishes acted upon. My right to challenge decisions about me

Rights

2.1 Many pieces of legislation in recent years have strengthened people's rights. These include the Human Rights Act, the Equality Act and the Mental Capacity Act. The UK also ratified the UN Convention on the Rights of Persons with Disabilities and signed up to the 2010 WHO European declaration on the health of children and young people with disabilities.

2.2 It is a core principle of the social care system that people themselves, often with the support of close friends, family and carers, have the right to be involved planning their own care and support. This is enshrined in the Care Act which states "the importance of beginning with the assumption that the individual is best-placed to judge the individual's well-being" and the duty to have regard to "the individual's views, wishes, feelings and beliefs". Similarly, duties in the Children and Families Act require Local Authorities to have regard to the views, wishes and feelings of the child or young person and to enabling them to participate in decisions relating to themselves (or their child in the case of families).

2.3 It is very important to be clear that *compulsory* admission, treatment or detention, can *only* occur if the proper legal safeguards are applied, for example, under the relevant Mental Health Act or in line with Mental Capacity Act provisions.³¹

2.4 The recently revised Code of Practice for the Mental Health Act strengthens statutory guidance where people are detained under the Mental Health Act to make sure that patients' views are taken into account as far as possible. This statutory guidance also requires professionals to take into account the choice of location and other factors raised by the patient and their family and requires them to be involved in decisions about renewals of detention. The Mental Health Act and the Code also contain a number of points where people and their families can challenge decisions about their care.

2.5 However, as Sir Stephen Bubb said in his recent report:³²

...the lived experience of people with learning disabilities and/or autism and their families is too often very different. Too often they feel powerless, their rights unclear, misunderstood or ignored.

In some cases, people with learning disabilities and/or autism and their families may not be aware of the rights they already have, or may not have access to the support they need to exercise those rights...

In other cases, there are doubts over whether the rights of people with learning disability are being respected in practice as originally intended.

31 This is with specific reference to adults. Arrangements for children are slightly different.

32 Winterbourne View – Time for Change (2014).

2.6 We know that some people still have concerns about how much people are listened to. People have told us that the default is set the wrong way round. Statutory agencies and professionals should have to justify why, against the wishes of individuals or families, they are doing things like sending people away or keeping them away from their communities, homes, families or friends, whether to an inpatient or residential care setting. At the moment it can feel to families that the burden is on them to challenge and justify why this should not happen.

2.7 We are therefore interested in exploring how we strengthen the rights of the individual to challenge and choose and how the system is set up to support them to do this rather than to oppose them, as many people say is their experience. This includes whether there should be a stronger mechanism to enforce these principles in practice.

Knowing your own rights and a responsibility for the NHS and LAs to justify decisions about you

2.8 Because we know that existing rights are complex and often poorly understood, we want to ensure that, whether admitted under the Mental Health Act or not, people and their families are informed of their rights³³ (and statutory agencies' duties) as soon as reasonably practical following the start of discussions about a potential admission – not once someone has been admitted. This information sharing should continue throughout the inpatient stay up to and beyond discharge. At the moment there are a range of responsibilities under the MHA Code and the Care Act and elsewhere in relation to providing information to people and families but these are not brought together consistently in a single place for both the NHS and LAs. We suggest that this information has to be shared by a named professional³⁴ (either a named social worker or alternate of their own choice). As is already clearly required under the Equality Act, it is vital that this is in a format that is accessible for the individual.

2.9 This information would form their own **personalised summary of rights** that are relevant to their individual circumstances – rather than a long potentially confusing or list of all potential rights which may or may not be relevant.

2.10 The individual and their family/carer (or other nominated advocate), should always be provided, by a named professional either a named social worker or alternate of their choice in a timely fashion with clear, easy read or accessible information by those responsible for overseeing these decisions. This should set out:

- The rights (and others' corresponding duties) which are relevant to their individual circumstance; and
- why a particular inpatient admission; or
- continuation of a particular treatment or assessment admission; or
- a particular residential placement

is *in their opinion* the most appropriate option for that person; and

33 This is not intended to refer to people needing to know their legal rights when involved in criminal justice procedures (including those under part 3 of the Mental Health Act which enable the courts to refer people to hospital). However, the general principle should apply right across public services that people should know what decisions are being taken about them and why and be able to make representation or challenge as appropriate.

34 See para 2.56 for Named Social worker proposal.

- unless the individual has requested/chosen that inpatient admission or residential placement, why there is no alternative closer to the community or location that matters to them or within a community setting either in place *or that could, within a reasonable timeframe, be put in place*; and
- when these arrangements will be reviewed.

2.11 The requirements to set out this information for the individual should influence behaviour in services which will help to ensure that proposed new duties to have regard to the need to be close to the community that matters to them (as set out in Chapter 1) make a difference and are being complied with. Of course, it is essential that this information is provided not for its own sake but to enable active participation in the processes of admission, care planning, review and discharge.

Questions

Q10 We want to explore whether a person and their family/carer or other nominated person, should be given clear, easy read or accessible information by a named professional about their rights. What do you think of this idea?

A right to challenge admissions

2.12 We think first and foremost people themselves have the right to choose and challenge what happens to them, if they are able to do so. We think this means that where people have the capacity to give informed consent, before they can be admitted to an inpatient setting³⁵ or to a residential care setting, the relevant NHS body or local authority needs to make sure they have got their ***explicit and accessibly documented approval or consent***. It isn't right for it to be up to the person or their family to have to challenge what is happening to them, it is up to the NHS or LA to discuss, involve and seek agreement with the person. Documentation should record not just a tick box on consent but reflect the fact that a proper discussion of genuine options, risks (including the risks of behaviour or health or other problems deteriorating in that setting) and possible alternatives has taken place. This is consistent with (and could be achieved by LAs through) new Care Act duties which already require the LA to involve people and reach agreement with them on how their care needs should be met and to record that within their care plan.

2.13 NHS England announced recently their intention to put in place nationally later this year new admission gateway processes, so that where admission is considered, a robust challenge is in place in the system to check there is no available alternative.³⁶ We want to work with NHS England and partners to learn from this gateway process and explore whether it could be used systematically to ensure that statutory bodies have to demonstrate to another expert group (ideally which entails family involvement where appropriate)³⁷ that it is necessary

35 Different considerations may be present for patients admitted under Part 3 of the Mental Health Act 1983. For example, patients subject to hospital orders or hospital directions will have been sentenced by a court. In addition, there may be circumstances where urgency means it is not possible for patients to make representations about transfer from prison to hospital.

36 Transforming Care for People with Learning Disabilities – Next Steps, (January 2015).

37 Unless not appropriate because of individual choice or circumstances of individual personal relationships.

and appropriate for an inpatient admission or certain comparable living arrangements to be made before they are made. This would complement and strengthen the focus on discussion with the individual and the importance of seeking proper, informed and documented consent. One of the issues we could look at explicitly is whether such a process could be given statutory force.

Questions

Q11 What do you think of the idea that local authorities and NHS commissioners should have to seek explicit and documented approval or consent³⁸ from an individual to admit them to an inpatient setting. This could include a record of discussion around options and risks.

Q12 What do you think about the idea of a gateway or approval mechanism for admissions to inpatient settings, in certain circumstances?

Q13 What would be the essential elements of such an approval mechanism?

Q14 If there were to be such a mechanism, should it be given statutory force?

A right to seek transfer or discharges

2.14 If people have consented to be placed or admitted to a particular setting, because they believed at the time this was the best option, we propose that they or their families or advocates should also have *every right* to change their mind later because something is not out working for them and to **request a move, or a transfer to a less restrictive setting or to a setting closer to home or to seek a discharge**.

2.15 For people who have the capacity to make such requests or decisions, any requested transfer should happen as soon as practically possible, unless there were clear reasons why not. These reasons should be shared by a named professional with people and their families in a format they can access and understand. We are looking at ways to make this clearer, for example, in statutory guidance.

2.16 As above, *compulsory* treatment or detention,³⁹ can *only* occur with the proper legal safeguards, for example, under the Mental Health Act or in line with Mental Capacity Act provisions.

2.17 There may, of course, be good practical reasons why, in some instances, alternative arrangements are difficult to put into effect *immediately*, for example, because practical arrangements have to be made with alternative providers to ensure high quality, appropriate care or support. Sometimes these can take time to arrange, for example, if bespoke housing or accommodation needs to be arranged. However, it is critical that the individual and their family/carer (or other advocate), if they want, are listened to and then kept informed and involved in what is happening.

38 Where individuals are assessed as not having the capacity to consent and are not being admitted under the Mental Health Act, the Mental Capacity Act must be followed. This means that, unless there is a deputy with relevant powers, the best interest process must be followed. Those admitted under the MHA also have certain procedural challenge rights (see pages 37-38). Clearly consent is not required for those being admitted via the courts or transferred from prison.

39 Including arrangements that amount to a deprivation of liberty.

2.18 A move to using Mental Health Act or Mental Capacity Act provisions to continue treatment or detention in a setting compulsorily⁴⁰ where a prior arrangement had been voluntary/with consent may be a warning sign of a serious breakdown in communications and relationship with the individual (or those supporting them) and should be considered very seriously and all legal duties followed very carefully.

2.19 We also think it would be ideal if *all* decisions and discussions with individuals around admission, transfer, renewals and discharge, involved, as far as practicable, professionals or staff based in the community or expert on community based options, for example, community LD nurses or social workers who are *not* based in inpatient settings and who are knowledgeable about what *can* be done in the community.

2.20 There needs to be accountability about these issues and a clear process that is person-centred and accessible.

Questions

Q15 What do you think of the idea of strengthening (for example in statutory guidance) people's rights to request a transfer to a less restrictive setting or a setting closer to home or to ask for a discharge?

Q16 Do you agree that, as far as practicable, such decisions and discussions should involve professionals or staff based in the community or expert on community based options?

Q17 How can we strengthen provider and commissioner accountability in their approach to such requests?

A right to early discharge planning

2.21 It should also be standard that discharge planning starts at the point of hospital admission, But we know that for many people this simply is not happening. The MHA Code also clearly states that the planning of after-care should start as soon as the patient is admitted to hospital. Although it is very clear that this is not happening everywhere at the moment.

2.22 We want to ensure that ***everyone receives discharge and after-care planning from the point when the patient is admitted to hospital*** and that CCGs and local authorities take reasonable steps to identify appropriate post-discharge care for patients well before their actual discharge from hospital. It is essential that individuals and their families/carers or other advocates have a right to be involved in this process and all care planning processes with a named professional and to have information in a format they can access and understand and within a clear time frame. The Mental Health (Wales) Measure 2010 places a duty on local health boards and local authorities to ensure that those receiving secondary mental health services have an eligible care co-ordinator and a statutory care and treatment plan. Regulations and a code of practice support this requirement.

⁴⁰ Including arrangements that amount to a deprivation of liberty.

2.23 NHS England recently announced their intention⁴¹ to require that, where individuals (with learning disability or autism) are admitted, they have an agreed discharge plan from the point of admission – with monitoring processes put in place to ensure that that discharge plan is followed. We will work with NHS England to monitor and understand how their new process is working. If necessary, we propose to make this a requirement in statutory guidance.

2.24 There are also a number of policies and guidance applicable to all hospital admissions which are aimed at reducing delayed discharge. We are interested in views on whether there are specific practices or processes in relation to delayed discharges that could be applied in the case of people with learning disabilities or autism in mental health inpatient settings.

Questions

Q18 We want to explore how everyone can receive care planning and discharge planning from the time when they are admitted to hospital. One way we could do this is through new statutory guidance (complementary to the Mental Health Act Code of Practice). What do you think of this idea?

Q19 Should we require a care plan, including a plan for discharge, to be produced involving individuals and their family within a specified number of weeks of admission and to specify when it will be reviewed?

Q20 Could more be achieved through any existing policies or guidance on delayed discharge?

Challenging Mental Health Act admissions

2.25 Many of the people with learning disability or autism who are admitted to inpatient settings are detained under the Mental Health Act (MHA). In these cases there are already certain safeguards and rights that apply on admission or on applications for admission – although we regularly hear from people who feel that these are not working well enough currently. For example, under the MHA,⁴² the person's nearest relative has the power to object to an application for admission for treatment under section 2. If the nearest relative objects (on reasonable grounds) the application for admission cannot be made.

2.26 AMHPs also have to interview the patient before making an application and take into account their wishes and feelings. We are looking at whether to make it **possible to challenge whether all the circumstances, including the patient's wishes and feelings, have been properly taken into account** in the AMHP's decision to make an application for detention. If a challenge is raised, there are a number of options on how this could be handled, about which we would want to consult further, for example, recourse to a tribunal, referral or requiring review and agreement by a second "independent" professional/expert or referral to a panel which might involve other family carers and self-advocates. The expert or the referral panel could be identified or approved through the local learning disability partnership board or equivalent.

41 Transforming Care for People with Learning Disabilities – Next Steps, NHS England (January 2015).

42 This does not apply to certain patients under the MHA (e.g. restricted patients/S35/S36/S38 patients).

Question

Q21 The Mental Health Act Code of Practice has just been updated. In line with this, we want to explore how people and their families can be more involved. One idea is that people and their families or advocates should be able to challenge whether an Approved Mental Health Professional has properly taken into account their wishes and feelings in the interview which takes place before they make an application for admission under the Mental Health Act. What do you think about this idea? (we would need to consult later on how the details of this process might work)

Challenging Mental Health Act renewals of detention and decisions on discharge

2.27 The revised Mental Health Act Code of Practice has strengthened the role of the individual and their family/carer or other advocate during a period in an inpatient setting by requiring that they must be involved during detention reviews/renewals for those detained under the Mental Health Act. The revised Code contains extensive new statutory guidance on what information should be provided to patients and their representatives and how hospital managers' panels should operate for contested renewals of detention.

2.28 However, some people have suggested that ***MHA safeguards and rights could also be strengthened further, particularly in relation to decisions around renewal of detentions and decisions not to discharge***. The process for the renewal of a detention should be as robust as the original detention decision. There are particular concerns around independent scrutiny of these decisions both in terms of potential conflicts of interest and in terms of accessing relevant knowledge about alternatives.

2.29 For example, when decisions are being taken around the renewal of detention, the responsible clinician (the approved clinician with overall responsibility for the patient's case) and a second professional involved with the patient's care have to agree that criteria for renewal of detention are met. However, in practice, this means both are, in most cases, from the same organisation. This could be seen as potentially resulting in a conflict of interest. In contrast, admission decisions don't give rise to the same concerns because regulations or statutory guidance prevent this.⁴³

2.30 We have three possible options, which are not mutually exclusive, we would like to seek views on:

Option 1⁴⁴

Just as for admission, in addition to the patient's responsible clinician, an additional approved clinician or section 12 doctor should also agree that the criteria for renewing detention are met and that this section 12 doctor should be from a different organisation. This could be in place of or in addition to the current requirement to consult a second professional described above.

43 Mental Health (Conflicts of Interest)(England) Regulations 2008, S.I. 2008/1205 (non-NHS admissions only), and, all admissions, including NHS admissions, also covered by the guidance given in the Code of Practice.

44 It is not intended that this would apply to patients under part 3 of the Mental Health Act.

Option 2

If a person is being treated out of area, one of the professionals (e.g. second professional as now or approved clinician/section 12 doctor as in option 1) involved in agreeing renewals of detentions, alongside the responsible clinician, should be employed by an organisation located within the person's "home" locality. This could be defined either by their LA area of Ordinary Residence or the CCG where resident/GP registered at the point of placement. This input would be funded by the commissioner normally responsible for paying for the inpatient care.

Option 3

That, building on option 1, one of the professionals involved in renewal decisions, alongside the responsible clinician, is both from a different organisation and has strong community knowledge and experience. This might include professionals from Home Treatment Teams, outreach teams, community mental health or learning disability teams, such as community LD nurses or social workers. In line with the principles of choice, the individual or their family or advocate might be able to nominate appropriate potential professionals or organisations they would like to be involved (for example, from providers agreed by local partnership boards).

2.31 We have only covered here decisions around detention renewals. However, the issue of decision making around Community Treatment Orders has also been raised with concerns that this also is less robust in terms of safeguards than original detention decisions. We want to seek further views on this issue.

Questions

Q22 Which of these options (options 1, 2 or 3), if any, do you think would have the most impact?

Q23 Do you have any views on risks or costs presented by any of these options?

Q24 Do you have any views on the decision making processes around Community Treatment Orders and how they could be improved?

Mental Capacity Act

2.32 If the individual does not have the capacity to make these particular decisions at a point in time, then the local authority and NHS bodies should be acting under the Mental Capacity Act (MCA). The MCA makes clear, in law, that:

- Professionals should take all appropriate steps to support individuals to make their own decisions (for example, by communicating information and options in a manner more easily understood by the individual).
- Professionals should ensure that the package of care provided to individuals is the least restrictive of their freedoms.
- Individuals should not be treated as unable to make a decision merely because others perceive it to be an "unwise" decision.

2.33 Only where individuals have been judged following a capacity assessment to be unable to make a specific decision at a specific time (capacity is not a fixed concept – it varies over time and for different decisions) can a decision be taken on their behalf. In such circumstances the MCA is clear that the decision must be taken in the best interests of the individual (not for example for the convenience of the commissioner or provider) and that the decision-maker must consider the individual's previously expressed opinions, wishes and beliefs and consult with all appropriate persons, for example, family and carers.

2.34 The placement of individuals who lack capacity far from their normal support network of friends and families can only be justified in terms of the best interests of the individual concerned. The MCA (and the Care Act and Children and Families Act) makes absolutely clear that the well-being of the individual is paramount. Wellbeing is not just about what professionals and statutory organisations see as important but what the individual and their family or carers do. It is the Government's expectation that placements distant from the normal support network should only occur in very rare cases and robust documented evidence must be in place to demonstrate why these placements are in the best interests of the individual.⁴⁵

2.35 A number of important steps are being taken at the moment in relation to the Mental Capacity Act, including the establishment of a National Mental Capacity Forum to look at how MCA implementation can be improved, a new streamlined process for applications to the Court of Protection and the Law Commission's work to review of Deprivation of Liberty Safeguards and propose new legislation that covers care homes, hospitals and community settings. We therefore do not believe it appropriate to propose any further changes to the MCA in this document.

2.36 However, because the interaction of the Mental Health Act and Mental Capacity Act is complex, we have included in **Annex C** a local case study illustrating how one local area has used both together.

Helping people to exercise their rights

2.37 We have also heard that people who may not easily be able to advocate for themselves or who need help expressing their views, wishes, feelings and beliefs in order to exercise their rights have not always been able to access effective support to do so.

Advocacy and the importance of self-advocacy throughout the system

2.38 The Care Act contains important new rights on advocacy,⁴⁶ ensuring that local authorities must provide independent advocacy to facilitate the person's involvement in the care and support assessment, planning and review and safeguarding processes where an individual would experience substantial difficulty in understanding, retaining or using information given, or in communicating their views, wishes or feelings and where there is nobody else appropriate to facilitate their involvement.

45 In the case of restricted patients, the Secretary of State for Justice and National Offender Management Service also clearly have to consider risks and public safety.

46 See *Care and Support Statutory Guidance*, Department of Health (June 2014).

2.39 People should be active partners in the key care and support processes of assessment, care and support planning and review. No matter how complex a person's needs, local authorities are required to involve them, to help them express their wishes and feelings, to support them to weigh up options, and to make their own decisions. The duty to involve applies to these care and support processes, including when they are undertaken jointly with health services, in *all* settings.

2.40 But statutory advocacy provision commissioned by the local authority can also work hand in hand with self-advocacy, community advocacy and peer support, as well as strong local partnership arrangements.

2.41 Self-advocacy groups should be supported and encouraged in all settings both in the community and in inpatient settings. A culture where self-advocacy is valued and supported should flow through the entire system from individual care decisions to the governance of providers, to local and regional partnerships which underpin strategic planning. Self-advocates and families are critical both in drawing up regional/ local and individual plans but also to monitor how effective they are, for example, through local Learning Disability Partnership Boards. Credible local partnership structures within which individuals, their families and self-advocacy groups can influence local decision making at all levels, are very important – not least to support market development duties – as well as working with professionals on local approaches to support and challenge admission and discharge planning.

2.42 We are considering how guidance could help to boost the role of self and family advocates in the system, for example, by setting 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. This could also look at how they engage in offering or supporting genuine employment opportunities to local people with learning disabilities which would further support health and wellbeing outcomes. We also propose to explore with the Care Quality Commission the role they could play in supporting this, for example, as a part of their consideration of how well led such organisations are.

Question

Q25 Guidance could say that only organisations that include self and family advocates in their governance should get contracts with the local authority or the NHS to provide services for people with learning disability or autism. What do you think about this idea?

Independent Mental Health Advocates (IMHAs)

2.43 We know that support from formal advocates can be a key way of safeguarding patient rights, especially for those lacking capacity or with no family or carer support. Under the MHA, people in certain circumstances have the right to access an Independent Mental Health Advocate (IMHA) if they choose to.⁴⁷ All patients in Wales receiving treatment for mental disorder can access an IMHA. They do not need to be detained under the MHA to receive this service.

⁴⁷ Patients are eligible for support from an IMHA if they are detained (subject to a few limited exceptions), if they are conditionally discharged restricted patients, subject to guardianship or subject to community treatment orders.

2.44 We want to ensure the right to access support from an IMHA is being used to full effect to support people. To increase the uptake of IMHAs, some stakeholders have suggested to us making access to IMHAs opt-out rather than opt-in.

2.45 However, we also need to make sure that all patients' rights are protected. This includes their rights⁴⁸ to have their personal data (including sensitive personal data concerning their health) protected. If details about a patient, including the fact that they have been admitted and/or treated under the Mental Health Act, were shared without their consent, this would be a serious breach of their rights to confidentiality and privacy. We are therefore considering how we balance these needs whilst increasing the uptake of IMHA services amongst patients who lack capacity.⁴⁹

2.46 So, **for patients who lack capacity or competence**, in addition to the new guidance in the revised MHA Code of Practice, we are considering ways to **establish an opt out mechanism which would contain the appropriate safeguards to protect patients' right to confidentiality and a private life**. One approach could be a statutory duty, for example on hospital managers, to refer such a patient to an IMHA if this would be in the patient's best interests within the meaning of the MCA, which includes consideration of the individual patient's wishes or feelings. Consideration of patients' relevant advance statements would also be important.

2.47 The legislation could also impose a requirement on the hospital manager to consult key parties, such as the patient's nearest relative (or other nominated representative, such as another family member) before disclosing the patient's personal data to an IMHA.

Questions

Q26 What are your views on making IMHAs available to patients who lack capacity (or competence) on an opt-out basis?

Q27 Have we considered all the safeguards we would need to protect patient confidentiality?

Nearest relative

2.48 The fundamentals of the definition of the "nearest relative" under the MHA have been in existence for over 50 years. It feels at odds with modern views of fundamental citizens' rights that people do determine themselves who their own "nearest relative" is.

2.49 The present definition of "nearest relative" may also be inconsistent with the common understanding of the concept of "nearest relative" that most people would use in their everyday lives. Nor does it align with the common usage of patient-nominated next of kin in health services (i.e. those who may be given authority by the patient to discuss their condition with staff, for example) or with provisions under the Mental Capacity Act, for example for deputies appointed by the Court of Protection or donees of lasting powers of attorney.

48 Rights here include Data Protection Act 1998 and right to a private life under Article 8 of the European Convention on Human Rights.

49 We are not proposing to consider further an opt-out for patients who have capacity or competence to make the decision about whether to have an IMHA.

2.50 This can have the unintended consequence of excluding certain close family members or carers from being legally recognised as the ‘nearest relative’ or main support for a patient detained under the MHA, and therefore not be involved in discussions around care and treatment, despite being best placed to do this and being the patient’s main carer when out of hospital. This could result in a detained patient having someone less familiar and involved fulfilling this role instead, as well as the complications and costs of having to have the legal nearest relative formally displaced in order to rectify this situation.

2.51 We think that this matters because it is a cost to the system and services to try to identify “nearest relatives” who may not even be in close contact with the people concerned, as well as the legal costs of challenges brought about because of problems identifying the correct nearest relative from the statutory definition, or displacing them. But far more importantly, it matters because it may get in the way of real, meaningful involvement by family members who have close relationships with the people being cared for under the MHA.

2.52 Because a “nearest relative” has very specific rights and responsibilities under the MHA,⁵⁰ it could be difficult in practice to have multiple nearest relatives for a patient because this makes it more uncertain as to when requirements under the Act had been complied with, it could delay treatment and it could impose a disproportionate resourcing burden, particularly in relation to AMHP’s duties to consult with nearest relatives and hospital managers’ duties to provide information to nearest relatives. There is also a risk of potential adverse consequences from more frequent challenge and change.

2.53 The current MHA definition is hierarchical from a specified list. The aim was that this would give practical benefits of being able to identify the nearest relative quickly and with certainty.

2.54 However, we have heard from practitioners on the ground that many feel the current definition simply does not reflect the complexity of people’s lives and family relationships and that it is not necessarily providing the speed and certainty intended – as well as feeling at odds with people’s rights. AMHPs tell us that they currently can be uncertain about whether the MHA has been complied with and whether they have tracked down the correct nearest relative.

2.55 Given the specific duties under the MHA of the nearest relative, it is even more important that the definition should be meaningful for the person being treated.

2.56 We are looking at how this could be changed so that ***the patient can choose their own nearest relative if they are able to***. However, we propose to retain a hierarchical list of persons who can be identified as the “nearest relative” as a back-up. If this approach were adopted, we would need to consider and consult further on issues such as:

- whether there would need to be any restrictions upon who could be eligible to be chosen by the patient;

50 For example: the right to receive a copy of any information given to the patient in writing, unless the patient requests otherwise (see para 14.31 of the Code); the right to request that the patient be visited and interviewed by an IMHA (see para 6.22 of the Code); the right to apply for a patient’s detention (see para 14.30); the right to require a local authority to arrange for an AMHP to consider the patient’s case (see para 14.32).

- how to manage a situation where a chosen person declines to act as “nearest relative”;
- what to do if the clinical team determines that the chosen person is unsuitable⁵¹ to be the “nearest relative” and the process for displacing an unsuitable “nearest relative” who the patient has chosen (e.g. if there were concerns they posed a risk to the patient – not simply because the clinical team did not like or agree with their decisions). Such a process would need to comply with Human Rights law;
- Whether patients who lack capacity would need another decision maker on their behalf e.g. a deputy appointed by the Court of Protection or the donee of a lasting power of attorney, or another specified person;
- Whether the right to choose the “nearest relative” would also be given to children under 16 who are competent.

Questions

Q28 What do you think about the idea that we should explore changing the law so that people choose their own “nearest relative” (retaining a hierarchical list to be used if necessary)?

Q29 Do you agree with our view that this should reduce the cost of displacement and disputes?

The role of social workers and/or named professionals in supporting people’s rights

2.57 Social workers can work with the individual, their networks and their communities and take a personalised approach focused on supporting people to be as independent as possible and included as citizens in their own right. However, in some cases, we hear that they are not as engaged in the process of care planning, placement, inpatient admission or review as they could be.

2.58 We think this distinctive role could be reflected in a **responsibility for a named social worker** to ensure that every individual’s plan is based on the least restrictive, least institutional setting and by giving them a primary professional responsibility to ensure that community based options have been fully considered. Where people are based in more restrictive settings, social workers would be responsible for reviewing care regularly and seeking less restrictive and more inclusive opportunities (this links to earlier sections on people understanding their rights and on challenge at admission, renewal, detention and discharge planning). We will consider whether this could be set out in statutory guidance.

2.59 We also think social workers are well placed to be the named individual to ensure a co-productive approach with individuals and their families in agreeing their care and support arrangements and to ensure they are kept informed and involved. In line with the core principle of respecting people’s rights to choice and control in their own lives we propose that, although the default might be that the social worker played this role, the individual and/

51 Section 1 of the Mental Capacity Act 2005 establishes that a person is assumed to have capacity unless it is established that they lack capacity. A person must not be treated as lacking capacity merely because they make an unwise decision. Therefore, unless the person is assessed to lack capacity, they should be entitled to make what others may think are “bad choices” with respect to their “nearest relatives”.

or their family would be in control. This means that individuals, supported as appropriate by their families, would have the right to choose someone else, such as community nurse, professional carers or a care coordinator if they were happy that the person had the right skills and were able to fulfil the role. This may be subject to further consultation on how or whether those not employed directly by the LA could carry out this function the issues around decisions relating to care and support arrangements for patients under part 3 of the MHA are different. However, it would also be of benefit for patients under part 3 of the MHA to be in contact with a named social worker, particularly as they approach potential discharge into the community.

Questions

Q30 A named social worker could be responsible for working with the person and their family to keep them informed and involved and to make sure less restrictive and community based plans are considered. What do you think about this idea?

Support and accountability if something goes wrong

2.60 One thing we also hear often from people and families is that it can be hard to know how to raise issues and get support if something goes wrong. Following the Francis Inquiry,⁵² as well as the review into Winterbourne View Hospital, a number of measures already have been put into place or are currently being put into place to strengthen the response, particularly of the NHS, in these circumstances.

These include:

- The Care Quality Commission is routinely examining how well organisations handle complaints. Where organisations fall short, this will be reflected in inspection findings.
- A new accessible guide has been issued by the Department of Health and NHS England on making complaints and giving feedback. This supports the right in the NHS Constitution to complain.
- The Parliamentary and Health Service Ombudsman, with Healthwatch England and the Local Government Ombudsman have published universal expectations for raising concerns and complaints to support improvements in complaint handling.
- In response to the review by the Rt Hon Ann Clwyd MP and Professor Tricia Hart of NHS complaints handling, the Government accepted that a review of NHS complaints advocacy services should be conducted to measure the effectiveness of the provision of complaints advocacy services to the public. This review is expected to be complete later in the spring of 2015.
- Accountability within organisations has been strengthened through CQC's new inspection regime and through the introduction of the new "fit and proper persons test" for directors which will apply to all health and adult social care providers registered with CQC from April 2015.

52 The Mid-Staffordshire NHS Foundation Trust Public Inquiry (2010)

- The new statutory fundamental standards of care against which CQC inspect can result in prosecution if standards are not met and this results in harm.
- Two new criminal offences of ill-treatment and wilful neglect have also been put in place which come into force in 2015.

In the light of these advances we are interested in views, particularly from people using services and families, whether there is anything further they think is required.

Question

Q31 What else, if anything, is needed to support people and families to raise issues if something has gone wrong?

3. My rights under the Mental Health Act

Application of the Mental Health Act to learning disabilities and autism

3.1 In the Mental Health Act (MHA), “mental disorder” is defined as “any disorder or disability of the mind’. The terminology of mental disorder reflects the clinical typology which is set out in clinical classification and diagnostic tools like the American Psychiatric Association *Diagnostic and Statistical Manual of Mental Disorders*⁵³ and the *International Statistical Classification of Diseases and Related Health Problems*.⁵⁴ Both of these include a wide range of mental illnesses, disorders and behavioural disorders (ICD) and both include autistic spectrum conditions and learning disabilities. However, ICD-10, also includes amongst listed mental and behavioural disorders dementia, Parkinson’s, dyslexia and stuttering.

3.2 The MHA does not currently specify which conditions fall within the definition of “mental disorder” for the purposes of the MHA, though it does exclude dependence on alcohol or drugs. The MHA does however limit its application to learning disabilities by providing that a person with a learning disability cannot be considered to have a “mental disorder” for the purposes of certain sections of the MHA unless ‘that disability is associated with abnormally aggressive or seriously irresponsible conduct’ (section 1(2A)). This exclusion is referred to in the MHA Code of Practice as the “learning disability qualification”.

3.3 We have heard a view from some people that they feel that, in practice, individuals are detained for treatment under the MHA purely because they have behaviour that is challenging as a consequence of their learning disability or autism,⁵⁵ even where there is in fact no appropriate medical treatment available for that person in that hospital in relation to such behaviours. This is unacceptable and illegal. The availability of appropriate medical treatment⁵⁶ in a hospital is required in order for someone to be detained for treatment under section 3 of the MHA.

3.4 We have also heard many concerns that a person’s behaviour may worsen as they are placed in more restrictive settings with less access to close friends, family and community, making it more difficult and less likely for the person to be discharged to live in the community again. There is a concern that this can lead to people, in the worst cases, spending many years in hospital.

53 <http://www.dsm5.org/Pages/Default.aspx>

54 <http://www.who.int/classifications/icd/en/>

55 We use the term autism rather than autistic spectrum disorder throughout this section as consistent with the approach and terminology throughout the rest of the document and *Think Autism (2014)*. The MHA Code of Practice uses the term autism spectrum disorder.

56 “Medical treatment” is defined in section 145(1) of the MHA.

3.5 We have therefore emphasised in the Introduction of the revised Code of Practice the importance of the oversight role of the Care Quality Commission and its enforcement powers against mental health providers which fail to apply properly the MHA and the Code.

3.6 Some people also argue that, as learning disability and autism are not mental illnesses, they should not be captured under the MHA definitions of mental disorder at all. They think that learning disability or autism are not conditions that make it appropriate for the individuals to receive medical treatment in hospital, as is required under Section 3, unless they have a mental illness as well. The Justice for LB campaign has gathered many views from a variety of stakeholders in support of this position.

3.7 Other people are concerned about the disparity between how learning disabilities and autism are treated under the MHA. A person with autism, for example, *can* be considered to have a “mental disorder” under the MHA whether or not that condition is “associated with abnormally aggressive or seriously irresponsible conduct”, which is not the case for a person who has solely learning disabilities.

3.8 In light of these concerns, we are considering ***whether, and how, the treatment of learning disabilities and autism under the MHA should be changed.***

Option 1: expressly exclude both learning disabilities and autism from the MHA

- We are interested in exploring views on the potential benefits and risks of excluding learning disability and autism entirely from the MHA definition of “mental disorder”. This would mean that a person with a learning disability and/or autism could not be considered on that basis alone to have a “mental disorder” under the MHA, regardless of whether their behaviour could be viewed as abnormally aggressive or seriously irresponsible. They would have to have a separate mental disorder or illness in order to be detained under the MHA.
- The MHA currently enables the courts to divert people who are accused of or have committed an offence to an inpatient setting for assessment and treatment instead of remanding them to custody or imposing a custodial sentence or other available option. If LD and/or autism were excluded from the definition of “mental disorder” under the MHA, this could prevent the court from diverting those offenders to an inpatient setting – when, for example, a prison or equivalent may not be appropriate for them. It is therefore necessary to consider what this option would mean for those offenders with learning disabilities or autism who the courts may currently divert to an inpatient setting.
- It has been suggested that this could also result in a rise in self harm, suicides or harm to others if people are not supported effectively.
- It could also result in seeking more deprivation of liberty authorisations under the Mental Capacity Act 2005 (MCA)⁵⁷ or other court orders⁵⁸ if they need to be in circumstances that amount to deprivation of their liberty and the person lacks the capacity to consent to that deprivation of liberty. However, this may not necessarily be a negative impact if this means people’s interests are being appropriately and legally safeguarded.

57 Schedule A1 to the Mental Capacity Act 2005.

58 The Court of Protection for those aged 16 and over, and the High Court for those under 16.

Option 2: amend the definition of “mental disorder”, by tightening the “learning disability qualification” and adding a new “autism qualification”

- Alternatively, we could look at changing the definition of “mental disorder” to make it more difficult for someone who has a learning disability or autism to be detained for treatment under the MHA. For example, we could amend the current learning disability qualification and set out a narrower set of circumstances in which a person with learning disability would still be considered to have a “mental disorder” for the purposes of the MHA.
- We could also add a new “autism qualification” so a person with an autism could also not be considered to have a “mental disorder” unless their condition was of a type that met certain criteria, similar to the learning disability qualification.
- However, as for option 1, we would need to consider carefully what this option would mean for any offenders whom the courts might currently divert to an inpatient setting but who could fall outside the definition of “mental disorder” if amended.
- This option would not tackle people’s fundamental concerns about the perception of learning disability and autism as mental disorders which need assessment and treatment for which people can be detained. Another risk of this approach might also be that each type of mental disorder ought to have specific provisions/qualifications in the MHA.

Option 3: exclude learning disabilities and autism from the civil sections of the Mental Health Act (part 2) but not the criminal justice sections (part 3)⁵⁹

- This would continue to allow the Courts to have all available options when dealing with an offender with learning disabilities or autism to ensure they were supported and managed in the way and place that is most appropriate for them, given their needs. This would not stop people with learning disabilities or autism from being treated in the same way as other offenders who have mental disorders for the purposes of part 3 of the MHA.
- It would mean, however, that, unless decided by the courts (under part 3 of the MHA), a person with learning disability or autism could not be detained under the MHA unless they had a separate mental disorder or illness.
- However, this could effectively create two definitions of mental disorder under the MHA. We would need to ensure there were no equality considerations or concerns. It may also, as for option 2, not address peoples’ fundamental concerns about the perception of learning disability and autism as mental disorders.

Questions

Q32 Which of options 1), 2) or 3), if any, seems most appropriate?

Q33 What is your view on the potential benefits or unintended consequences of the options set out?

⁵⁹ In full this means this option would be to exclude people with learning disabilities and autism from being considered to have a mental disorder *for that reason* for the purposes of the civil provisions of the Mental Health Act (Part 2).

A single gateway to MHA assessment and treatment with a single clearer set of safeguards

3.9 We also hear that the Mental Health Act can be complex. We are concerned that the complexity may add costs and may impact on compliance. The more complex the law is, the more difficult it is for patients and families to understand their rights. If complexity is not necessary to support people's interests, we should seek to remove it. In this context, we are, in particular, seeking views on sections 2 and 3 of the MHA.

3.10 Currently people can be detained under section 2 for up to 28 days for either just assessment or assessment followed by treatment or under section 3 for up to 6 months for treatment. Section 2 itself *cannot* be renewed, but a person can move onto section 3 from section 2; section 3 *can* be renewed for an initial period of 6 months, and for subsequent periods of one year *indefinitely*; renewals are subject to reports from the Responsible Clinician (and consultation with a second professional) that the person still meets the criteria to be detained. The recently revised MHA Code provides guidance about the circumstances in which detention under one section should be preferred over the other.

3.11 The use of the different sections is important because it also means that people detained under these sections receive different levels of safeguards. For example, a patient may apply to a tribunal *within 14 days* of the patient being admitted under section 2 of the Act, while for section 3 patients, a patient can apply once during the first *6 months* of the date of admission. This reflects that admission under section 2 is for up to 28 days, whereas admission under section 3 is for up to 6 months. A nearest relative does not have to be consulted for admission under section 2 but they do under section 3 – and can object, preventing detention. Patients also have different entitlements when discharged. For example, section 3 patients qualify for s117 after-care which can encompass healthcare, social care and other services and is provided free of charge, but section 2 patients are not eligible for after-care. It can be hard for patients and their families to understand these complex different rights.

3.12 The differences between sections 2 and 3 could be addressed through a **single gateway to assessment and treatment**, in other words, one set of criteria for detention which could reinforce the least restriction principle for all patients, while providing equity in other aspects of their care to ensure that perverse incentives were not driving unnecessary or prolonged detentions. We think this could make it easier for individuals and their families and advocates to understand their rights and make sure the current legal safeguards are used most effectively. This may be subject to further consultation to determine how this change could be put into effect.⁶⁰ We would need to ensure that, first and foremost, patients' rights were equally protected and that there is no diminution of their rights.

3.13 We do not believe that this would, in itself, have any impact on costs of providing mental health services. Any potential factors which would have significant cost implications in putting this into effect would be subject to further consultation.⁶¹

⁶⁰ Further detailed consultation would also be needed on how to bring this into effect, including elements such as S117 implications. We are clear such a change would need to be at worst cost neutral for services.

⁶¹ As set out at the start of this document, any changes will not entail additional unfunded costs.

Questions

Q34 We want to explore changing the law so that there is one set of criteria for detention for assessment and treatment under the Mental Health Act (amending sections 2 and 3). What do you think of this idea?

NHS commissioners and the Mental Health Act

3.14 Clinical commissioning groups and NHS England in their specialised commissioning role have a very important role to play in making sure that the MHA works well in practice.

3.15 The Code of Practice highlights the importance of health commissioners ensuring that they are familiar with the requirements of the Code and that they have appropriate training on this.⁶² However, the Code of Practice is not currently statutory guidance for CCGs or NHS England, as they are not included in Section 118 of the MHA as one of the bodies to whom the Code of Practice applies as statutory guidance.

3.16 The Code of Practice makes clear that it is there to provide guidance for what commissioners do in relation to mental health services, as well as providers. Stakeholders have told us, however, that they are worried that the commissioning guidance that we provide to clinical commissioning groups in the revised Code has no statutory backing, in the event that CCGs are non-compliant. We are therefore proposing to amend legislation to ***make the MHA Code applicable to CCGs and NHS England on a statutory basis.***

Question

Q35 We propose to clarify in law that the Mental Health Act Code of Practice should apply to clinical commissioning groups and NHS England commissioning. What do you think of this idea?

Interactions with police and the criminal justice system

3.17 Some people who are in inpatient mental health settings, including some people with learning disability have come into previous contact with the police or criminal justice system. We need to ensure these systems are working together well so people receive the right care in the right setting, whilst keeping them and the community safe.

“Section 135 and 136” review: use of police cells

3.18 Sometimes, it is also the case that people experiencing a mental health crisis, are taken to police cells as a “place of safety” for them.

3.19 The government is seeking to ***substantially reduce the use of police cells as a place of safety for anyone experiencing a mental health crisis who is detained under the Mental Health Act.*** The government’s own review of the operation of Sections 135 and 136 of the mental Health Act 1983 was set up in response to concerns over the use of police cells

62 Introduction to the Mental Health Act Code, Figure ii, page 13.

as places of safety,⁶³ especially for children and young people,⁶⁴ and about the maximum length of detention under sections 135 and 136 (currently 72 hours).⁶⁵

3.20 The MHA Code of Practice makes clear that police cells are not an appropriate place for people to be placed when in mental health crisis, except in exceptional circumstances (for example, because the other person's behaviour would pose an unmanageably high risk to other patients, staff or service users if the person were to be detained in a healthcare setting). The Code also makes clear that a police station should not be used as the automatic second choice if there is no health based place of safety immediately available, although, if it is to be used for that purpose, the person's assessment should be made a priority and done as quickly as possible.

3.21 The Government's review of the operation of sections 135 and 136 reported its recommendations in December 2014.⁶⁶ The review engaged external stakeholders including academic experts, professionals in health, ambulance services and policing, people who have experienced being detained under these parts of the legislation, and their carers, families, and friends.

3.22 The government has made clear its commitment to take forward the recommendations when possible, including legislation where necessary. The review recommendations should:

- bring an end to the use of police cells for under 18s;
- significantly reduce the use of police custody as a place of safety for adults so that it becomes a genuinely exceptional event;
- encourage and enable innovation in using alternative places of safety;
- remove barriers preventing a person in mental health crisis from accessing help wherever they are while protecting human rights and civil liberties;
- encourage more rapid assessment and to ensure a person is not detained for longer than the minimum time necessary;
- reduce inappropriate use of section 136;
- improve the operation of section 135; and
- ensure that police, paramedics, AMHPs and health professionals have appropriate powers.

3.23 The review also proposed that powers should be created for professionals other than the police to be able to remove a person from a public place to a place of safety when they are experiencing a mental health crisis. We will be exploring options on how to take forward

63 Her Majesty's Inspectorate of Constabulary (HMIC) (2013) *A Criminal Use of Police Cells*, online at: <http://www.justiceinspectorates.gov.uk/hmic/media/a-criminal-use-of-police-cells-20130620.pdf> and Independent Police Complaints Commission (IPCC) (2008) *Police Custody as a 'Place of Safety'*, online at: http://www.ipcc.gov.uk/sites/default/files/Documents/guidelines_reports/section_136.pdf

64 For example, <http://www.theguardian.com/society/2014/aug/17/mentally-ill-children-police-cells>

65 Mental Health Alliance (2007), online at: http://www.mentalhealthalliance.org.uk/pre2007/documents/LordsCtteeStage_136_Briefing.pdf

66 Review of the Operation of Sections 135 and 136 of the Mental Health Act 1983 Review Report and Recommendations, Department of Health and Home Office (December 2014)

this recommendation. However, we are interested in hearing views on the principle of this proposal as part of this consultation.

Questions

Q36 What is your view on the proposal that children and young people aged under 18 detained under sections 135 or 136 should never be taken to police cells?

Q37 What is your view on the proposal that the use of police cells for people aged over 18 should be more limited in terms of frequency and length of time they can be detained?

Q38 What is your view on any other recommendations in the Review?

Q39 What is your view on the review proposal to create powers for professionals other than the police to be able to take a person from a public place to a place of safety?

Q40 Are there any practical considerations we should take into account during further developmental work and implementation of the Review proposals?

Restricted patients: discharge with conditions

3.24 Restricted patients under the Mental Health Act are patients who have been diverted from the criminal justice system into secure hospitals. This may be via direct Court Order at the time of sentencing, being transferred from prison or as a result of a hospital order prior to a term of imprisonment. Because of concerns about public safety, the patient may be subject to a “restriction order” which results in the Secretary of State for Justice having a role in the management of that patient, including in relation to decisions about leave in the community, transfers between hospitals, remission to prison and discharge.

3.25 It is the Secretary of State for Justice or the Tribunal that can determine when the patient can be discharged from hospital, unless the patient is a transferred prisoner subject to release by the Parole Board. Discharge can be conditional, in which case specific conditions are applied, or it can be absolute. The patient will remain liable to be recalled or brought back to hospital by the Secretary of State for Justice.

3.26 Because of the need to safeguard the public, some patients will need very intensive and potentially restrictive conditions on discharge in order to allow them to live in the community in a way that ensures their own or others’ safety.

3.27 In a case known as “the RB case”, the Court of Appeal ruled that a patient cannot be conditionally discharged from detention in a secure hospital into a care home subject to conditions that amount to a deprivation of liberty.⁶⁷ This was because the MHA only provides for detention in a hospital, with all the necessary procedural guarantees and safeguards required, when deprivation of liberty is an issue. In this case, the condition in question required the patient to be supervised at all times. As a result, a number of patients are continuing to be detained in secure hospitals, even after they may be in a position appropriate for conditional discharge. If a patient cannot be discharged subject to conditions which

67 Secretary of State v (1) RB v (2) Lancashire Care NHS Foundation Trust [2011] EWCA Civ 1608.

amount to a deprivation of liberty, then certain patients are likely to remain within the inpatient setting indefinitely as a consequence of “the RB case”.

3.28 This is not readily compatible with one of our core MHA guiding principles that the right care is care in the least restrictive setting possible. It also adversely affects a number of people with learning disability or autism spectrum conditions who have behaviour that may challenge, or those with mental health problems who are currently in inpatient settings and who could, and should, be moved to alternative less restrictive settings – even where such a setting would still amount to a deprivation of liberty. It is also potentially more costly to continue to detain people in hospital when they could be living, with conditions, in other settings.

3.29 A self-advocate with learning disability said to us:

People on Ministry of Justice restrictions should be able to be out, supported by the right sort of provider to live in a supported flat and able to do the right sort of activities with staff who are specially trained in the legal system and know how to help that person to get sorted – attend counselling, attend probation service, help them sort out drink or drug problems. Then they might eventually be able to set up in their own home safely after being out with restrictions.

3.30 We want to seek views on ***whether the MHA should be amended to allow restricted patients to be discharged from hospital subject to conditions imposed by the Secretary of State for Justice (SSJ) or the Tribunal which would amount to a deprivation of liberty in the community.***

3.31 Further consideration would need to be given to:

- how the new restrictions would work with both the MHA and the MCA;
- what restrictions there should be on the care settings to which a restricted patient could be conditionally discharged which could amount to a deprivation of liberty;
- who could apply for such a discharge on this basis; and
- what right of review a restricted patient subject to these discharge conditions would have.

Questions

Q41 Do you think it would be desirable in principle to amend the MHA to enable restricted patients to be discharged by the Secretary of State for Justice or a Tribunal subject to conditions amounting to a deprivation of their liberty?

Q42 Does the MHA need to provide for another form of detention for patients who do not need to be in hospital but who must be in effect deprived of their liberty in order to be discharged from hospital into a community based setting?

4. My right to control my own support and services with a personal budget. My right for my NHS and Local Authority to work together for my benefit

Integrated care planning

4.1 All services and systems should start from the individual. People are best placed to determine their own needs, wishes and preferences. This means, wherever possible, being able to choose providers of care and health, choose how they want to be supported and by whom.

4.2 To achieve this vision, health and care, and other systems, such as services to help people gain and sustain employment, should join up around the individual. This means an integrated approach should be taken to individual plans across care and support and health and, where possible, the other factors that contribute to wellbeing and inclusion and independence including employment.

4.3 There is now a clear model in operation for this approach. The Children and Families Act sets out that the clinical commissioning group and local authority will now jointly commission services for 0-25 year old children, young people and young adults with SEN and disability. The local authority must present the services available publicly as a local offer, including how to complain. Clinical commissioning groups and local authorities must oversee a coordinated assessment of the needs of an individual child or young person and agree an individualised outcomes-focused Education Health and Care plan (EHC). Clinical commissioning groups are under a statutory duty to secure the health provision specified in the plan. The plan has to be developed in partnership with the child or young person and their family. Its starting point is not existing care or the existing offer of services but the needs and aspirations of the child or young person. The EHC plan should be focussed on preparing the child or young person for adulthood, including independent living and a smooth transition to adult services. Those with an EHC plan have the right to request a personal budget.

4.4 Local authorities and clinical commissioning groups should be learning from the EHC approach and using it to help develop the way they ensure adults' needs are met too. Learning disability and autism are lifelong. The new EHC plan approach could guide a person centred plan individual care plan for adults' employment or inclusion, health and care.

4.5 Personal budgets are vital to this. Personal budgets are currently available in social care and are being introduced in health. All types of personal budgets centre around personalised care and support planning, focusing on the whole of the person's life, not just on health and care needs. Individuals and their families should be fully included in planning – based on what is important to them. In addition, people should be able get the information, support and advocacy they need to help them be involved in planning their care and support effectively.

Personal budgets

Personal Budgets for Care and Support

4.6 Personal budgets in social care have grown significantly and now nearly 760,000⁶⁸ people in England have one. Self-directed support is the norm for community social support and many who were previously in residential care are able to live independently and choose their own care and support. The introduction of direct payments in the 1990s was in direct response to the call from disabled people for independent living.

4.7 The Care Act will place personal budgets into law for the first time. It will ensure that more people with care and support needs receive a personal budget as part of a care and support plan, regardless of the setting they are in.⁶⁹ The Care Act also reinforces the existing right that an individual can request a direct payment to meet their needs providing that the conditions in the Act are met.

4.8 The Department of Health is also currently testing the use of direct payments in residential care, with the intention to roll this out across all local authorities in 2016.

Personal Health Budgets

4.9 Personal health budgets can successfully enable people with long term conditions or disabilities, who need higher levels of support, to be involved in planning their own care and support and to use money that would have been spent on their care differently in ways that work for them.

4.10 A right to have a personal health budget for people in receipt of NHS Continuing Health Care (NHS CHC) was introduced in October 2014. However, clinical commissioning groups are able to offer them on a voluntary basis to others who may benefit. The *Forward View into action: Planning for 2015/16*⁷⁰ requires Clinical Commissioning Groups to set out their local personal health budget offer and include this in their Joint Health and Wellbeing Strategy.

4.11 NHS England has set clear expectations that personal health budgets will be rolled out beyond NHS Continuing Healthcare. As set out in the 2015/16 planning guidance, Clinical Commissioning Groups will be expected to work with their local authority partners and their local communities to plan their local offer. There is a requirement that their local offer specifically includes people with learning disabilities and autism and children with special educational needs and disabilities, including autism.

4.12 For adults, we know that currently people with learning disabilities can and do already have personal budgets and/or personal health budgets which make a difference to their lives. As Sir Stephen Bubb recommends in his report,⁷¹ one step towards achieving people having more control so they can be cared for in the right place and not institutionalised is to expand the provision of personal budgets in both health and social care.

68 This figure includes 647,000 users and 112,000 carers. <http://www.hscic.gov.uk/searchcatalogue?productid=16628&topics=0%2fSocial+care&sort=Relevance&size=10&page=1#top>

69 There are some exemptions in the Act.

70 www.england.nhs.uk/ourwork/forward-view/

71 Winterbourne View – Time for Change (2014).

Case Studies

Jason lived in a long stay in-patient unit for 22 years.⁷² A personal budget, managed by his sister has enabled him to move to a self-contained bungalow on a farm supported by carers chosen by them and he is involved in planning his care and activities. Since moving to his new home there have been no incidents of self-harm, and there has been a significant reduction in the frequency and duration of Jason's seizures. In addition Jason's challenging behaviour has ceased and there is no need for 2:1 or 3:1 staffing. Jason continues to have his problems, but his sister reports that his life now has meaning and not just containment and survival.

Pete, 20 and from Nottingham,⁷³ has autism and type I diabetes. He has an integrated personal budget for health, social care and education. Pete and his mum Michelle chose carers that he has known since childhood who have been trained to manage his diabetes they attend college with him, enabling him to continue his education. Pete has also been able to remain at home rather than entering residential care; he has more opportunities for social interaction and is a happier young man.

4.13 However, despite these positive case studies, we know that uptake differs across different groups of people. We would like to increase the uptake of personal budgets across health and social care for both children and adults with learning disabilities. We think that, in particular, this would be a crucial move for those with complex needs and behavioural problems. We believe that this personalised approach could significantly help to ensure that they can remain living in the community or help to return people to the community.

4.14 We want people who receive both health and social care funding to be able to have a seamless integrated budget, and single planning discussion and plan in the same way that many children with learning disabilities will in future have a single assessment, and an Educational, Health and Care Plan.

4.15 The new Integrated Personal Commissioning (IPC) programme was launched by NHS England in July 2014. It will for the first time, blend health and social care funding at the level of the individual for some of the people with the highest care needs and allow them to direct how the money is used. The joint NHS England, Local Authority led programme will run for three years from April 2015. Sites were invited to apply to be part of the pilot and we know that 4 out of the 9 areas selected plan to include people with learning disabilities. The programme will give us key information about how funding streams, for example those used to fund individual placements in institutions, can be blended and used differently in ways that work best for individuals and their families. The programme will be independently evaluated.

4.16 New rights to make individual choices will need to be matched by the development of more diverse provider markets with new kinds of intervention. Commissioners will need to use the information about met and unmet choices generated by Personal Health Budget Holders and their advocates to build a picture of what kinds of intervention and care provider are available in that area and what needs to be further developed.

⁷² http://www.thinklocalactpersonal.org.uk/_library/Reports/TLAPIncludingLD.pdf

⁷³ <http://www.personalhealthbudgets.england.nhs.uk/About/faqs/Personalhealthbudgetsandlearningdisabilities/?parent=8751&child=8574>

4.17 To build on the actions set out above, we are proposing **introducing a legal right to have a personal health budget for some people with learning disabilities or autism**. We are considering two options, which are not necessarily mutually exclusive, either:

Option 1:

- Aimed at the, up to 3,300 people with learning disability or autism and either mental health problems or behaviour that challenges who are currently in inpatient institutions. This would be targeted to help those where there is no longer a justifiable clinical or legal⁷⁴ reason for them to be there, move back into the community. The aim of this is not to change the way their institutional care is paid for, except in exceptional circumstances, but rather help them to be discharged and then live as independently as possible; or

Option 2:

- Aimed at those people with learning disabilities who have mental health needs or challenging behaviour and are subject to the Care Programme Approach⁷⁵ whether in the community or institutional care.

Questions

Q43 Which of the options above (option 1 or option 2) do you think would be most effective?

Q44 What else might need to happen in order for such Personal Health Budgets to enable people to choose new providers and/or new kinds of service or interventions?

Q45 How can we ensure that the new arrangements under the Children and Families Act can also be used to prevent unnecessary admissions in adulthood?

4.18 Ultimately, with personal budgets and the Integrated Personal Commissioning Programme, we are seeking to expand the ways in which people might be able to join the funds up for their own identified needs. Joint planning and commissioning ought, of course, to be fully inclusive of and in partnership with local self-advocates and family carers. Individual rights will always be undermined if processes remain entirely professionally led when it comes to local planning, commissioning and scrutiny.

Pooled budgets

4.19 In many areas local clinical commissioning groups and local authorities already pool budgets for mental health and for learning disability services. But we know this does not happen everywhere. For example, in the 2013 stocktake, only 27 per cent of local authorities

74 People with learning disabilities or autism that are in institutional care settings because: there is a clearly agreed clinical need; because they have been convicted of an offence; or because they are under restrictions by the Ministry of Justice, would not be eligible.

75 The Care programme Approach (CPA) is a way that services are assessed, planned, coordinated and reviewed for someone with mental health problems or a range of complex needs. More information can be found at: <http://www.nhs.uk/conditions/social-care-and-support-guide/Pages/care-programme-approach.aspx>

reported they had pooled budgets with health for learning disability services.⁷⁶ At times, we have heard that separate NHS and LA budgets can prove a barrier to individuals getting the care, treatment and support that is right for them.

4.20 Current legislation provides a clear legal basis for local areas to pool budgets. However, we know that not everywhere is doing this. It may be the case that the strongest driver for this is simply relationships between people locally – which is extremely difficult to legislate for.

4.21 However, there have been growing calls for the Department to mandate this pooling. Sir Stephen Bubb recommended in his report⁷⁷ that:

Through a mandatory framework, NHS England should require local NHS Commissioners to pool their spending with commissioners of social care and housing services for adults with learning disabilities who present behaviour that challenges, and mandate them to produce a single, outcomes-focused plan for using that spending, covering a period of a number of years.

4.22 The Care Act enabled the integrated health and social care budget, the Better Care Fund, to be set up. Where the NHS Mandate sets objectives relating to service integration, a specified sum of money can be used for service integration objectives and NHS England can require CCGs to use a designated amount of money for service integration objectives through pooled funds between health and social care. This can have conditions, such as requiring spending plans for how to use the designated amount (a “spending plan”) which includes performance objectives in a spending plan and what happens if those objectives are not met.

4.23 In their recent report,⁷⁸ the National Audit Office (NAO) also made the following recommendation:

The government should use the mechanisms offered by the Better Care Fund to mandate pooled budgets for care services for people with learning disabilities from April 2016.

4.24 Following the NAO recommendation, we are interested in exploring the extent to which this existing legal framework could also be used to ensure that people with learning disability or autism and mental health problems or behaviour that challenges could be supported in their community both by providing a funding mechanism specifically to secure the set-up of appropriate community based care and treatment options to enable discharge and to reduce the number of future admissions.

4.25 This is not about altering the Better Care Fund itself but exploring whether the legislation provides a mechanism whereby a smaller mandated integrated budget could be set up (with a NHS mandate requirement for a ring-fenced amount within the NHS England budget) to be used for these specific service integration purposes with a set of specific conditions attached. This could include an element of the NHS England specialised commissioning budget. On the LA side, the LD grant element could be notionally separated and mandated to be pooled. This could help local areas manage set up and also ensure joint working. Autism budgets

76 Winterbourne View joint improvement programme stocktake of progress report, September 2013, Local Government Association.

77 Winterbourne View – Time for Change (2014).

78 Care services for people with learning disabilities and challenging behaviour, National Audit Office (February 2015.)

might also need to be considered. It would not be appropriate to expect learning disability budgets to absorb autism as well if they do not currently cover both. Directors of Adult Social Services and CCG Chief Executives could be jointly accountable locally for delivering a plan with clear performance measures for their locality on which they have to report. The Health and Wellbeing Board has a vital role to play in local joint planning and needs assessment. Local partnership boards such as Learning Disability or Autism Partnership Boards can also provide a vital forum to enable genuine involvement of and accountability to local people. Accountability to local people with disability and their families is particularly important.

4.26 As Sir Stephen Bubb recommended in his report,⁷⁹ joint planning and commissioning has to go hand in hand with pooled budgets. Pooled budgets cannot operate in a way that is detached from commissioning or detached from procurement activities or from individual care planning decisions. Service planning, procurement and delivery all need to be joined more effectively to deliver the real benefits from an integrated or pooled budget.

Questions

Q46 We could seek to set up and mandate specific pooled funding, with joint planning, to help people with learning disability and/or autism get discharged from hospital or help prevent them being admitted. This could include specialised commissioning funding. What do you think of this idea?

Q47 Are there further ways we could strengthen local accountability, particularly to disabled people and their families?

Information sharing

4.27 One of the main elements of the Better Care Fund is better data sharing between health and social care as it is clear that the safe, secure sharing of data in the best interests of people who use care and support is essential to the provision of safe, seamless care.

4.28 All commissioners of health and care services in England, in exercising their commissioning functions, need to ensure that the services they are commissioning provide high quality and safe care for individual patients. Whenever commissioning responsibility is transferred between commissioners, people should experience continuity of high quality, safe and appropriate care.

4.29 The lessons from Winterbourne View demonstrate only too clearly that those responsible for commissioning health or social care services, particularly bespoke or intensive packages of care, must have the ability to monitor the performance of the provider under every contract they commission. In order to do this they need to have access to information on quality and potentially on individual patients' needs and care plans which will be generated or facilitated and held by the provider.

4.30 We have heard that, sometimes, commissioners have not been able to do this effectively for individuals whose care they are responsible for commissioning because they cannot access the information in care records are held by providers in a timely manner, with

⁷⁹ Winterbourne View – Time for Change (2014).

clear legal authority to do so. This is because a care record is held by a provider who is rightly under a duty of confidentiality to the individual who is the subject of the record. The team involved in providing direct care and treatment for someone are clearly able to share information legally but some providers do not think they can lawfully share this information with commissioners.

4.31 This matters because, if the commissioners are trying to put in place alternative care arrangements, for example in the community, or to check whether the provider is providing the right sort of care, they may need access to information about an individuals' care and treatment.

4.32 In many cases explicit consent can be sought from the individual receiving care to enable the commissioner, in particular those responsible for commissioning individual bespoke or intensive packages of treatment, care or support, or the case manager (i.e. the person or persons within the commissioning body with responsibility for that person's individual care) to obtain the information contained with the care record.

4.33 However, there could be circumstances where it is not possible or practical to obtain explicit consent, or where a person's refusal to the sharing should be overridden in their best interests. These could include:

- If there is a potential conflict of interest for providers. In practice, in some circumstances consent to share patient information is likely to need to be sought or facilitated by someone employed by the provider. If there are concerns about quality, safety or, in particular, issues related to patient involvement and consent within that provider, this might not be a very robust or reliable way of seeking consent; and, in particular;
- where a person receiving care is vulnerable and there are concerns that they may be fearful of those providing them with care and make decisions to please them; or
- when an individual is referred to and starts to receive specialised mental health care services or is admitted for treatment under the Mental Health Act, the request for consent may be refused by that individual making it extremely difficult for the case manager to ensure access for the person to the most appropriate care to meet their needs.

4.34 We are interested in views on ***whether providers of specialist inpatient services and residential care services should either be explicitly permitted to or have a duty to share confidential patient information or care records with case managers***, or those responsible for commissioning individual, bespoke or intensive packages of treatment, care or support, only in order to support case managers to work with others to make or monitor commissioning arrangements for the care of vulnerable individuals, where that care includes in effect, or is intended to include, the provision of accommodation.

4.35 We envisage that this duty to provide the confidential patient level information (or care records) would apply to a provider who is providing, or has provided, health or social care to an individual, under a contract or other arrangement with the commissioner who is requesting access to that individual's care record. This could also extend to a request from a commissioner who is also, or who will subsequently become, responsible for commissioning their care (where there may be no current contractual relationship with that provider). This would mean that, for example, where a person's inpatient care was being commissioned

by an NHS commissioner and that person might be discharged into primarily local authority commissioned care, the relevant local authority staff who needed it could also have access to the information. This would ensure that we could not have a situation where local authority commissioners are not able to start work on setting up the right care package because of a lack of information from NHS commissioners about individuals' needs.

Question

Q48 We want to explore whether providers of specialist hospital services and residential care services should be allowed or have a duty to share confidential patient information with case managers and other relevant commissioners directly involved in arranging a person's care in certain circumstances. What do you think of this idea?

5. I want to know who is responsible for supporting my physical as well as my mental health

5.1 Although recent health and care legislation sets out clear responsibilities across the health and care system, we have heard from stakeholders of some particular circumstances or instances where there could be greater clarity over the responsibilities of organisations and of individuals.

5.2 One issue which has been raised a number of times is a concern about lack of clarity for people's physical health when they are admitted primarily for mental health reasons to a mental health setting. This is a particular concern for patients with learning disability and/or autism where diagnostic over-shadowing (where symptoms of physical problems are misperceived as manifestations of the learning disability or autism). It is simply unacceptable to fail to attend to the physical health needs of someone in a mental health hospital.

5.3 For people living in the community, their GP and community health team are clearly responsible for helping them to maintain their physical health.

5.4 For those living within a residential care home, there will similarly be a GP practice responsible for the care of those patients. Residents of the home will be registered patients of that practice.

5.5 However, we do know that GP's knowledge of their local learning disabled population is very variable.

5.6 For patients in some mental health hospitals out of area, responsibility is much less clear. The usual responsible commissioner for someone detained under the mental health act is based on where a patient is registered on a GP list or the geographic area where they are usually resident. In some inpatient mental health settings, patients may be admitted from a whole range of local areas, some of which may be very far away geographically. At the point of admission, it may be very hard to predict how long that patient may need to remain there. In practice, many admitted patients are unlikely to de-register and re-register with a new practice and the area where they were registered and/or where they were resident before admission will remain the responsible commissioner. But their local GP in that area will not be able in reality to have any oversight whatsoever of their physical health while they are inpatients.

5.7 There is also a potential perverse incentive for local GP practices not to register patients in their local inpatient unit, even if they are there for some considerable period of time, because, under NHS guidance on "who pays", their CCG may then become responsible for funding that care, unless it is funded through specialised commissioning.

5.8 We do know that some providers have formed very strong relationships with local primary care and community health teams and some areas are really prioritising this issue.

There have also been some recent measures in this area, for example, the CQUIN National Mental Health Indicator.⁸⁰ However we also hear of other situations where inpatients and their families feel they have little or no support for their physical health needs, including lack of liaison with previous clinicians who they were working with or failure to listen to information that families and carers are providing on physical health needs – sometimes with very serious adverse consequences.

5.9 We are seeking views on how to make responsibilities clearer. We are interested in exploring whether:

- we could or should clarify that the local CCG where a unit is located is responsible for commissioning the *physical* health care (primary and secondary) of anyone who is de facto resident in their geographic area because they are in an inpatient mental health setting in that area (regardless of where in the country they are usually resident in, Ordinary Residence determinations, or which GP practice they are usually registered with);
- the provider should more explicitly be responsible for the person's whole health (for example, through regulation and inspection and set out in contracting);
- the Medical Director or equivalent of inpatient mental health providers should also have a clearer responsibility for ensuring access to and quality of physical healthcare for patients within their organisation as well as the quality of the mental health treatment their patients are receiving; and
- the responsible clinician for MHA patients could also have clearer responsibility for ensuring their individual's' physical healthcare needs are met appropriately.

Questions

Q49 What are your views on how we could be clearer around responsibilities of:

- **clinical commissioning groups**
- **providers**
- **medical directors; and**
- **responsible clinicians**

for the physical healthcare of people in mental health inpatient settings?

80 CQUIN 2014/15 – additional guidance on the national mental health indicator, NHS England (June 2014).

6. Conclusion

6.1 This is an exploratory consultation which sets out a range of potential options on which we want to hear views. The proposals in this paper do not all need to be taken as a single package of measures.

Question

Q50 Thinking about all the things described in the document:

- which would have the greatest impact and benefit on people's lives? (so we know what should be highest priority)
- which carry the greatest potential costs or risks?

Annex A: Summary of issues and questions

| Aim | Summary Proposition | Consultation Questions |
|---|---|---|
| <p>Promote inclusion in the community</p> <p>Reduce inpatient admissions far from home and family</p> | <p>Extend new Care Act LA duties on individual wellbeing (which includes factors related to community inclusion like social and economic wellbeing and participation in work, education, training or recreation) 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].</p> <p>LA and NHS commissioner in determining living arrangements or longer inpatient stays to have regard for:</p> <ul style="list-style-type: none"> • The need to ensure people remain in or close to the community that matters to them • the need to maintain links with family and friends • the need to maintain opportunities to participate in work, education, training or recreation; and • in the setting that is least restrictive | <p><i>Q1 The Care Act says that local authorities have to put individuals' wellbeing at the heart of what they do. We want to explore whether NHS commissioners should have the same duties, for example, for people with learning disability or autism who are at high risk of long stays in hospital in relation to their lifelong needs. What do you think of this idea?</i></p> <p><i>Q2 In determining living arrangements – (whether suitable accommodation or inpatient stays) – both LAs and NHS commissioner could have to have regard for factors which support inclusion in the community, staying close to home, links with family and friends and opportunities for participation and the least restrictive setting? What do you think of this idea?</i></p> <p><i>Q3 What might the appropriate length of inpatient stay be where this should apply for the NHS?</i></p> <p><i>Q4 What are your views on how this might impact on LAs or the NHS?</i></p> |

| Aim | Summary Proposition | Consultation Questions |
|--|--|--|
| <p>Ensure sufficient community provision to reduce unnecessary and costly inpatient admissions</p> | <p>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 (e.g. for people with LD or autism most at risk of inpatient admissions).</p> | <p><i>Q5 We think that local authorities and clinical commissioning groups could have to think about how to ensure there is enough community based support and treatment services (for example for people with learning disability or autism most at risk of going into hospital). What do you think of this idea?</i></p> <p><i>Q6 What steps could we take to ensure such as duty is as effective as possible?</i></p> <p><i>Q7 What is your view on the likely cost and impact on the NHS or local authorities?</i></p> |
| <p>Reduce detentions under the Mental Health Act and increase assessment and treatment in the community</p> | <p>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 just why they need to be detained).</p> | <p><i>Q8 What do you think about the idea to change the information required by Mental Health Act regulations in the application for detention and supporting medical recommendations? This would mean that Approved Mental Health professionals and doctors have to consider and record whether assessment and treatment could be provided without detention in hospital.</i></p> <p><i>Q9 What is your view on the likely costs and impact of this idea?</i></p> |

| Aim | Summary Proposition | Consultation Questions |
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| <p>People (supported by families) able to play an active role in discussions and decisions about their own care</p> | <p>The individual and their family/carer (or other nominated advocate), should be provided, in a timely fashion, with clear, easy read or accessible information by a named professional. This should set out:</p> <ul style="list-style-type: none"> • a summary of their rights; • why a particular inpatient admission; or • continuation of a particular treatment or assessment admission; or • a particular residential placement <p>is in their opinion the best option for that individual; and</p> <ul style="list-style-type: none"> • why there is no closer or community based alternative either in place or that could, within a reasonable timeframe, be put in place; and • when these arrangements will be reviewed. | <p><i>Q10 We want to explore whether a person and their family/carer or other nominated person, should be given clear, easy read or accessible information by a named professional about their rights. What do you think of this idea?</i></p> |

| Aim | Summary Proposition | Consultation Questions |
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| <p>People able to make choices and challenge decisions others make about themselves</p> | <p>LAs or NHS bodies clearly to seek explicit approval or consent of an individual to admit them to an inpatient setting (where they have capacity to consent) or a residential care setting.</p> <p>Individuals or their families or advocates should also have every right to subsequently change their mind because something is not out working for them and to request a move, transfer or discharge.</p> | <p><i>Q11 What do you think about the idea that local authorities and NHS bodies should have to seek explicit and documented approval or consent from an individual to admit them to an inpatient setting? This could include a record of discussion around options and risks.</i></p> <p><i>Q12 What are your views on the idea of a gateway or approval mechanism for admissions to inpatient settings, in certain circumstances?</i></p> <p><i>Q13 What would be the essential elements of such a approval mechanism?</i></p> <p><i>Q14 If there were to be such a mechanism, should it be given statutory force?</i></p> <p><i>Q15 What do you think of the idea of strengthening (for example in statutory guidance) people's rights to request a a transfer to a less restrictive setting or a setting closer to home or to ask for discharge?</i></p> <p><i>Q16 Do you agree that, as far as practicable, such discussions should involve professionals or staff based in the community or expert on community based options?</i></p> <p><i>Q17 How can we strengthen provider and commissioner accountability in their approach to such requests?</i></p> |

| Aim | Summary Proposition | Consultation Questions |
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| <p>Discharge can take place as soon as possible as it is planned from the point of admission</p> | <p>All patients to receive discharge and after-care planning from the point when the patient is admitted to hospital and that CCGs and local authorities take reasonable steps to identify appropriate after-care services for patients well before their actual discharge from hospital. Individuals and their families/carers or other advocates should be involved in this process with information provided in an accessible format.</p> | <p><i>Q18 We want to explore how everyone can receive care planning and discharge planning from the time when they are admitted to hospital. One way we could do this is through new statutory guidance (complementary to the Mental Health Act Code of Practice). What do you think of this idea?</i></p> <p><i>Q19 Should we require a care plan, including a plan for discharge, to be produced involving individuals and their family within a specified number of weeks of admission and to specify when it will be reviewed?</i></p> <p><i>Q20 Could more be achieved through any existing policies or guidance on delayed discharge?</i></p> |

| Aim | Summary Proposition | Consultation Questions |
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| <p>People more able to challenge decisions about them taken under the Mental Health Act and stronger safeguards of their interests</p> | <p>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.</p> <p>Strengthen the safeguards around renewal of detention under the Mental Health Act, including:</p> <ul style="list-style-type: none"> • Requiring section 12 doctors to agree renewals of detention, as well as admission and that this section 12 doctor should be from a different organisation; and/or • Requiring that one of the responsible clinicians involved in agreeing renewals of detentions should be from the “home” locality which is responsible for that person if they are placed out of area; and/or • Requiring that one of the responsible clinicians involved is from a different organisation and has strong community knowledge and experience. | <p><i>Q21 The Mental Health Act Code of Practice has just been updated. In line with this, we want to explore how people and their families can be more involved. One idea is that people and their families or advocates should be able to challenge whether an Approved Mental Health Professional has properly taken into account their wishes and feelings in the interview which takes place before they make an application for admission under the Mental Health Act. What do you think about this idea? (we would need to consult later on how the details of this process might work)</i></p> <p><i>Q22 Which if these measures, [3 potential options for safeguards around renewal] if any, do you think would have the most impact?</i></p> <p><i>Q23 Do you have any views on risks or costs presented by any of these options?</i></p> <p><i>Q24 Do you have any views on the decision making processes around Community Treatment Orders and how they could be improved?</i></p> |
| <p>Self-advocates actively engaged in the governance of providers</p> | <p>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.</p> | <p><i>Q25 Guidance could say that only organisations that include self and family advocates in their governance should get contracts with the local authority or the NHS to provide services for people with learning disability or autism. What do you think about this idea?</i></p> |

| Aim | Summary Proposition | Consultation Questions |
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| Better access to advocacy in inpatient mental health settings to support 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 (or competence). | <p><i>Q26 What are your views on making IMHAs available to patients who lack capacity (or competence) on an opt out basis?</i></p> <p><i>Q27 Have we considered all the safeguards we would need to protect patient confidentiality?</i></p> |
| Ensure people’s “nearest relative” under the Mental Health Act is someone who is meaningful to them | People to be able to choose their own “nearest relative” (who has specific legal responsibilities/duties/ powers) under the Mental Health Act. Current hierarchical list remains as default if necessary only. | <p><i>Q28 What do you think about the idea that we should explore changing the law so that people choose their own “nearest relative” (retaining a hierarchical list to be used if necessary)?</i></p> <p><i>Q29 Do you agree that this should reduce the cost of displacement and disputes?</i></p> |
| People have a named social worker contact with clear responsibility to work with them | Responsible, named social worker to ensure that the individual plan is based on the least restrictive, least institutional setting and to have a primary professional responsibility to ensure that non-residential or community based options have been fully 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. | <i>Q30 A named social worker could be responsible for working with the person and their family to keep them informed and involved and to make sure less restrictive and community based plans are considered. What do you think of this idea?</i> |
| Support for people and accountability when something goes wrong | A number of things have been put in place to strengthen accountability and make it easier to complain. We are interested to explore views on whether anything else is required. | <i>Q31 What else, if anything, is needed to support people and families to raise issues if something has gone wrong?</i> |

| Aim | Summary Proposition | Consultation Questions |
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| <p>Ensuring that the MHA covers people with learning disability and/or autism appropriately</p> | <p>Either (i) Excluding learning disability and autism from the MHA definition of “mental disorder”; or (ii) changing the definition of “mental disorder” to make it more specific or narrower, including altering the current learning disability qualification and also adding a new “autism qualification”; or (iii) Excluding learning disability and autism from the MHA definition of “mental disorder” under part 2 (civil sections) but not part 3 (criminal justice sections)</p> | <p><i>Q32 Which of options 1) 2) and 3), if any, seems most appropriate?</i></p> <p><i>Q33 What is your view on the potential risks or unintended consequences of the options?</i></p> |
| <p>Simplified Mental Health Act detention – easier to understand rights and support least restriction</p> | <p>One set of criteria for detention (for both assessment and treatment) which could reinforce the least restriction principle for all patients, while providing equity.</p> | <p><i>Q34 We want to explore changing the law so that there is one set of criteria for detention for both assessment and treatment under the Mental Health Act (amending sections 2 and 3). What do you think of this idea?</i></p> |
| <p>Statutory Code of Practice for Mental Health Act can be fully effective</p> | <p>Clarify that the Mental Health Act Code of Practice also applies to CCGs and NHS England commissioning.</p> | <p><i>Q35 We think we should clarify in law that the Mental Health Act Code of Practice should apply to clinical commissioning groups and to NHS England commissioning. What do you think of this idea?</i></p> |

| Aim | Summary Proposition | Consultation Questions |
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| <p>Reduce use of police cells as a place of safety for mental health crises</p> | <p>Implementing the findings of the cross-Government review of S135/136 of the Mental Health Act, including use of police cells as a place of safety. Includes ending use for under 18s and reducing maximum length of detention in cells under S135/136.</p> | <p><i>Q36 What is your view on the proposal that young people aged under 18 detained under section 135 or 136 should never be taken to police cells?</i></p> <p><i>Q37 What is your view on the proposal that the use of police cells for those over 18 should be limited more in terms of frequency and length of detention as proposed by the review?</i></p> <p><i>Q38 Do you have a view on any other recommendations in the Review?</i></p> <p><i>Q39 What is your view on the review proposal to create powers for professionals other than the police to be able to take a person from a public place to a place of safety?</i></p> |
| <p>Reduce unnecessary stays in inpatient settings for “restricted” patients</p> | <p>Allow restricted (“Part 3”) patients to be discharged from hospital onto a new type of order which could contain conditions imposed by the Secretary of State for Justice (SSJ) or the Tribunal which would authorise deprivation of liberty in the community.</p> | <p><i>Q40 Are there any practical considerations we should take into account during further developmental work and implementation of the Review proposals?</i></p> <p><i>Q41 Do you think it would be desirable in principle to amend the MHA to enable restricted patients to be discharged by the Secretary of State for Justice or a Tribunal subject to conditions amounting to a deprivation of their liberty?</i></p> <p><i>Q42 Does the MHA need to provide for another form of detention for patients who do not need to be in hospital but who must be in effect deprived of their liberty in order to be discharged from hospital into a community based setting?</i></p> |

| Aim | Summary Proposition | Consultation Questions |
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| <p>More control and choice for individuals through personal health budgets</p> | <p>Right to have a personal health budget for either:</p> <p>(i) People with learning disability 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.</p> <p>Or</p> <p>(ii) 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 care.</p> | <p><i>Q43 Which of the options above (option 1 or option 2) do you think would be most effective?</i></p> <p><i>Q44 What else might need to happen in order for such Personal Health Budgets to enable people to choose new providers and/or new kinds of service or interventions?</i></p> <p><i>Q45 How can we ensure that the new arrangements under the Children and Families Act can also be used to prevent unnecessary admissions in adulthood?</i></p> |
| <p>More integrated/ pooled budgets across health and care – joined up around people's needs</p> | <p>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.</p> | <p><i>Q46 We could seek to set up and mandate specific pooled funding, with joint planning, to help people with learning disability and/or autism get discharged from hospital or help prevent them being admitted. This could include specialised commissioning funding. What do you think of this idea?</i></p> <p><i>Q47 Are there further ways we could strengthen local accountability, particularly to disabled people and their families?</i></p> |

| Aim | Summary Proposition | Consultation Questions |
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| <p>Information shared appropriately to support people's care</p> | <p>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.</p> | <p><i>Q48 We want to explore whether providers of specialist hospital services and residential care services should be allowed or have a duty to share confidential patient information with case managers and other relevant commissioners directly involved in arranging a person's care in certain clear circumstances. What do you think of this idea?</i></p> |
| <p>Clear responsibility and accountability for physical healthcare in mental health provision</p> | <p>Clarify that the local CCG where a unit is located is responsible for commissioning the physical health care (primary and secondary) of anyone who is de facto resident in their geographic area because they are in an inpatient mental health setting there. The Medical Director or equivalent of inpatient mental health providers to have a clearer responsibility for ensuring access to and quality of physical healthcare for patients within their organisation. The responsible clinician for MHA patients to have clearer responsibility for ensuring their physical healthcare needs are met appropriately.</p> | <p><i>Q49 What are your views on how we could be clearer around responsibilities of:</i></p> <p><i>clinical commissioning groups</i></p> <p><i>providers</i></p> <p><i>medical directors; and</i></p> <p><i>responsible clinicians</i></p> <p><i>for the physical healthcare of people in mental health inpatient settings?</i></p> <p><i>Q50 Thinking about all the things described in this document:</i></p> <ul style="list-style-type: none"> • <i>which would have the greatest impact and benefit on people's lives (so we know what should be highest priority)?</i> • <i>which carry the greatest potential costs and risks?</i> |

Annex B: the future look and feel of community provision: views from the people closest

This document is not intended as a service specification or a new operational delivery plan to secure discharges for people currently in inpatient settings. NHS England have already announced their intentions to work on these.⁸¹

However, this annex sets out the picture that some self-advocates and professionals closest to the issues at the heart of this paper, have shared with us. It sets out their personal views on what good, inclusive services might look and feel like:

How might it feel for people with learning disabilities?

*As people with learning disabilities, first of all, we would have choices. **We would make the decisions about how we want to be supported.** We would have personal budgets. We could choose to advocate for ourselves or choose to have independent advocate or a self-advocacy group or someone of our own choice like friends or members of our family or a solicitor to able to support us with our personal budgets. We would be able, if we choose to, to have support from an independent living service or to pay our staff directly ourselves or through an organisation that offers payroll services for personal budgets direct payments to set up their own bank account.*

Choices and information would be made easy read with pictures that make them accessible to suit the person's communication needs. We would have support to be in control including training on employment laws and how to be an employer. This would be done by a self advocacy group or a disabled persons user led organisation.

*As people with learning disabilities, we would have a say in **where we live** as tenants or be able to buy our houses or use shared ownership schemes. This is better than it being owned by a big provider. Staff would support people in the house but ... staff would be managed by the tenants or their family to act on their behalf with the support of provider. There would not be company offices in our homes. If a person requires sleep in support, then it would be a bedroom only. The provider would have a office elsewhere – not in our houses where we live. As people with learning disabilities, we should have a say in staff rotas so they are flexible around our requirements. We would have reviews once a year and we would be in centre of the plan. We would be able to choose **who we live with** or by ourselves. Social services and health commissioners and the providers would not be allowed to choose for that person and just put anyone they want to live there in our homes just because it's a vacant bed and not give us a say about who we share our homes with.*

⁸¹ In *Transforming Care for People with Learning Disabilities – Next Steps* (January 2015).

*People with learning disabilities and their family members or someone else they chose **would be involved in every level of provision**, that means writing job descriptions and short listing and being on interview panels... we would be involved right from start and this would be in the contract as a requirement local authorities' and NHS contracts when commissioning a provider, having a say in staff supervision and feedback, on the board of directors for providers. We could elect people to be our representatives on the board. We would have the same rights and have the same say and be treated as equals as the other directors in running of that provider organisation... People with learning disabilities would be employed by the provider. The providers would be able to show that people with learning disability have same powers and input in the service as everyone else.*

Local authority responsible assistant directors of social services would have regular meetings with people with learning disabilities and family carers and would set up a monitoring group with them involved.

Local clinical commissioning groups would have community learning disability teams joined up with mental health crisis intervention teams, with out of hours services. Community learning disability liaison nurses would be in or linked to GP practices. There would be early intervention teams. Counselling services would be accessible for people with learning disabilities. The counselling service would work in partnership with health and social care teams with community learning disability teams, mental health teams and care management teams. Each local clinical commissioning group and local authority would have to try to prevent people from going out area. This support would reduce people entering hospitals.

I also think local councillors would have training so they know more about what their social services departments should do for local people and so they themselves are aware what to do around people with disabilities, including learning disability and autism and how to involve and include them in local decisions.

What might commissioners look for in local services?

I think there are 5 essential elements that commissioners need to attend to for a good local service offer:

- *Sufficient Specialist Learning Disabilities Clinical Capacity as part of comprehensive and well-integrated community support services, with sufficient Community Team resource that can readily access responsive specialist professionals*
- *Adequate, skilled, community support and community provider capacity, including a range of supported home, education and occupation options*
- *Access to expert, learning disability informed Case Management Capacity*
- *Jointly funded capacity and panels to enable delivery of flexible support arrangements and on-going tracking of individual and wider services*
- *Appropriate models for the integration of health care and social care service provision so as to ensure a 'seamless service' for the user*

This should be accompanied by a core local learning disability capacity enhancement framework and joint local action plan to actively reduce need for current and future admissions and to enable the reality of least restrictive placements for many more people. This includes:

- *Basic mainstream (“low-level”/preventative) services to people with LD/families/carers – especially to people with mild LD/autism who often do not meet eligibility criteria but who then risk escalation into crisis admissions*
- *Training and health facilitation/consultancy support offered by community learning disability teams (CLDTs) to mainstream services by LD services – especially mental health and criminal justice system liaison and diversion*
- *A mix, range and availability of a spectrum of supported homes (tenancies, residential and nursing care homes), day services (including supported education, employment, leisure, training) and planned/crisis respite or short break options*
- *CLDTs – capacity, competence, confidence, care management and coordination roles*
- *Crisis Admission options – LD and MH – including access to linked Gatekeeping Inreach/ Outreach LD specific crisis resolution and Assertive Home Treatment Team/s backing up local CLDTs*
- *Step-down from crisis admissions – a choice and range of supported living and other options (e.g. residential nursing) as well as some rehabilitation or continuing care beds*
- *Links with Secure services*
- *Access to Advocacy*
- *Transition support and forward planning for young people with complex support needs – especially in context of SEND reforms*
- *Continuing Health Care/Joint funding/Pooled Budget and integrated commissioning models”*

Annex C: Case study: use of the mental health act and mental capacity act

JC is a 24 year old woman who has been diagnosed with a learning disability with associated ADHD, psychosis and depression. She was living in a supported living environment and attending college daily until January 2014 when there was a safeguarding incident which resulted in a breakdown of both her living and care arrangements. This was the second breakdown of living arrangements, a previous placement having failed when she decided to go and live with associates she had met at college.

JC's mental health had deteriorated and she was admitted as an informal inpatient to a local learning disability mental health unit. At this time it was not felt that she met the criteria of the Mental Health Act (MHA), as although she was deemed to lack capacity to agree to admission, had a mental disorder or disability of the mind that were both to a nature and degree could warrant a detention under the MHA she did not appear to be objecting to the admission, an indicator against compulsory admission.

The Unit did feel that JC required ongoing admission to a hospital environment. She had experienced further deterioration in her mental health, this presented largely as symptoms of psychosis. JC reported that she was hearing voices and feeling increasingly worried and scared. At this stage JC was overly sensitive to stimulus, changes in her environment, completely reliant on staff for medication, self-care and monitoring of her dietary needs.

As part of the admission process consideration was given to whether the level of restrictions, supervision and monitoring experienced by JC at the Unit would need to be authorised by either the MHA or the Deprivation of Liberty Safeguards (DoLs). Both the Mental Health Act and the Deprivation of Liberty Safeguards (DoLs) regimes were regularly used at the Unit to authorise and oversee patients care arrangements. As C was not objecting to her hospital admission both the Mental Health Act and DoLS are available.⁸²

It was felt by the assessing matron that the restrictions imposed by JC's current care and treatment plan may now amount to a deprivation of her liberty. The Unit then had a duty as a Managing Authority to request a DoLs assessment from the relevant Supervisory Body. The Best Interest Assessor (BIA) was instructed by the Supervisory Body to undertake 4 of the required 6 DoLs assessments, Best Interests, Age, Mental Capacity and no refusals assessment. A Mental Health Assessor was ask to reach conclusions on diagnosis and eligibility for the MH Act.

82 It should be noted that the Supreme Court in the case of *Cheshire West* ruled that the presence of absence of objection is not a relevant criterion for determining whether a "deprivation of liberty" may or has occurred. However, it is a relevant consideration in determining whether the MHA or DoLS should be used to authorise that deprivation of liberty.

The BIA concluded that the Unit was a locked unit, where to some degree JC would be monitored and supervised continuously. The care and treatment plan detailed a number of restrictive practices put in place to reduce risk and address current needs. For example, JC was observed and prompted whilst carrying out all personal care and she was on medication that helped modify her behaviour. Level 2 observations were in place to monitor her every 15 minutes. This was evidence of JC being subject to frequent and long standing restrictions which amounted to continuous supervision and control. JC was also assessed as not being free to leave as staff exercised complete control over her movements and JC or her family needed to seek permission to leave the Unit. Using the recent Supreme Court Judgement in the case of *Cheshire West and Chester Council v P* (2014) UKSC 19, (2014) MHLO, the BIA concluded that JC was deprived of her liberty. Discussions took place with the MH Assessor, who felt that JC was in fact eligible for both the MH Act and the DoLs regime but that, on this occasion, the DoLs regime was most appropriate to her circumstances.

The BIA then needed to consider if it was in JC's Best Interests to be deprived of her liberty under the current care arrangements at the Unit. This assessment needed to consider if the current care arrangements were necessary and proportionate to the potential harm and if there would be a conflict with a valid decision of a donee or deputy. Consultation with both JC, her family and care team was key to this decision. The BIA struggled to engage with JC during their first meeting, though after undertaking a joint visit with JC's parents she was able to establish her thoughts and views about the current arrangements. JC stated that she was frightened, though this did not appear to be as a result of being at the Unit. JC also advised that she liked sleeping with the light on, enjoyed daily walks, liked cooking her own food and listening to the radio. Everyone involved in JC's care agreed that a hospital admission was required.

The BIA concluded that JC did require an intensive care plan within a hospital setting and that given the current risks to JC's health and welfare, authorisation should be sought from the Supervisory Body to deprive JC of her liberty. The BIA felt that the authorisation should only be granted for a period of 2 months in order to allow time for assessment, treatment and aftercare planning.

Whilst the BIA agreed that overall it was in JC's Best Interests to be in hospital receiving care, she had concerns that the care plan needed to be revised to ensure that the current arrangements were less restrictive. The BIA asked the Unit to consider how they could support JC to undertake regular walks away from the unit, the managing authority advised that resources would not allow them to arrange daily walks but that they would arrange community access as often as possible. The BIA also advised that JC should be more closely consulted in regard to the particulars of her care plan such as bed time routines, food choices and being able to access resources such as the radio. Careful consideration of JC's best interests ensured personalised ways of reducing JC's anxiety and affording her more personal choice. This may in turn have led to a speedier recovery and return home. The Supervisory body made these recommendations within Conditions attached to the Standard Authorisation.

As part of the DoLs Standard Authorisation JC was appointed a Relevant Persons Representative (RPR) who could ensure that any conditions set were met. They could also ask for a review if JC's situation changed and support her to appeal the decision via the Court

of Protection process. JC's mother was appointed the RPR. As it was a role that was new to her, the Supervisory Body appointed a 39D IMCA to support both JC and her mother to understand the DoL, conditions set and options available to them.

JC remained on the ward for the duration of the Standard Authorisation and the Unit asked for the DoLs to be renewed as they felt that JC still required care and treatment in hospital. At this time JC appeared increasingly depressed, with decreased appetite and accompanied weight loss. JC frequently reported hearing voices, she was resistant to staff supporting her with both personal care and medication. There had been occasions when JC had assaulted other inpatients. The BIA and Mental Health Assessor met with JC, they concluded that a 24hr care environment was still indicated but that, given the further deterioration in her mental health, the need to consider the protection of others and the fact that JC was now objecting to elements of her mental health treatment, she was no longer eligible for the DoLs regime. The Unit were advised that they needed to request a Mental Health Act assessment if they wished to continue to authorise JC's admission and current care plan.

An AMHP and two Doctors completed their assessment and JC's Nearest Relative was consulted as part of the assessment process. JC was detained under a Section 3 of the Mental Health Act. Although JC's mother had taken on the role of Relevant Persons Representative under DoLs, as the older parent, her father was her Nearest Relative.

JC's mental health took a number of months to stabilise. JC attended a tribunal, but it was found by panel members at the time that she should stay in hospital in order to safeguard her health, safety and for the protection of others. After a lengthy hospital admission JC's mental health was much improved and it was felt that periods of leave to a less restrictive environment would be beneficial to her progress. There remained concerns that JC required a high level of monitoring and support and that she had periods where she refused to engage with the care and support available. She also appeared ambivalent about consistently taking her mental health medication. It was felt that JC currently lacked capacity around decisions about medication and a number of her support needs. It was also identified that the hospital setting may have deskilled JC and that she needed a period of rehabilitation in a residential unit prior to a return to supported living.

Given the ongoing concerns about engagement, reluctance to take mental health medication and the previous pattern of JC leaving care environments and placing herself in vulnerable situations, there was discussion about what safeguards could be put in place to maximise the success of any discharge plan. It was felt that JC needed to live in a residential care setting where the staff could monitor and support her at all times, it was also important to have the option of preventing JC from leaving the provision on her own. The consultant psychiatrist felt that JC's mental health medication and engagement with Community Psychiatric Nurse were key to ongoing recovery and he was not convinced that JC would engage voluntarily.

Guardianship under the MHA was considered as a means for ensuring she lived at a particular place, but it was felt that, whilst it would require JC to attend review and appointments, that she was not likely to follow these requirements as there were not actual powers to enforce them. Instead it was felt that JC may benefit from use of both DoLs and a Community Treatment Order (CTO) working alongside each other. The DoLs could support the staff team to ensure JC did not leave the provision unaccompanied at her more vulnerable

times, as well as ensuring her care needs were met. The CTO could ensure that JC complied with mental health treatment and review. JC was assessed for both regimes and the care team had to work through what powers and authorisations were needed in her specific circumstances and which legislation was most appropriate. It was felt that she currently lacked capacity about where to reside for care and treatment and that it was in her best interests to leave hospital to a less restrictive environment.

Subsequently the DoLs was put in place for six months as it was felt that that it was in her best interests to remain in the care home and that the deprivation was a proportionate response to the potential harm to herself. The DoLs allowed staff to prevent her from leaving if it was unsafe, something not covered by the CTO. The BIA again attached conditions to ensure that JC's individual needs were considered, a review period of 6 months was set in order to review how much nearer JC was to moving to a less restrictive care plan and environment. The CTO was in place as this had a focus on requiring her to accept treatment and provided a way of recalling her to hospital if necessary. With these regimes in place JC engaged well with the care team and her mental health continued to improve to the point that she could return to college.

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