

Mencap response to the Draft Care and Support Bill 2012

Mencap is the UK's leading learning disability charity, working with people with a learning disability, their families and carers. We want a world where people with a learning disability are valued equally, listened to and included. We want everyone to have the opportunity to achieve the things they want from life.

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Executive Summary

Mencap welcomes the draft Bill as care and support is of critical importance to people with a learning disability and their families. Our submission is based on our consultation¹ with people with a learning disability, families, carers, experts and sector workers which established a true picture of social care services and identified areas for reform.

¹ Mencap's Don't cut us out! Consultation, 2009 and Mencap's Don't cut us out! Consultation, 2011 received over 1300 submissions using a range of methods, including online surveys, printed surveys, focus groups, interviews, online polls, conference exhibitions, video submissions, SMS messages and case studies.

Results showed the impact that social care support has on the daily life of many people with a learning disability enabling people to live independently and play an active role in society. However, there are many areas which are not working well.

The current social care system is failing many people with a learning disability and we are concerned this could get worse, with increasing numbers of people with a learning disability needing care and support.

The current legal framework is outdated and complex and with cuts to front line services, many individuals do not have the choice, control and independence in their lives they deserve. Over the last 12 months, we have experienced a 139% increase in calls and emails to our helpline about community care; concern about cuts and changes to services is at an all time high.

While we welcome the Draft Bill as we believe it will deliver a legal framework which is fit for purpose, there are several areas in the bill, which we believe could be strengthened or amended.

Our policy recommendations are:

- All individuals should be meaningfully engaged during their assessment and setting their care plan. This needs to be reflected throughout the Bill.
- Everyone should have access to free independent advocacy during the assessment and care planning process.
- A legal definition of Continuing Health Care should be on the face of the bill to clarify what is expected from local authorities and health services in meeting care and support needs.
- The Draft Bill and supportive guidance should reflect that prevention services are wider than assistive technology and home adaptations for people with a learning disability. Providing low levels of support and accessible information can help to prevent needs from reaching a critical level.
- The Draft Bill must address the urgent need for specific preventative services for people with a learning disability who live with parents aged 70 and over
- The Government should introduce a national system of assessment to ensure the national eligibility criteria system works
- The Bill should define an assessment and introduce standards in regulations plus set a timescale which all assessments should operate in to end the practice of local authorities screening out people before assessing them.

- The Bill should require local authorities to have a transparent commissioning process whereby quality of services is the driver for decisions.
- The clauses on ordinary residence and portability need to be tightened to minimise disputes, this should include a definition of ‘genuine intention’.
- Mencap wants to see a duty on local authorities to keep a register for people with a learning disability to be maintained, as they are an important source of evidence for planning services.
- Adult Safeguarding must be properly resourced, to ensure it is effective. Safeguarding Adult Boards must be able to satisfy themselves that thorough safeguarding investigations are taking place. This will involve putting the right mechanisms and procedures in place to ensure that concerns are properly investigated.

Mencap’s detailed response

Introduction

Mencap believes the current framework for adult social care is overly complex, confusing and letting down the very people that it was designed to support. Many individuals and their families struggle to identify and understand their rights and entitlements; this must change.

The Draft Bill offers the chance to address the current failings and to shape the system to make it fit for purpose. We have drawn upon the real life experiences of people with a learning disability and their families, as well as the expert knowledge from service providers and local groups to inform this submission.

Well-being principle – clause 1

Mencap welcomes the Draft Bill's overarching duty on local authorities to promote the well-being of individuals. As we set out to create a system that puts the individual at the heart of the system this principle is a necessary step. Mencap agrees with the suggested definition of well-being.

We would encourage the Department of Health to support this clause with strongly worded guidance that sets out the important role of local authorities in embedding this principle. This guidance should state how it relates to the other duties and powers in the draft Bill, as well as offering a clear indication that local authorities will be held to

account if this principle is ignored. The guidance should also be clear that no one is excluded from this principle, no matter the complexity of their needs or their level of capacity.

Clause 1(3)

We agree that the best judge and expert of a person's well-being is the individual themselves and their families. Clause 1(3) sets out strong requirements local authorities to follow and we urge that this is retained in the future statute.

We would, however, suggest an amendment to clause 1(3)(d) on engagement with the individual. We believe that as well as 'fully' engaging with an individual, the Bill needs to stipulate that the engagement should be meaningful as this will prevent cases where individuals are involved in a tick-box exercise.

Mencap supports the definition of local authority in clause 1(4) and adult in clause 1(5).

Broader local responsibilities – clauses 2-7

Information, advice and advocacy – Clause 2

Information, advice and advocacy should be seen as an integrated social care service for everyone and should be accessible to all, particularly people with a learning disability.

Mencap supports the Care and Support Alliance's (CSA) position on the need for local authorities to be proactive in the provision of information and advice, to reach people who may require encouragement to access services, including those at risk of social isolation. We also support the calls from the CSA on the need for independent information.

The duty to provide advice and information to everyone regardless of need or income is welcome but must be widened to place a duty on local authorities to provide or facilitate the provision of independent advocacy.

We believe it is vital that people going through the assessment and care planning process, as well as those involved in safeguarding proceedings, should have access to free independent advocacy.

People with Profound and Multiple Learning Disabilities (PMLD) often do not use verbal communication and therefore require specialist advocacy services and need access to advocates trained in non-instructed advocacy. No individual should be alienated from this vital service due to their complex needs and therefore the future statute should set out this requirement.

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Supporting guidance should be used to promote diversity and quality of advocacy services. It should promote the use of professional, citizen and peer advocates (where self advocates with a learning disability get to know and speak up for people with profound and multiple learning disabilities). Advocacy should be free of charge to those who are eligible for social care, to ensure that no one is excluded from the service.

We encourage the Department of Health to explicitly add the term 'advocacy' to any reference to information and advice throughout the Draft Bill.

Promoting diversity and quality in provision of services – clause 3

The diversity and quality of service provision varies widely for people with a learning disability. Whilst many people with a learning disability have a positive experience with their care provider, some on the other hand have had terrible experiences which often lead to catastrophic consequences.

In the revisited Mencap *Don't cut us out! Survey*² participants were asked for suggestions on how to improve the quality of care. Overall, the biggest barrier to quality services identified was the lack of choice and a monopoly of services. We believe that improvements to the levels of choice will assist in rooting out underperforming services.

Mencap welcomes the proposed duty on local authorities to promote efficient and effective operation in services, ensuring that everyone has access to choice of services, choice of high quality providers and provision of information for individuals to make an informed decision (clause 3(1)). We would hope that the Department of Health would engage with providers to look at imaginative ways of promoting and stimulating local markets, creating greater choice for individuals, and driving up quality.

Information, advice and advocacy

Mencap firmly believes that empowering individuals to be able to speak up and raise concerns over quality is one way to improve the quality of care. Where individuals and their families know what they should expect from a service, they are able to spot when services are falling below the acceptable standard. The use of independent advocacy is vital in this respect and should be available to anyone going through the care planning process.

Mencap recommends that the Department of Health adds 'advocacy' to sub-clauses 3(1)(c) and 3(2)(a).

Planning for future demand

² Don't cut us out! Survey (revisited) 2011

Mencap believes a crucial element of a local authority's role in social care is strategically planning services for individuals who live in the area, particularly as a key method of promoting the diversity and quality of services. At our consultation event³ to feed into the Law Commission review, service providers and Mencap local groups shared experiences of poor planning which led to poor management of funding and a lack of choice for individuals. We are also aware that generally there is a poor knowledge of numbers of people with a learning disability amongst local authorities and as such the ability to understand future demand is limited.

We welcome the requirement on local authorities to understand future demand and therefore prepare for the future under sub-clause 3(2)(b). We do however believe that this needs to be strengthened in either the statute or in regulations so local authorities are required to produce strategic plans identifying how they will promote diversity and high quality services, specifically preparing for changes in future demand. The Government should require that the Care Quality Commission (CQC) review strategic plans as part of its inspection programme.

Commissioning

Mencap believes that the commissioning process is central to promoting diversity and driving up quality. If it is not correct at this stage there will be poor choice for individuals and quality standards will be low.

Role of commissioning

The role of commissioners is vital to promoting diversity and driving the quality of care, we believe commissioners need make quality the greater priority during the decision making process and the future statute must reflect this. We are concerned that with the pressures on local authority budgets and the growing demand on services, some commissioners may put cost before quality.

Specialist services providing high quality care are not the cheapest and we have seen these services undercut by other providers who provide generic care at a lower cost. We also have evidence of experienced providers being asked to deliver the same level of service on a reduced budget. Indeed Mencap has been forced to walk away from contracts where local authorities wanted to heavily reduce the funding for the contract. This would have led to reduced wages for staff and therefore quality would have been at risk.

We would urge that the Department of Health through published guidance and engagement with local commissioners, assists them to invest and consider alternative

³ Consultation event, Law Commission and Mencap, June 2010

forms of market testing other than the tendering process, which is costly and has not been proven as a successful way of selecting the ‘best service’ for the individual.

Mencap understands that wider work by the Department of Health is underway in this area, however we believe that the importance of commissioning in promoting diversity and quality requires must be reflected in the future statute. We urge the Government to set clear standards in commissioning practices on promoting diversity and quality. The Government should require CQC to monitor the success of local commissioning activity.

Diversity and quality of services for people with Profound and Multiple Learning Disabilities (PMLD)

Although the concept of personalisation has been around for a number of years, we have heard of numerous examples where people with PMLD have been excluded from person-centred planning. A common barrier to diversity of services for people with PMLD is the lack of availability of a suitably skilled workforce to support them, paired with a lack of choice about what to do during the day. When day services close and there are not the appropriate alternatives in place, many people with PMLD are forgotten and remain at home with nothing to do.

Reform of the social care system must ensure there are high quality options in terms of activity and support which people with PMLD can access. Part of this should be ensuring that local areas continue to provide somewhere which can be used as a base, from which adults with PMLD can go to different activities during the day.⁴

Mencap urges the Department of Health to provide regulations and supportive guidance specifically on the promotion of diversity and high quality of services for those with complex needs, including people with a learning disability.

Finally, Mencap recognises the importance of promoting good practice amongst commissioners. One area where we would like to see further advancements is commissioners publishing the reasons behind their decisions in a tendering process. This goes beyond the current requirements to explain why organisations are not successful but would in our view be good practice.

Workforce

Developing the workforce is important to the promotion of diversity and driving standards of services, from social workers to support workers. Across England, individuals enter into a competition for good staff, which has often resulted in those able to financially ‘top-up’ care packages securing the best staff. The Government needs to

⁴ See Recommendation 26 in Raising our sights: services for adults with profound intellectual and multiple disabilities, by Professor Jim Mansell (2010)

evaluate the social care workforce and implement a strategy that aims to have a workforce that matches the vision for the reformed system.

With the increasing uptake of direct payments there are more people with a learning disability employing staff, than ever before. The social care system needs to ensure that everyone has access to high quality services, including those who are employing their own staff. Mencap urges the Department of Health to work with organisations and local authorities to ascertain how best to develop the workforce and maintain good standards in care for those with direct payments.

Cooperation – clauses 4-6

Strong cooperation between differing social care and health agencies is integral to the experience of an individual accessing care and support. Individuals that come into contact with social services will interact with a number of other statutory services due to their range of needs. Where interaction is disjointed, the impact on the individual can be damaging and often put the individual at risk. The cases of Francesca Hardwick and her mother Fiona Pilkington⁵ provides a clear example of where a breakdown in communication and joint working between local agencies can lead to serious consequences.

People who took part in Mencap's consultation called for greater joined-up working. Too many are tired of form filling, telling their story to dozens of key workers and being given conflicting advice. It is for this reason we strongly welcome the duty to cooperate in clause 4(1)(2).

Internal local authority cooperation

Failures of joint working between the different departments of a local authority have a huge impact on people and their families. Individuals have seen delays to their packages of care and in some places have been subject to a complete breakdown in progress. Common scenarios include when a young person goes from children to adult services or when a person is moving from health care to social care services. We therefore support the duty on local authorities to make arrangements for ensuring cooperation between the officers within the local authority who exercise the authority's functions in care, housing and childrens services.

We do however believe that the statute should place an express requirement on local authorities to identify a lead person, who is ultimately responsible for the coordination of work within the local authority and across relevant departments. We would suggest that the Director of Adult Social Care would be best placed for this role.

⁵ www.equalityhumanrights.com/media-centre/council-s-compliance-with-disability-equality-duty-to-be-checked-following-inquest-findings/

Relevant partners

Mencap agrees with the list of agencies in clause 4(5) as those who need to be working jointly with adult social services.

In addition to the list provided, we suggest that this be widened to include local public or social housing providers to improve the joint working between social care and housing services.

We also urge the Department of Health to consider how best to engage those who work on the front line of services; support workers and service staff. It is this group of staff who are often best placed to understand the needs and wishes of the individual and it is the support staff who witness firsthand the breakdown between different agencies.

Support staff employed by Mencap often feedback on the barriers they face when trying to support an individual through the health system. Whilst it may not be appropriate to widen the clause to cover all support workers, there should be the ability for support workers to be engaged in the process and be seen as an equal partner by the other agencies.

Integration of care and support with health services

Mencap supports the definitions in clause 6.

Mencap believes that one of the greatest barriers to successful joint working is the separated funding streams of each body. Our report *Out of Sight*⁶ into the abuse found at Winterbourne View highlighted the adverse incentives on local authorities to take on the funding of adults with behaviour that challenges, so they can leave institutions like Winterbourne View. These individuals have complex needs and often require costly packages of care as well as intensive management by social services. Integrating budgets for care and support with health services would have a positive impact.

In the meantime, Mencap encourages the Department of Health to use the Draft Bill to clarify the duty of cooperation of Continuing Health Care services with the wider care and support system. Mencap is supporting a number of individuals who are at the heart of disputes over how the care and support that they need is funded. This has led to people being left without the care and support they need or being put in an inappropriate care placement until the dispute is resolved.

Mencap strongly urges the Department of Health to put a clear legal definition of Continuing Health Care onto the face of the bill, with a clear dispute mechanism in supporting guidance. We would urge that a similar approach to that of the portability

⁶ Mencap & Challenging Behaviour Foundation, *Out of Sight; Stopping the neglect and abuse of people with a learning disability*, 2012

rules later in the bill should be applied here to reduce negative impacts on those at the centre of such disputes.

Prevention – clause 7

Mencap supports the Government's commitment to strengthen preventative services to reduce pressures on the social care system, and to improve the well being of individuals who need care now and in the future. People with a learning disability can face a sudden change of circumstances and this can quickly become a crisis requiring urgent care and support. By introducing preventative and early intervention services, local authorities will be able to reduce crisis placements.

While we welcome the duty on local authorities to arrange for the provision of services, facilities or resources, we would encourage the Department of Health to ensure that there is emphasis on a wide range of preventative services i.e. not just physical adaptations and technology.

Mencap would encourage the Department to find a suitable way of highlighting the urgent need for preventative services for all individuals but specifically for those who live with elderly parents – who are also their main care provider.

Mencap's research shows that only half of local authorities know how many people with a learning disability live with parents aged 70 and over, leaving many vulnerable older carers isolated and struggling to cope.⁷ 56% of people with a learning disability are living with parents aged 70⁸ and over, and many do not have plans in place when for they are no longer able to care for their son or daughter.

Local authorities must become more proactive and have a better understanding of the number and needs of older carers in their area, so they can provide the right support before carers reach breaking point.

Starting the care and support journey – clauses 8-16

How to meet needs – clause 8

Mencap welcomes this clause and the list provided under sub-clause (8)(1). However, we recommend that both transport services and equipment be added to this list.

We accept the ways in which a local authority may meet needs under sections 17-19. We urge the Department of Health to produce statutory guidance promoting best

⁷ Mencap, The Housing Timebomb: the housing crisis facing people with a learning disability and their older carers (2002)

⁸ Mencap; Interim findings of Cordis Bright research

practice in these areas, as well as emphasising the importance to involve the individual in deciding how the local authority will meet the assessed needs.

Assessments – clauses 9-12

High quality care and support begins with a high quality assessment. When done properly the assessment identifies the care and support needed by the individual. Poor assessments result in the individual getting the wrong level of care and support or missing out on the care and support that they need. In order to ensure that there is a good level of assessment, the legal framework must set out clearly what is expected.

Access to assessments

Mencap agrees with the Department of Health that the assessment itself equates to a service for people with a learning disability and family carers. It is an opportunity to signpost individuals to voluntary services, user-led organisations, advocacy groups and information providers. Therefore it is important that the trigger for an assessment is kept as low as possible.

Mencap welcomes the broad entitlement to an assessment in Clause 9(1) for any person who may have needs for care and support. We also welcome the clear duty in Clause 9(3), stating that a local authority must assess regardless of the level of the person's needs or financial resources.

Defining an assessment

It is imperative that the assessment process is used to identify a person's needs and desired outcomes, in order to establish which services they will require.

Mencap has heard from a number of individuals and families who believe that they have been screened out of the assessment process, with an 'informal' questionnaire or a telephone interview. Important case law has set out the legal differences between screening and a legal assessment for care and support⁹. The case establishes the principle that an assessment must properly consider all of the individual's needs, with the Court stating that 'assessments cannot be said to have been carried out unless the local authority concerned has fully explored the need in relation to the services it has the power to supply'. Mencap urges the Department of Health to include such a statement in the future statute.

Clause 9(4) sets out what the assessment should assess. Mencap firmly supports the Government's commitment to moving the current system from being crisis led to one

⁹ R v Bristol ex parte Penfold – 1997-8 1 CCLR 315

which promotes independent living. As such we support the definition of an assessment to one which focuses both on the needs and desired outcomes of the individual.

We note that the draft bill does not indicate what types of need the local authority should consider when looking at undertaking an assessment, for example personal care, social and housing needs. We would suggest that the Department of Health may wish to publish guidance in this respect to assist authorities. We would ask that any guidance make express reference to the importance of the need for suitable and good quality accommodation.

Involving the individual

The people who are best placed to identify needs and desired outcomes are the individuals themselves and their family. Mencap supports the suggested clause 9(5) which says the local authority should consult with the individual, their family and any nominated persons where feasible to do so. However, in addition we ask that an explicit duty on local authorities to provide for, or facilitate, an independent advocate for anyone going through the assessment process, is put in place.

We urge the Department of Health to encourage local authorities to truly involve individuals and to highlight the benefits of doing so. Any guidance should also state clearly that people who are not able to verbally communicate should also be consulted during their assessment.

Carers Assessment – clause 10

Mencap's *Breaking Point* report¹⁰ and its follow up report *Breaking Point – Families Still Need a Break*¹¹ showed the harmful impact on people with a learning disability when a local authority fails to meet the needs of the family carers. Breaking point is a physical and emotional crisis, where the persistent lack of short break services and the endless pressure for providing intensive care finally take their toll.

In *Breaking Point*¹² we reported that 60% of parents of children and adults with profound and multiple learning disabilities (PMLD) spent more than ten hours per day on basic physical care. One third of these had a continuous caring role 24 hours per day. 78% of families received either no support at all or less than 2 hours per week. Unsurprisingly few families were satisfied with this. Very little has changed for families since our original report. This was illustrated by our 2nd report in 2006 in which we reported that 7 out of 10 families have reached or come close to breaking point because of a lack of short break services.

¹⁰ Mencap, *Breaking Point* (2001)

¹¹ Mencap, *Breaking point – families still need a break* (2006)

¹² See 9.

Mencap welcomes the Draft Bill's commitment to put the carer's assessment on a statutory footing.

It is crucial that family carers get the support they need. Mencap welcomes the inclusion of a duty on local authorities to assess a carer where it appears that they may have needs for support.

Mencap particularly welcomes clauses 10(4) and (5) which sets out clearly that all local authorities must assess whether the carer is able and willing to continue to care for the individual, as well as giving regard to whether the carer works, is in education or wishes to pursue employment or education opportunities.

Mencap agrees with the observations of the Care and Support Alliance that as it stands the carers assessment is primarily focused on the assistance that the carer requires to continue their caring role, rather than ensuring the carer has an acceptable quality of life. We suggest that the subsection of clause 10 should state clearly that assessments for carers should assess need and desired outcomes – similar to clause 9 for individuals.

We seek clarification from the Department as to whether clause 10(7) would result in carers who are being paid for part of their contribution through a direct payment being excluded from the definition of a carer, for the purposes of S.9 only or more widely across the provisions of the Bill.

Refusal of an assessment – clause 11

The Draft Bill should be tightened to ensure the duty on local authorities to assess is not discharged where an individual or carer has refused an assessment because they feel unable to participate due to a lack of appropriate support.. Mencap supports the CSA's recommendation to include a sub-clause stating that the local authority's responsibility to assess is not discharged if the adult refuses on the grounds of inadequate support to participate in the assessment.

Further provision – clause 12

Mencap welcomes the requirement for regulations set out in this clause, particularly for the circumstances where specialist assessments are required. We encourage the Department of Health to consider the need for specialist assessments for adults with PMLD and individuals whose behaviour challenges.

The Department must also tackle poor assessment practices through the Regulations, by establishing minimum standards in respect of content and timescales for completion.

The Regulations should set out a reasonable timeframe from when the local authority is aware of a need, to when the full assessment should have taken place. We would like to

see, wherever possible this timescale made known to, discussed and agreed with individual.

We would also urge the Department to consider whether a local authority, if looking to charge, should publish its charging strategy widely and in an accessible form so that people can clearly understand charges they may have to meet.

With regard to the assessment process, our experience is that for many individuals this is a long and somewhat inefficient process. We would hope that in the Regulations, or the guidance, charging authorities be required to act in a way which is timely and so does not result in financial hardship to the individual.

The proposed Regulations will also explore the powers that local authorities will have in delegating the powers of assessment to third parties. Mencap urges the Department to hold a full consultation on this. Whilst this power could be used positively there is a danger of local authorities commissioning third parties, who are not trained in social work to carry out assessments as a way of saving money causing a reduction in the quality and accuracy of assessments. Mencap supports the CSA's recommendation that the responsibility for the fulfilment of the assessment duties remains with the local authority thereby ensuring eligibility is based on proper consideration of the person's needs.

Due to the importance of the assessment, Mencap believes that the quality of assessments should be regulated. Mencap looks to the regulations to set a minimum standard of the quality expected. The legal framework must be designed to hold local authorities to account if they have a poor assessment process.

Mencap firmly believes that no one should be charged for an assessment. This needs to be explicitly set out in future regulations.

Eligibility – clause 13

Mencap has several concerns in relation to the current system of eligibility, including;

- wide interpretation of eligibility amongst local authorities,
- increasing practice of tightening eligibility criteria,
- lack of public knowledge and,
- the definitions for each of the bandings under current guidance.

We strongly urge the Department of Health to look at reforming the existing eligibility criteria framework.

Duty – 13(1)

Mencap supports the CSA's recommendation for the clause to explicitly state that where a person's needs are found to meet the local authority's eligibility criteria; the local authority is responsible for ensuring that those needs are met in a manner which is appropriate and in a timely manner.

National system of eligibility

The current system of eligibility is interpreted differently in the 152 local authority areas in England. They each have their own eligibility criteria resulting in situations where an individual is found not eligible as they do not meet their authority's criteria, even though someone with the same needs in a neighbouring authority does receive services; a point made by the Dilnot Commission.¹³ This has several knock on effects; firstly it prevents people moving freely to other areas, secondly it has made the system confusing and non transparent for the public and finally it has created unfairness.

Mencap support the power for the Government to introduce subsequent to consultation, a national system. An option we strongly encourage the Department of Health to undertake.

Charging – clauses 14-16

The current charging framework is complex, and with an increasing number of local authorities charging for care and support there is a strong need to ensure that people's legal rights and entitlements are clear.

As is the case now, clause 14 of the Draft Bill gives local authorities the power to charge for social care and sets out when they can do so. However the Draft Bill does not make it clear that local authorities also have a power not to charge. Mencap recommends that the Department of Health includes an explicit sub-clause to this affect.

Mencap firmly believes that assessments should be free from charge and that this should be set out on the face of the bill.

Mencap fully supports the well-being principle and believes that this duty must be emphasised throughout the Draft Bill and any future Regulations, including in this clause. In particular it is crucial that local authorities ensure that no one is prevented from accessing the care and support that they need because they can not afford to pay charges.

Future regulations

¹³ Commission on Funding of Care and Support, Fairer Care Funding – The report of the Commission on funding (2011)

Mencap looks to the regulations to set out clearly:

- what income can not be charged against
- what services should be free from charges, and
- the minimum level of income required to meet the means test.

An area that will require significant attention in the regulations is that of disability related expenditure. Over the last 18 months, Mencap has witnessed the varying lists amongst local authorities of what constitutes a 'disability related expenditure' (DRE) showing a clear postcode lottery in the system. Furthermore, we are also aware of a number of local authorities who have introduced a sum which is automatically applied to the means testing process, rather than calculating on a case by case basis, and where they have capped the total of what someone can claim to be a DRE. Mencap is concerned as to the legality of this practise and asks that it is addressed through Regulation.

Who can have their needs met? Clauses 17-23

Mencap welcomes the duty and powers set out in clauses 17 and 18 of the Draft Bill as it pulls together existing duties in an explicit and clear way. Likewise, we welcome the duties and powers to meet the needs of carers in clause 19.

Process to meet needs

Mencap agrees with the CSA that it is necessary for the Bill to clarify the order of the process by which this duty is delivered. Whilst the draft Bill implies the order of assessing and meeting needs, we believe the wording could be amended to spell out the order of this process more clearly. This would avoid any potential issues arising from the perception of ineligibility acting as a barrier to identifying needs.

Mencap believes a clause setting out the process in the following order would be helpful; needs assessment, application of eligibility criteria, financial assessment, service planning and care package put in place.

Exception for provision of health services

It is important for the future statute to set out clear recognition of the boundaries of Health Care and Social Care. Cases heard by the Health and Local Government Ombudsmen provide evidence that people have been placed in inappropriate services whilst the local authority is in dispute with the NHS. With changes coming into force from the Health and Social Care Act, the need for clear distinctions is ever more important.

Exception for provision of housing services

Historically social care services have included a form of housing provision, for example residential care homes. Over time, policy developments and the introduction of the personalisation agenda has seen a move away from these services towards supporting people to live independently, changing the landscape of housing provision.

Although housing and social care services are so closely aligned, the cooperation between adult social care departments and housing departments is often fragmented. Therefore Mencap would welcome clarity and guidance on the ways in which these services should collaborate to meet an individual's needs.

Mencap therefore encourages the Department of Health to go further than the proposed duty to cooperate and set out specific guidance on how social services should work jointly with housing providers and authorities, particularly for authorities in a two-tier system.

Housing strategy for people with a learning disability

Mencap recently commissioned Cordis Bright Consulting to undertake detailed research into the housing situation and needs of people with a learning disability, now and in the future. The interim findings have found that the most common housing arrangements for people with a learning disability known to social services currently are, living with parents (38%), registered care homes (22%), supported accommodation (16%) and living as a tenant in accommodation provided by local authorities and housing associations (12%). A survey conducted by Mencap (2011) showed that most people with a learning disability want to live independently – either by themselves (43%) or sharing a home with friends (30%).

Mencap is fully supportive of the move towards independent living but we are concerned that there is a lack of suitable housing provision for people with a learning disability. This has resulted in greater pressure to stay in the family home and for some hindered their ability to move out of registered care homes. We are also concerned that there is a breakdown in joint working between adult social care and housing services, which needs to be addressed by the Government.

Case study

Victoria lives in her own tenancy in the London borough of Islington. She has 24 hour support, a circle of friends and a person centred plan and very much lives the life of her choice. Her mother Jean has had to consistently fight to keep this in place. Islington have now made the decision that they will never again fund individuals with complex needs to live independently because the costs are too high.

Mencap urges the Department of Health and the DCLG to create a Housing Strategy for people with a learning disability, which should address current failures in the system.

What happens after the assessment? Clauses 23 – 27

The steps a local authority has to take - clause 23

Mencap welcomes this clause as it provides clear steps which all local authorities are required to take. We particularly welcome and support the introduction of a duty on local authorities to prepare a care and support plan. Care plans are a pivotal part of an individual's care and support. Often it can amount to a service in its own right as it is the opportunity for individuals to be signposted to services, as well as pulling all aspects of a person's life into a plan. As written, the clause emphasises the importance of involving the individual in this process, which is welcome.

Currently, many people with a learning disability and their families feel unclear as to what the outcome of their assessment is, what decisions have been made and why. This leads to many people feeling isolated from the process and does not give them an opportunity to monitor the progress of their situation.

Mencap welcomes the requirement on local authorities to provide a written record of the assessment, as well as providing advice and information, to those who the local authority has at that time no duty to promote services for. We would like this clause be widened to everyone who has an assessment undertaken. This would ensure that those who are eligible for state funded care and those who are not both have access to a transparent system.

We would also highlight our previous arguments on advocacy services as being relevant here.

Care and support plans - clause 24

Mencap has anecdotal evidence that many local authorities are failing to provide care plans or are providing care plans that are of a poor quality.

The Draft Bill's definition of a care and support plan, as well as what it should entail, in clause 24, is very helpful and will go along way to improve the system.

Involvement

We welcome the inclusion of personal budget and direct payment information in the care and support plan. The availability of this information will provide individuals with facts that they need to make a decision about their care and support arrangements.

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However, Mencap believes that the wording in clause 24 needs to be strengthened to embed the importance of involving the individual in drawing up the care and support plan. We suggest the word 'consult' is replaced with the word 'involve' to emphasise how the plan should be created in collaboration rather than through consultation.

We urge the Department of Health to add a clause to place a requirement on local authorities to produce a plan which is both accessible and meaningful to the individual and to produce the plan in a timely manner subsequent to the assessment.

Involvement of third parties

Mencap suggests that the regulations and supportive guidance should set out the merits of involving professionals in reviews of plans, as well as extending the clause on access to the care and support plan to those who are paid to support them.

Support workers often know the individual very well, their likes and dislikes, and their past history, and this could provide a strong contribution to the individual's plan and ensure a consistent approach which is really important to people with a learning disability.

Personal Budgets - clause 25

Mencap was one of the founders of In-Control, a project in 2003 set up to develop personal budgets,¹⁴ which led to the introduction of Individual Budgets. The key principle behind personal budgets was self-directed support. So far there has been a good deal of progress in the roll out of personal budgets, yet there are still some local authorities who are not as advanced as others. By not having personal budgets on a statutory footing, there has been confusion and a lack of confidence amongst local authorities in extending access to personal budgets.

Mencap welcomes the inclusion of personal budgets in the Draft Bill, particularly the definition given. This will help to make the support package transparent by giving everyone access to the same information.

Many local authorities lack confidence in personal budgets, often hesitating in being creative and allowing individuals to try new schemes of support. Mencap believes that it would be helpful to have supporting guidance promoting flexibility and creative thinking amongst local authorities when developing a care package for an individual's personal budget.

Reviews - clause 26

¹⁴ Then it was referred to as individual budgets. The project since evolved into a charity, which continues to work in this field.

It is very rare for an individual's needs to remain the same for their life time. There will always be changes in a person's life, both positive and negative, which will change what they need from their care and support package. Our support staff often feedback on the difficulties that they face in getting reviews or reassessments for the individuals who we support. It can be as long as a year before a review of a person's care plan happens.

We therefore would welcome an additional sub-clause in 24(1) for the care plan to have a set required date for a review meeting – where the local authority and the individual should collaboratively review their care plan. This should be at least on an annual basis.

Furthermore, we believe individuals should be able to request a review of the plan, if they can evidence that there has been a significant change in their circumstances. Local authorities must then undertake a collaborative review within a timely manner, which should be as set as low as possible. It may be that this can be managed in guidance specifically as regards the introduction of suggested timescales in which the local authority must respond.

Preference of accommodation – clause 27

Mencap endorses the personalisation agenda and believe the person is best placed to decide what they need and how those needs can be best met. Therefore it is important for this principle to be embedded throughout the legal framework. We welcome any regulation which requires local authorities to provide the type of accommodation which the individual chooses.

This regulation must be for every individual, including those with complex needs and those without capacity.

Mencap encourages the regulations to define 'type of accommodation' to avoid potential misinterpretation. We believe that individuals should have a choice between the nature of accommodation (e.g. supported living) and a choice over individual placements.

Direct Payments - clauses 28-30

Mencap believes that everyone should be given the option of a direct payment, unless there is a very strong reason not to. Adults without capacity should not be excluded from direct payments. Equally no individual should be forced to have a direct payment.

As with the other avenues of decision making in the care experience, individuals should be given support and have access to advocacy when deciding on whether they want a direct payment. Likewise, those who take the direct payment should have access to independent advocacy to be meaningfully involved in decision making. This should be incorporated on the face of the bill.

Furthermore the clauses in the bill should seek to remove barriers to direct payments for people with profound and multiple learning disabilities (PMLD). Due to the high level of support that people with PMLD need, they will often require large staff teams. It is crucial that family members who take on the role of managing someone with a PMLD's direct payment get the support needed to do it. Where families do not want to manage the direct payment, the local authority must make arrangements for an independent person to step in. Otherwise the individual will be prevented from accessing the direct payment.

Establishing where a person lives - Clauses 31-33

Continuity of care when an adult moves – clause 31

The current legal standing of ordinary residence is complex, unclear and regularly has a negative impact on the lives of people with a learning disability.

In some cases, local authorities have left individuals without the care and support that they need while they dispute with another local authority who will fund the care service. Mencap welcomes the Draft Bill's commitment to address the existing loopholes and grey areas of law with clear direction in the future statute.

Mencap welcomes the introduction of this clause to ensure that there is no interruption to the provision of care and support or the payment for care and support when a person with a learning disability moves to another local authority.

As the clause stands, the duty kicks in when the receiving authority is notified that the individual wishes to move there. This means that it is vital for the individual or their family to know who to contact so that they can notify their intention to move. Mencap looks to the regulations and supporting guidance to set out a clear expectation for accessible information and advice to be readily available.

Regulations should also set out clearly what constitutes an 'intention' to move and clearly identify the individual (or their representative) as the person who decides whether they want to move or stay in a local authority – not the local authority.

Deregistration of care homes

In the last decade local authorities have undergone a significant process of moving people with a learning disability from residential care homes towards supported living. This has led to some care homes changing the way that they operate and deregistering themselves. While this is a positive step, this process has led to many disputes between local authorities and individuals, in relation to ordinary residence.

It is very common for people with a learning disability to have lived in a care home out of the area for a long time. Often their family will move nearby and the individual will have made strong friendship networks in the area of the care home. Mencap often hears about situations whereby the local authority in which the care home is located refuses to relocate the individual in the area, forcing them back to their previous areas where they may no longer have family or friends nearby.

Clause 31(2) is a good starting point to eradicate these scenarios between local authorities. Mencap urges the Department of Health to use this opportunity to address the wider issue of care home deregistration looking to support local authorities to follow the correct procedure by involving the residents in the decision making process.

Genuine intention to move area

This section of the Draft Bill introduces some much needed improvements to the law. Potentially it will lead to a significant reduction in the number of disputes, as well as minimising the numbers of people with a learning disability who have to go without any care when they move area.

However the success of these improvements will depend upon how local authorities interpret the law and as such the future statute and supporting regulations needs to be very clear and transparent. Mencap is concerned that the use of ‘genuine intention’ in clauses 31(1)(c) and 31(2)(c), potentially offers local authorities an opportunity to walk away from their responsibilities. We urge the Department of Health to set out clearly what constitutes “genuine intention” in the Regulations and guidance. In addition we would suggest a presumption in favour of “genuine intention” is included with the Regulations. This should emphasise the importance of an individual’s say in the matter, as well as having a robust and simple to access appeals process should an individual (or their representative) disagree with either the sending or receiving local authority.

Requirements on local authorities

Mencap welcomes the steps set out in 31(3), whereby the receiving local authority will have the power to meet the needs of someone who is not yet ordinarily resident. This will be beneficial in a number of ways including allowing the receiving local authority to undertake a robust assessment and care planning process whilst the individual continues to get interim care and support.

Mencap believes that both the receiving and sending authorities should have a responsibility to keep the individual informed about the progress being made and setting out the rationale for decisions made. That way the individual would be able to hold both local authorities to account if they believe progress is not fast enough or their views are being ignored.

Portability of package

Frequently, where individuals have moved, they and their family carers have had to battle to get the care and support that they need, often going for months at a time without any support or settling for a lesser package.

Whilst clause 31(6) places a duty on a receiving authority to meet the needs identified in the existing assessment – until a new assessment is carried out, there needs to be an express requirement that they should aim to provide equivalent care and support to meet assessed needs. If we want a system where a move between authorities is as seamless as possible, it will be important to encourage local authorities to provide a package of services which mirrors that of the previous local authority. Although this is implied in the Draft Bill, we recommend that clause 31(6) is expanded with a requirement that the receiving authority must have regard to the care and support plan already in place.

With a localised assessment system, it is very common for local authorities to come up with different conclusions from an individual's assessment. Therefore when a person with a learning disability moves to another area they are at risk of the receiving authority's assessment disagreeing with the sending authority assessment. We would encourage the Draft Bill to explicitly require receiving authorities to give written explanation if the needs identified by the new assessment are different from those identified by the previous local authority. We would encourage that this be incorporated on the face of the bill rather than regulations.

Alongside this, the Department of Health should explore the range of assessments and consider introducing a standardised national assessment system to end the postcode lottery.

Disputes

Although the Bill will be making major improvements to the ability of people to move between areas in a seamless way, disputes between local authorities will continue. Therefore we welcome further regulations and guidance in this matter.

There should be clear expectation within any guidance that where disputes occur, no individual should have their care and support or payment for it stopped pending resolution of disputes between authorities and that the well-being of the individual must be of prime consideration.

Safeguarding adults at risk of abuse or neglect - clauses 34 – 38

There has been widespread concern that the mechanisms and procedures currently in place to safeguard adults at risk of abuse or neglect are inadequate.

It often appears that safeguarding is not taken seriously by the agencies concerned, as evidenced by the delays in dealing with safeguarding concerns at Winterbourne View. Many would agree that at present adult safeguarding is not fit for purpose.

Time after time we have witnessed how gaps in provision have led to serious consequences for people with a learning disability, for example, the death of Francesca Hardwick and her mother Fiona Pilkington, the murder of Steven Hoskin and most recently the abuse scandal at Winterbourne View Hospital:

Relevant information was held by social services, the police, the health service and the housing association. Put together, this information might have saved Mr Hoskin (Cornwall Adult Protection Committee, 2007, paras 5.2 – 5.8)

Information had not been shared with other agencies by the police, and the police had not linked together the complaints or recognised the vulnerability of the family (Leicester, Leicestershire and Rutland Safeguarding Adults Board, 2008)

The multi-agency response was ineffective. When the policy and procedures were invoked, there were missing elements, including a shared multi-agency safeguarding objective and information sharing and retention (Serious Case Review - Winterbourne View Hospital, South Gloucestershire Safeguarding Adults Board, 2012)

The movement to clarify and strengthen the law on adult safeguarding, made by the draft bill, is welcomed by Mencap. This is something we have long called for¹⁵.

We urge the Department of Health to take every opportunity to ensure that people are able to live independent, happy and fulfilling lives, free from the threat of degrading or inhumane treatment. We urge the Department of Health to ensure that the statutory guidance and good practice guidance to reflect the new legislation, reflects all the recommendations from relevant Serious Case Reviews, most recently, the Serious Case Review into Winterbourne View. We would welcome the opportunity to work closely with the Department of Health on this.

Principle of safeguarding and embedding prevention

¹⁵ Most recently we have called for this in Mencap and the Challenging Behaviour Foundation's campaign report Out of sight: stopping the abuse and neglect of people with a learning disability

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Mencap believes that there is a need to add two further clauses to the bill. The first of these should focus on prevention. We are concerned that the first reference to safeguarding in the draft Bill is in relation to an enquiry – when an individual has already suffered abuse, and that this does not recognise the need for local authorities to take steps to prevent abuse occurring in the first instance.

We believe that the fundamental basis of safeguarding work should be prevention through the raising of awareness about what abuse is, what can be done to prevent it and how to report abuse or concerns. The draft Bill should therefore include an additional clause at the beginning of the safeguarding section which places a new duty on local authorities to empower individuals to understand what abuse is, and how to protect themselves from it. This focus on empowering an individual to protect themselves from abuse should also be reflected in the wording of Clause 1(2)(b) and Clause 1(3)(f) in regard to the principle of wellbeing, and Clause 2(2)(d) in regard to providing information, advice and advocacy.

A further clause should be designed to emphasise the importance of the local authority balancing the protection of a person at risk with the individual's own rights by introducing a 'principle' of safeguarding. This should incorporate Article 12 of the UNCRPD, the right to live independently and be included in the community. The UK has ratified the UNCRPD and incorporating Article 12 into UK law would be an important step towards complying with this.

Local authorities should always consider the wishes and decisions of the individual yet be ready to take action if that individual is at serious risk or has suffered a form of abuse. As stated in Article 12 of UNCRPD, all safeguards should be proportional to the degree to which such measures affect the person's rights and interests. Case law has shown that we do not want people to be 'safe but unhappy'¹⁶. This principle should ensure there is the balance between protecting people from abuse and protecting the right to independence and inclusion.

The role of 'decision-making' in prevention

We believe the role that decision-making by the local authority (and the health trust) plays in preventing a person with care and support needs being at risk of abuse or neglect should be highlighted at the start of the Safeguarding section of the Bill. At the moment this section starts with 'Enquiry by local authority'. We believe there should first be an explicit link to the important role that good decision making by the local authority or health trust has in prevention.

¹⁶ Munby

Thorough assessments, proper care planning and commissioning of services which truly meet a person's needs will have a crucial role in preventing a person being put at risk of abuse and neglect.

We would urge that the legislation and guidance ensures local authorities and health authorities reflect on their own practice, so that the decisions they make about a person with a learning disability's care and support does not contribute to or cause the person to be put at risk of abuse and neglect. An illustration of this would be commissioners taking note of what was said in the Serious Case Review on Winterbourne View – 'Hospitals for adults with learning disabilities and autism should not exist but they do. While they exist, they should be regarded as high risk services i.e services where patients are at risk of receiving abusive and restrictive practices within indefinite timeframes' – and deciding not to send a person with a learning disability to a place like Winterbourne View, but ensuring the person can access personalised support and services close to home.

It should be highlighted that the main aim of the local authority and others should be prevention. But of course it is crucial that agencies ensure that robust procedures are in place for dealing with incidents of abuse, for when the preventative strategy fails.

Enquiry by local authority – Clause 34

Mencap welcomes the power given to local authorities to make enquiries as outlined in clause 34. This is an important power which gives local authorities the powers to protect people who are at risk of abuse or who have already suffered abuse or neglect.

We support the draft bill's attempt to define financial abuse as current rules are not always used to protect people from this form of abuse. The definition of financial abuse given in clause 32(2) gives a good definition of the different scenarios of such abuse.

It is important that local authorities take the action that is needed to protect those whom they suspect are experiencing or at risk of all forms of abuse, and the bill must reflect this. Mencap is concerned that the current wording of this clause may lead to interpretation that financial abuse is the only form of abuse whereby local authorities have a power to make enquiries. Therefore the bill must explicitly state what types of abuse are covered by this clause, i.e. financial, physical, psychological, sexual, institutional abuse. We would encourage the Department of Health to also introduce supporting statutory guidance adding further clarity about the different types of abuse, giving the local authorities clear guidance.

When clarifying abuse and neglect we would urge the following to be highlighted:

- that neglect can occur when a person does not get the care and support that they require – both by social care and health services.

- That overuse of medication and inappropriate restraint are abuse. ‘It is shocking that the practice of restraint on a daily, routine basis was not seen as constituting abuse by any professional’ (Winterbourne SCR)
- Identifying institutional abuse will involve better collecting, linking and sharing of concerns.

It is crucial that abuse and neglect is spotted and appropriate enquiries made.

Proposed new safeguarding power to support the duty to make an enquiry

Mencap has submitted a response to the DH consultation on whether a new safeguarding power is needed to support LAs to meet the duty to make an enquiry and gain access to speak to a person with mental capacity who may be at risk of abuse. We support the proposal but we suggest it should cover people with and without capacity unless guidance can explain how the Mental Capacity Act 2005 can be used practically in situations where the person lacks capacity or where capacity is not known. It would need to be ensured within the Regulation that local authorities use the power proportionately and after full enquiry. It would be important that the power was only used as a last resort. We have recommended a number of safeguards that would need to be in place if the power was introduced. Please see our separate response to this.

Adult Safeguarding Boards – Clause 35

Mencap strongly agrees with the need to put adult safeguarding boards on a statutory footing, better equipped both to prevent abuse and respond to it when it occurs. We envisage Safeguarding Boards should act as the local leader for safeguarding, ensuring those who are at risk are protected and that serious cases are kept to an absolute minimum.

As regards the proposals at s35(3) and (4), we believe these should be clearer that the responsibility in respect to safeguarding is to ensure that their powers are used effectively and that they follow the statutory guidance. Their responsibility is to ensure issues are identified and appropriately investigated and remedial actions are agreed and monitored.

Membership

The suggested members of the SAB as set out in Schedule 1, is a good starting point, however we suggest some crucial amendments to this.

We believe the ‘local authority’ representation need to be broken down further, as to cover the differing departments which need to be involved in this process. For instance there must be representation from housing and education, as well as social services. A need for this was highlighted in the case of *x & Y v Hounslow Council* where there was

serious failings of communication between different departments led to a serious breakdown in the safeguarding practice. The claimants argued that the different departments within the local authority should be treated as separate legally identifiable entities rather than a single body.

In order for the SABs to work all members must be fully active and they can not rely merely on one of the members e.g. the local authority. Whilst the plan will set out the role and actions of the members, we encourage the primary legislation to set out explicit duties on all members of the SAB to ensure that they fully cooperate and share information.

We believe there needs to be more clarity about the distinction between ‘members’ of the SAB and ‘relevant partners’ which are referred to elsewhere in the Bill. As explained elsewhere, we want providers (all levels: managers through to support staff) to be on the list of relevant partners, which have a mutual duty to cooperate with the LA. Providers will be those who are responsible for delivering safe care on a daily basis. It is crucial they are seen as relevant partners. It is important that the LA listens to them and cooperates with them. It is also crucial they listen to and co-operate with the LA. For the SCR into Winterbourne, the provider, Castlebeck, withheld information. We want to see true partnership between providers and SABs with everyone working together to protect people with a learning disability from abuse.

Relevant partners could be seen as ‘associate members’. It is important that their role in SABs is clarified.

Links with CQC

Mencap urges the Department of Health to consider how the SABs will work with the Care Quality Commission. Recent cases of abuse, including Winterbourne, have shown that there is a lack of joined up working between local authorities and the regulator, which hinders attempts to safeguard for individuals at risk. This makes it every more important for the legal framework to encourage joint working.

When there are notifiable events (incidents or events where the safety of patients has been affected) in services regulated by CQC, CQC should be notified (although we know this doesn’t always happen). The provider and adult safeguarding team are responsible for investigating and will notify CQC of the outcome of safeguarding investigations. In CQC’s internal management review into Winterbourne View which reflected on their practice, CQC said ‘there was no follow-up on these notifications to ensure they had been investigated effectively and that the outcomes had been shared with CQC’. They recommended to themselves that ‘CQC should build new protocols about working with local safeguarding adults teams and safeguarding adults boards to ensure timely investigation of alerts.’

In CQC's revised safeguarding protocol they also highlight the importance of joint working with Safeguarding:

'CQC recognises that the relationship between CQC and local safeguarding boards is critical and valuable to ensure that the local safeguarding arrangements are working effectively.'

'It is an expectation that Compliance Managers will maintain regular contact with the safeguarding leads within their LA areas. Although the frequency and nature of meetings can be mutually agreed at the local level, the importance of maintaining this working relationship and ongoing dialogue cannot be underestimated.'

The Serious Case Review into Winterbourne also found a lack of appropriate sharing of information between the SAB and CQC. It found that Mental Health Act commissioners were not invited to be part of the SAB and that the evidence they held was not formally part of the considerations of the Board. The SCR said that appropriate information was exchanged but not routinely and systematically.

It is clearly crucial that CQC is properly joined up with SABs. Mencap suggests that the CQC should be required to identify a person within the regulator who should act as a link with each of the SABs. This position should be responsible for sharing information, advice and guidance with the board as well as be a champion for joint working. It would ensure that both the work of the SAB and the work of the regulator are informed by each other which is likely to mean better safeguarding of vulnerable individuals.

Local strategy

The strategy for how safeguarding works in a local area is going to be very important. We welcome the opportunity to be involved in the development of guidance for this.

We expect that the duty on all members of the Board will strengthen the commitment to Adult Safeguarding. Much of the guidance in No Secrets is useful and we hope the guidance to accompany the new legislation will build on this.

As already highlighted we would like to see all the recommendations from the SCR into Winterbourne View reflected in legislation and guidance on safeguarding. We have included some key points and recommendations from the SCR and the other reviews into Winterbourne below:

- The Serious Case Review into Winterbourne said that whilst 'high risk' services (hospitals for people with a learning disability) do exist 'such service require more than the standard approach to inspection and regulation. They require frequent, more thorough, unannounced inspections, more probing criminal investigations and exacting safeguarding investigations.'

CQC has acknowledged in its internal management review of Winterbourne View that places like Winterbourne are higher risk services. They said that this will act as an alert system to staff when looking at data and information and when carrying out inspections. We think a similar alert system should be part of the local safeguarding strategy. People in services considered 'high risk' should be identified and appropriate steps taken to ensure they are adequately safeguarded.

- 'Social workers and the police with responsibility for investigating allegations at hospitals for adults with learning disabilities and autism should bring a more challenging filter and lens to the task of safeguarding patients. This is the case most particularly when anti-therapeutic outcomes come to light eg. physical harm resulting from being restrained.' (SCR)

It is important that the guidance clarifies how local areas can ensure exacting safeguarding investigations. We would like to see real scrutiny of care plans and ensuring people are getting the care they need.

- The SCR into Winterbourne found: there had been 40 safeguarding alerts, 29 incidents where the police were involved, and 78 attendances at A&E. Safeguarding treated safeguarding alerts concerning Winterbourne View as discrete cases. The PCT confirmed that clinical staff would not have been aware of patients previous attendances at A&E as no alerting system in place.
- SCR said: 'Drawing together information from patients complaints, from Health and Safety Executive notifications, from restraint practices, from concerns known to CQC, from attendance at A&E, from police attendances, from the first tier MHA tribunal, would have identified the risks to which patients at WV were subject. Given that so many patients were isolated and disconnected from sustaining relationships, the case for aggregating such information sources is compelling.'

It is clear from the SCR that no agency took an overview of what was going on. There were plenty of warnings that something was seriously wrong at Winterbourne View. These incidents should have been properly linked up. They weren't.

- SCR said: Clinical Commissioning Groups should explore how Accident and Emergency can detect instances of re-attendance from the same location as well as by any individual.

It is crucial that A&E staff are properly alert to adult safeguarding issues and have a clear understanding of what to do with any safeguarding concerns. Mencap has submitted a response to the Health mandate consultation. It has called for the Mandate to the NHS commissioning Board to include an objective: Ensure every CCG has a robust system in place to record and monitor serious untoward incidents and safeguarding alerts and to guarantee they are acted upon.

- CQC's internal management review recommended: 'CQC should develop its analysis of safeguarding alerts to look at particular trends at individual locations, and across service providers. This is particularly important in looking at concerns across chains of providers which cross CQC's geographical boundaries.'

It is important that the SAB's safeguarding strategy ensures information is linked up. This is going to be crucial in spotting institutional abuse.

- The SCR gives the chronology of events at Winterbourne. It explains that the whistleblower alerted Adult Safeguarding. Adult Safeguarding forwarded this information to CQC. Adult Safeguarding believed the manager of the Winterbourne View was investigating. The Whistleblower also contacted CQC. CQC did not respond to the whistleblower. CQC did not contact the whistleblower because it was assumed the provider or safeguarding were contacting them.
- The SCR said 'It is both necessary and appropriate for employers to assume a prominent role in investigating safeguarding concerns. However, when there is evidence of partial and/ or delayed investigations an LA should assume this responsibility'. 'When a hospital fails to produce a credible safeguarding investigation report within an agreed timeframe, the host SAB should consult with the relevant commissioners and the regulator to identify remedies.'
- The SCR said 'NHS commissioners are required to use the NHS standard contract for providers of NHS funded care. This would have ensured that the commissioner was informed at the same time as CQC of any notification of a serious incident concerning a patient'. It said 'it does not appear that the health and social care professionals responsible for monitoring patient placements were contractually required to forward concerns about abuse to the commissioning organisations responsible for funding the placement.' It said 'Arrangements should be in place to share information about safeguarding incidents and alerts between those responsible for monitoring patient safety, the provider and commissioners and this should be routinely monitored through contracts.'
- CQC internal management review said 'There is a lack of clarity in the safeguarding system about roles and responsibilities'.

It is clearly crucial that the local strategy clearly sets out roles and responsibilities of all agencies in relation to safeguarding and local policies are clear to all. It must be clear that ultimate responsibility for investigating safeguarding concerns lies with the safeguarding team/ SAB. As the SCR into Winterbourne says, it is both necessary and appropriate for providers to take a prominent role in investigating safeguarding concerns, however, it appears that all too often providers are just left to do this, without safeguarding/ SAB taking overarching responsibility for ensuring this is done properly and in an appropriate timeframe. Regulation needs to place emphasis on the importance of timescales, and the need to agree these timescales with providers.

It important that relevant information from H&W boards and LDPBs is fed into the strategy of the SAB, for example, information about how many people are in 'high risk' services.

As mentioned in our response to the DH consultation on a new safeguarding power – it will be important that if this power is introduced, that its use is reported and monitored. The safeguarding strategy will need to show how it will be used to ensure vulnerable people are safe-guarded in the short and long-term.

Strategic planning and reporting

Mencap agrees with schedule 1's introduction of a strategic plan and annual report. This will be a vital action of the SAB and will ensure that they move towards the set objectives.

We particularly welcome the suggestion that the plan will set out what is expected of each member. We also agree that where possible the community is consulted when making the plan. Any guidance which accompanies this legislation should make it clear that accessible information on the SAB and its plan is available to all.

We would like to see the legislation and guidance help ensure that there is learning from Serious Case Reviews and recommendations are taken on board and used to inform the Board's strategy. Whilst the proposed legislation says that an SAB must publish a report on the finding of the reviews, there is nothing about implementing the learning. We know that of those who were at Winterbourne, many have gone on to be placed in other 'high risk' services and experience further abuse. It appears that not all commissioners have changed their practice as a result of the SCR and have continued to commission places at services like Winterbourne View. We want the recommendations of the SCR to be implemented and practice to change.

In order to be able to monitor the progress made in safeguarding, share learning more widely and address serious failures, the Department of Health must collate strategic plans and annual reports. We suggest that the Secretary of State for Health is added to the list given on Schedule 1(3).

Furthermore there needs to be a serious case reporting mechanism, whereby the Department of Health are alerted to any serious failings of safeguarding practices so that they can support the local SAB to prevent such cases in the future.

A minimum standard of SAB

Clauses 35(3) and (4) of the draft bill, quite rightly provides a level of flexibility to allow safeguarding boards the ability to decide for itself how to meet its objectives. However as to ensure that they are working to a minimum standard, Mencap urges the

Department of Health to provide statutory guidance on the practical workings of the boards and on the monitoring of their effectiveness. For example, there needs to be clear guidance on timescales of action and guidance emphasising the need for boards to monitor progress.

We welcome that the draft Bill places a duty on all members of the SAB. However, we have some concerns about 'group responsibility'. It does leave the question of where the buck stops. If it is all the key agencies in a local area on the Board and there are real failings in safeguarding, who is responsible – 'group responsibility' can mean 'no-one's responsibility'.

It is important that the legislation and guidance makes the lines of accountability and scrutiny clear. For example, it has been suggested that the each Board member will be accountable to its own organisation. It also needs to be explained how the workings of the Board will be scrutinised. We have suggested that the strategic plans and annual reports of the SABs are collated by the DH. We hope this proposal is accepted and would welcome detail on how information would then be acted on constructively.

Scrutiny is important. Systems can be in place but it is the outcomes for people that matter. For example, The SCR into Winterbourne says 'On paper the policy, procedures, operational practices and clinical governance of Castlebeck were impressive.' SABs may have a good strategy on paper but the results need to be scrutinised.

Resources

A study of existing Safeguarding Boards¹⁷ found that their work and ability to protect can be weakened by financial pressures on resources and where participant members are not fully committed to making the board work.

We propose that the statute retains existing requirements in guidance that 'the local authority shall take steps to ensure that the Director of Adult Social Services has the powers and resources necessary to encourage a culture of vigilance against the possibility of adult abuse¹⁸. We believe that this would ensure that there are adequate resources given over to safeguarding issues as well as maintaining social services as the lead authority on those issues.

In the current climate there is a real risk that adult safeguarding won't be resourced properly. It is crucial that it is, so that it can be effective.

Safeguarding adult reviews – Clause 36

¹⁷ The governance of adult safeguarding: findings from research into Safeguarding Boards, SCIE 2011'

¹⁸ DH, No Secrets

Mencap agrees that part of the role of SABs is to undertake reviews of cases where there is suspicion that an adult is experiencing abuse or neglect and where a person dies or there is reasonable concern over how an agency has acted. We do however urge the Department of Health to widen this to cover cases where the adult sustains a serious injury of which has no reasonable explanation, as well as death.

Mencap is also pleased that clause 36(2) places a duty on SAB members to cooperate and contribute to carry out the review. This will be an important function of the SABs and therefore it is crucial that this duty remains in future legislation. We would suggest statutory guidance is used to set out best practice processes.

We also want there to be a requirement on all relevant agencies to supply information for reviews. Private and third sector providers will not be members of the SAB so there will not be a duty on them to cooperate and contribute to a review. It is crucial there is a requirement for them to provide information so that lessons can truly be learned. Without a requirement, providers will not always share this information, as illustrated recently: 'Castlebeck Ltd declined to share the un-redacted report they had commissioned from PwC after the transmission of Panorama. Similarly, their Individual Management Review was redacted' (Winterbourne SCR).

We also suggest that this clause names a 'lead' agency in the review process. This lead agency should be ultimately responsible to make sure the review process has been fulfilled and meets the minimum standards. We would suggest that local authorities would be best placed to lead.

Abolition of local authority's power to remove persons in need of care – clause 47

Mencap agrees that the compulsory power under S.47 National Assistance Act, should be repealed as proposed by the Law Commission. As the DH has said: its language and intentions are not compatible with the current approach to community-based support that promotes and protects people's human rights.

Protecting property of adults being cared for away from home – clause 38

Mencap welcomes the duty that is designed to protect the property of adults who are being cared for away from home.

We urge the Department of Health to ensure that any charges for such services are kept to a minimum and that they are truly affordable for the individual. We would not agree to any form of charging that does not take into account the individual's ability to pay the costs.

Advocacy

Mencap firmly believes that any individual for whom protective measures are being considered or who is currently affected by Safeguarding measures of a local authority, must have access to independent advocacy.

We also believe that when any individual is in a service which is widely considered to be 'higher risk', for example, hospitals for people with a learning disability, they have must have access to independent advocacy.

This must be addressed in the Draft Bill, although this might be more appropriately done in other sections. Please refer back to our section on information, advice and advocacy.

Transition for children to adult care and support - clauses 39 – 44

Mencap welcomes the incorporation of transition services in the draft social care bill. Both the individual and the local authority reap the benefits of good transition. If transition is done properly, it can lead to greater independence and outcomes such as employment for the individual, reducing reliance on benefits and support services, as well as improving the wellbeing of the individual.

Currently people with a learning disability and their families are not being well supported in their transition to adulthood. This is particularly important because of the different systems and eligibility criteria which exist between children's and adults' social care. Local authorities are failing to ensure every young person has a personalised transition plan and many individuals are simply slipping through the net.

Case study - Tom's transition story

Tom was a very sociable young man with profound and multiple learning disabilities, including complex health needs. Although he had no speech he had a great sense of humour and a whole range of ways that he communicated his keen interest in food, films, beer and blondes! He attended a residential special school. His parents were both teachers, his mother a teacher of pupils with profound and multiple learning disabilities. They knew the system and they did everything they could to get transition planning underway for Tom so there would be a good plan for when he left school. They were told not to worry; it was too early to start planning. But despite their best efforts, by the time Tom was approaching 19 no provision had been identified for him. The school kept him on for a bit longer, but eventually set a deadline for him to move on. His parents, and eventually a social worker, searched frantically for a residential placement for him but to no avail.

In the end, Tom spent 96 days in an NHS psychiatric assessment unit. His parents think that this was because there was nowhere else for him to go. Eventually a suitable placement did come up in the area and he was transferred to a suitable residential service. But during this time, when he was not in an environment where he was supported by people with the right skills, his health was deteriorating. Tom was eventually diagnosed with a number of serious conditions but it was too late for Tom and he died a short while after his 20th birthday.

Tom's parents complained to social services about the lack of transition planning and the failure to plan for or commission new provision for him. Both complaints were upheld:

"I agree with the conclusion that both Tom and yourselves were entitled to expect accommodation would be available within a reasonable time to meet Tom's needs and we have failed to deliver this" – Head of adult care services

However far Tom's death may also be attributed to the care he received in the NHS (on which, see Tom's story in Mencap's 2007 report *Death by indifference*), the question Tom's parents continue to ask is, "If good planning had been in place, and Tom had reached 'safe hands' sooner, would he still be alive today?"

Good personalised transition planning for young people with a learning disability includes:

- Adequate pre-planning to determine future need so it can be planned for during the transition process;
- A holistic approach, covering all aspects of the support, including health and social care needs, and not just education;
- Continuity so people do not have to start all over again because information is not passed on;
- An up to date communication passport to go with them through all transition points;
- A health action plan which includes all aspects of people's complex health needs;
- A transition social worker to help the individual and their family move through to adult services;
- Maintenance of therapeutic support (no sudden reductions in access to speech therapy and physiotherapy, for example).

Child and adult social care law

Currently the law is often contradictory and complex, which has led to many disputes between children and adult services. Whilst we welcome the Draft Bill's attempts to bring clarity and provide adult services with stronger powers in this area, we remain concerned.

For example, the only proxy in the Draft Bill for providing transitional support is Section 17 of the Children's Act 1989. However, disabled children and young people may also receive services under the Chronically Sick and Disabled Persons Act 1970 or through other means, such as through educational settings and would therefore not be eligible for the provisions listed in clauses 39-43.

Mencap recommends that the provisions in this section of the Draft Bill should be extended to also apply to services provided for under the existing Chronically Sick and Disabled Persons Act. There should also be an equivalent care duty on local authorities to continue to provide relevant aspects of a young person's care which were previously received under education until appropriate alternative provisions have been implemented.

We also ask that the department set out clear plans for how the provisions for children and young people will continue in the future, when the future adult social care statute is passed. As the Draft Bill plans to replace all previous adult social care statutes with a single Act, we are concerned that crucial provisions for children and young people will be lost. Alongside the statute, the department should undertake an impact assessment of the relevant provisions for children and young people in the 1970 Act.

Children assessments – clauses 39 - 42

Mencap has long criticised the current system of assessment for children and young people. Commonly adult services do not assess a young person until it is late in the day, therefore not giving them and the individual time to holistically plan and prepare for the future.

Mencap believes it is essential for timeframes to be implemented which ensure that assessments under clause 39 are conducted in a timely manner so that there is no excessive delay to the planning process which might negatively affect a young person or their family. As part of this, Mencap calls for a statutory mechanism to be put in place to prepare for transition at the time a young person reaches 16 to ensure that the process begins in time.

Mencap regularly hears from young people and their families where the individual leaves compulsory education, residential college or turns 25 and there is no care plan in place,

often resulting in the young person moving back into the family home. This shows the importance of the planning of services at transition in enabling independence. This not only benefits the individual who is able to gain greater control over their life, but also for the local authority as this can act in a preventative function by reducing someone's reliance on social care services throughout the course of their life.

Mencap urges the Department of Health to produce statutory guidance to lead local authorities to take a pro-active approach to providing preventative services to all young people aged between 18-25. These preventative services should be available for all young people who received care services as a child, even if they do not meet the eligibility for adult services. This would help local authorities to reduce reliance on the social care system over the long-term.

Mencap welcomes the inclusion in clauses 39 and 40 of the power for adult services to assess a young person and their carers and begin the planning process. However, we believe the clauses in this section of the draft Bill need to go further to strengthen the cooperation between children and adult services.

Children and Families Bill

In order to ensure co-ordination between the future statute and the Children and Families bill, it is important to consider the interdependent nature of education, health and social care which will come about through the proposed Education Health and Care Plans in the draft sections of the Children's and Families bill. Changes to someone's social care will consequently have an impact on their educational provision, and vice versa. Mencap therefore believes that local authorities must use the assessment process for adult services to look at the individual holistically, identifying any health and educational need that they may have, in order to fulfil the well-being principle. Whilst the well-being principle extends to education and training, it should be made clear that this applies to provision as part of someone's special educational needs. Supportive guidance should be designed to emphasise the importance of health and educational need for a young person and offer guidance for local authorities on how to deal with this.

Mencap would also like to see consistency in the strength of the duties in clauses 39 and 40. Clause 39 of the Draft Bill suggests that local authorities may assess a young person's needs for adult services ahead of their 18th birthday. Under clause 40 it states that the local authority must assess a carers needs if it appears that the young person will have needs. Mencap believes that where a young person requests an assessment from adult services the local authority must undertake the assessment.

Continuity of services under section 17 of the Children's Act 1989

Clause 28 of the draft SEN proposals in the Children and Families bill enables local authorities to remove children's social care support after the age of 18 if they lose their

Education Health and Care Plan (EHCP) as a result of no longer being in education or training. This means that a young person in this position could simultaneously lose their social care support if provision has not been made for them to receive adult social care by that point.

Mencap recommends that the Department of Health places an additional sub-clause to this section of the bill in relation to young people who lose their Education Health and Care Plans, because they are no longer in education. We suggest that this sub-clause should take inspiration from the very clear powers and duties on local authorities when someone moves into a new area. It should clearly set out that adult services should adopt the child or young person's care plan and meet those needs until they are able to conduct their own assessment and care planning process. This will help stop young people from slipping through the net

In addition to this, the Department of Health should introduce regulations which set out timeframes for adult social care services to arrange and implement provision for someone following them turning 18. This should be undertaken as long as the needs assessment is requested before the person reaches 18. This should be supported by similar additional changes to the Children and Families Bill.

Furthermore, regulations should be used to clarify the importance of the children and adult social care departments working together, identifying a clear dispute resolution process to support individuals and their families to hold the local authority to account.

Enforcement of debts - clauses 45 and 46

Mencap endorses the position and recommendations of the Care and Support Alliance in relation to clauses 45 and 46. We urge the Department of Health to provide clear regulations and guidance which emphasises the importance of meeting an individual's needs and desired outcomes. No one should ever feel the need to turn down care and support due to fear of being unable to meet existing debts or accrue further costs.

Registers of disabled people – clause 49

Whilst this clause offers a power for local authorities to keep registers, Mencap is concerned that this is not strong enough to protect registers. If we lose registers, we stand to lose existing knowledge we have of learning disability demographics.

One of the greatest problems for strategic planning is the fact that local authorities do not have accurate records of the number of people with a learning disability in their area.

At a Mencap consultation event¹⁹ service providers and Mencap local groups gave examples of poor strategic planning in areas where the local authority has failed to keep accurate records of people with a learning disability. At the same event participants who practiced in areas with a learning disability register, believed those local authorities to have a good standard of strategic planning for services due to the register.

Mencap urges the Department to explore how the future statute can encourage better recording of numbers of people with a learning disability to enable better strategic planning.

Good practice Case study - Lambeth

Register Services* have set up, and maintain, a voluntary register of people with learning disabilities in Lambeth.** This is commissioned on behalf of Health and Social Services, through the pooled budget for Learning Disability.

The Register has information about people's health and social care needs and also information such as how people spend their time and where people live.

Data is updated annually from source as well as from other data. Registered people and their families 'own' their information, have access to it and the ability to make changes. Access to data on the register is via a secure website for stakeholders and GP practices can access information about their patients.

The Register means that there is good, up to date data about people with a learning disability in Lambeth. Two key benefits of this:

- Appropriate services can be planned
- GP practices can identify patients with a learning disability for health checks.

Lambeth and Mencap PMLD project

The Register has also meant that Lambeth has been able to identify the numbers and needs of people with profound and multiple learning disabilities (PMLD) in Lambeth, and use this information to improve services for them.

Register Services worked with Mencap to develop criteria based on the PMLD Network definition of profound and multiple learning disabilities, which were then applied to the register data. Register Services will be able to continue to identify the numbers and needs of people with PMLD by applying these criteria.

People with PMLD are a particularly marginalised group of people and Professor Jim Mansell highlighted in his report, 'Raising our sights: services for adults with profound intellectual and multiple disabilities (2010), the importance of local areas having good information about people with profound and multiple learning disabilities to enable effective planning of services.

**Register Services' websites: www.registerservices.nhs.uk and www.i-count.org*

***Lambeth 'I Count' Register for People with Learning Disabilities*

much needed reform of adult social care law in England.

¹⁹ Consultation event, Law Commission and Mencap June 2010

We urge the Department to seriously consider the recommendations made in our submission, as we believe that these changes will help to create a legal framework which will improve care and support for people with a learning disability.