

Written evidence submitted by the Royal Mencap Society (MCAB23)

About Royal Mencap Society

Mencap supports the 1.4 million people with a learning disability in the UK and their families and carers. Mencap fights to change laws and improve services and access to education, employment and leisure facilities, supporting thousands of people with a learning disability to live their lives the way they want.

About learning disability

A learning disability is caused by the way the brain develops before, during or shortly after birth. It is always lifelong and affects someone's intellectual and social development. It used to be called mental handicap but this term is outdated and offensive. Learning disability is not a mental illness. The term learning difficulty is often incorrectly used interchangeably with learning disability.

Executive summary

- We are concerned at the **'break neck' speed** of the Bill - time must be taken to; consider the recommendations from the Mental Health Act Review, publish an updated impact assessment, publish a draft code to aid debate and consult with people with a learning disability, families, professionals and the sector.
- We **welcome Government amendments** tabled during Committee, which tackle some, but not all of our concerns.
- The **Bill must be strengthened** in order to uphold key rights and protections for people with a learning disability who lack mental capacity.
- **Liberty is precious**, so it is vital there are robust safeguards to ensure that people who lack mental capacity to consent to their care arrangements receive the least restrictive care possible and that any restriction of liberty if it is genuinely in the person's 'best interests'.
- Any **conflict of interest** must be removed from the Bill both in terms of care homes but also independent hospitals.
- The **wishes and feelings** of the person must be at the Bill's heart.
- **Appropriate advocacy** must be available to all who need it.
- Peers voted in an important amendment **on rights to information** for families. We are concerned the Government's counter amendment weakens these.
- As drafted **detention can continue without renewal for up to 3 years**. We believe this should be reduced back to one year.
- We welcome inclusion of **16-17 year olds** but the Government must guard against unintentionally reducing protections or eroding parental rights.

About the Bill

1. Introduced into the Lords in July, the Bill amends the Mental Capacity Act 2005. In particular, it replaces the Deprivation of Liberty Safeguards (DoLS) with a new regime Liberty Protection Safeguards (LPS).
2. DoLS are used to deprive someone of their liberty in order to provide care and treatment. They are used in hospitals and care homes and are applied where the individual lacks mental capacity to consent to the arrangements. Examples include:

- a. using locks to prevent people leaving a care home or hospital,
- b. restricting access to things which could be used for self-harm,
- c. physically stopping someone from doing something.

Why Mencap is interested in the Bill

3. The impact assessment predicts that **300,000 people** will be affected. This includes some of the most vulnerable people in our society. While the largest group of people are those with dementia, **people with a learning disability** make up a substantial number of those that would be affected.
4. **Liberty is precious**, so it is vital there are robust safeguards to ensure that people with a learning disability who lack mental capacity to consent to their care arrangements receive the least restrictive care possible.
5. Any restriction of liberty must genuinely be in the person's 'best interests' with their wishes and feelings central to the process.
6. **We therefore believe the Bill must be strengthened** in order to uphold key rights and protections for the significant numbers of people with a learning disability and their families who will be affected. This is vital as too often the voices and rights of people with a learning disability and their families are ignored.

Break neck speed without adequate consultation and assessment of impact

7. We are deeply concerned at the 'break neck' speed with which the Bill is progressing and during debate in the Lords and Second Reading in the Commons, we urged a pause for further consultation.
8. While the Law Commission consulted widely in the lead up to their Draft Bill, the Government's version differs in a number of significant ways and has changed yet again due to a series of amendments made in the Lords.
9. We remain concerned that there is simply not time to consult in detail on this important proposals with the sector, families, advocates, professionals and importantly people with a learning disability themselves.

Impact assessment

10. The **impact assessment** (published alongside the Bill in July 2018), focused on the perceived costs and savings associated with the Bill. This is now completely out of date considering the raft of Government Amendments tabled in the Lords.
11. Furthermore, the under resourced care system is at breaking point and there is little information about where the money and workforce will come from to implement this effectively.
12. We urge the Government to publish a **revised impact assessment** together with a **robust appropriately resourced implementation strategy** is essential.

Draft Code of Practice

13. Much of the debate has focused on what should go on the face of the Bill and what should go in the Code of Practice. This is problematic as the Government has not published a draft code.
14. We urge the Government to publish a draft Code to aid MPs during debate. This was done during the passage of the Mental Capacity Act 2005 and was invaluable to parliamentarians.

The Interplay with the Mental Health Act (MHA) review

15. Currently, the interface between DoLS within the MCA and the MHA is confusing in practice and often leads to delays and problems. This interface is not acknowledged or dealt with in the Bill.
16. Sir Simon Wessely's Independent Review was published on 6th December 2018 and the Government has committed to bringing forward legislation to reform the MHA.
17. Sir Simon's review proposes to redraw the dividing line between when a person should be detained under the MHA and when they might instead fall under the MCA.
18. The proposed dividing line is objection, so that if a person without capacity does not object to admission or treatment they should be placed under the MCA.
19. The proposed new dividing line of objection needs thorough and broad consultation, possible pilot testing, and pre-legislative scrutiny – none of which are possible under the timescales set by Government for this Bill.
20. Given that Sir Simon Wessely's review has only just been published, there is a strong case for looking at the interplay between this Bill and the recommendations around the MHA. To not do so, risks creating legislation which fits together poorly.

Amending the Bill

21. We welcome the Government amendments tabled in the Lords which tackle some, but not all of our concerns.
22. The Bill must be strengthened in order to uphold key rights and protections for people who lack mental capacity and their families.

Information on rights

23. We welcome an amendment voted in by Peers which obliged for **information on rights** to be given as a matter of course to the individual, their family and advocates.
24. The Government has tabled its own amendment in response to this which limits the provision of information until *after* authorisation.

25. This is deeply concerning as we believe it is crucial that people know their rights around accessing an Approved Mental Capacity Professional (AMCP) and Independent Mental Capacity Advocate (IMCA), at the start of the process *before* arrangements are authorised.

26. We therefore urge the Government to return to the principles of the Lords' amendment to ensure rights to information are not watered down in any way.

Care homes

27. As the bill is currently drafted the care home manager is responsible for carrying out consultation with the cared-for person, the main purpose of which is to ascertain their **wishes and feelings** in relation to the care arrangements.

28. We believe this is not appropriate as it represents a conflict of interest with care home managers heavily involved in the assessment as well as delivering the care and treatment itself.

29. There are further concerns that in a care system stretched to breaking point, placing further duties on care home managers will take them away from their primary role of service management.

30. We support amendments which would remove this conflict of interest and return responsibility to the local authority as the responsible body.

Independent hospitals

31. Currently in the Bill the responsible body for an independent hospital is the independent hospital itself. It is not appropriate for an independent provider to be responsible for authorising deprivations of liberty of people within its own hospital.

32. This would be a serious conflict of interest, as there is a huge financial incentive for the independent hospital to keep people.

33. In addition, as the responsible body, the independent hospital would decide if there is a suitable person to be an 'appropriate person'. Too often we hear from families of people with a learning disability in inpatient units who have been excluded from decisions, especially when they raise concerns. It is important that it is not up to the independent hospital to decide if there is an appropriate person and who that is.

34. It is also important that the person carrying out the pre-authorisation review in relation to independent hospital settings do not have a prescribed connection to the hospital. The Bill needs to be amended to ensure this.

Advocacy

35. **Appropriate advocacy** must be available to all on an 'opt out' basis. The new scheme must ensure the right of the person to object to and challenge arrangements if they wish and have the support and representation to do so (Article 5 ECHR).

36. The role of the **Independent Mental Capacity Advocate (IMCA)** and appropriate person (usually a family member) needs to be clarified.
37. If an appointed appropriate person is either unwilling, or unable to support and assist the individual in understanding and exercising their rights of appeal, or requesting a review from an Approved Mental Capacity Professional (AMCP), then an IMCA referral should be compulsory.

Access to an Approved Mental Capacity Professional (AMCP)

38. As the Bill is currently drafted, where someone objects to the proposed arrangements they will have a pre-authorisation review from an AMCP. However, not everyone with a learning disability will be able to express an objection, for example those with the most significant disabilities. A person interested in the cared-for-person's welfare who objects to the arrangements should trigger a review by an AMCP as well.
39. We also believe a referral to an AMCP should be triggered where the arrangements include use of restraint, or use of sedating medication, or where someone is in hospital for assessment or treatment for mental disorder. The average length of stay for people with a learning disability in inpatient units is over 5 years.
40. There are often high levels of restrictive practices used in inpatient settings. It is recognised that children, young people and adults with a learning disability and/or autism in inpatient services are at risk of overmedication, restraint, and being kept in solitary confinement. The Learning Disability Census 2015 stated that 72% of people in inpatient units had received antipsychotic medication but only 29% were recorded as having a psychotic disorder, 56% had experienced self-harm, an accident, physical assault, hands-on-restraint, or been kept in seclusion. It is vital that where LPS are being considered in relation to treatment for mental disorder in inpatient units (whether NHS or independent) that the cared for person has a pre-authorisation review from an AMCP.

Renewals

41. As drafted the Bill would allow responsible bodies to **detain someone without renewal for up to 3 years** (previously it has been 1 year). We are concerned this will leave people deprived of their liberty for inappropriate lengths of time and believe the Bill should be amended to reduce it back to one year.
42. Liberty is precious and there should be a continuous focus on maximising independence and reducing restrictions for people with a learning disability.

Key issues relating to 16 & 17 year olds

43. While we support the inclusion of young people in the scope of the LPS system, we believe that further consideration is required to ensure that this does not unintentionally reduce the protections they currently have, nor erode the rights of those with parental responsibility to be involved in decisions about their care and treatment.

44. We are particularly concerned that the LPS proposals were predominantly developed with a focus on people aged 18+ and so do not contain the necessary analysis of the impact on young people and their families. As such, we urge the government to conduct further public consultation on this area to fully understand the implications of these measures on these groups.

Current protections

45. There are already safeguarding arrangements in place for the 16-17 age group: young people's deprivation of liberty **must** be authorised by a court (or in the case of psychiatric care, the Mental Health Act 1983).

46. There may be cases in which the LPS system might be an appropriate mechanism for authorising a deprivation of liberty, but **we are concerned that the LPS system fails to offer adequate safeguards** and falls far below the level of protection and scrutiny for **young people** under the current system. The LPS system must only be used where they provide appropriate and proportionate safeguards for the young person concerned.

Scope of LPS with regard to 16-17 year olds

47. We believe that there are some situations in which the LPS system will not be the appropriate framework to authorise interventions. For example, where young people's care arrangements include physical restraint, we believe more scrutiny would be required and should therefore be undertaken by the courts.

48. While we agree with the Law Commission that LPS should adopt a proportionate approach to care arrangements, the objective of proportionality means that where higher levels of restrictive practice are proposed, the LPS system will not be an adequate system for safeguarding the rights of young people who are deprived of their liberty.

49. It is therefore essential that the scope of the LPS system is clear and limited to circumstances in which this administrative scheme for authorising a deprivation of liberty provides a proportionate safeguard.

Inclusion in Education, Health and Care (EHC) needs assessments and plans

50. For those situations in which the LPS system is a proportionate response - such as long term support for young people who may lack capacity but where there is not a risk of restraint being used - we would like to see an assessment of an individual's capacity being embedded into existing processes such as the EHC needs assessment. For example, as part of someone's proposed Preparing for Adulthood outcomes, we would expect supported decision-making to be discussed in advance of their 18th birthday.

51. These assessments must be undertaken by individuals with sufficient training on the Mental Capacity Act so that they can assess the young person's capacity to make day to day decisions. When it comes to EHC plans, for example, it is important to remember that the current scope of the EHC needs assessment is to assess the education, health and social care support that a child or young person needs in relation to their special educational needs and so further scrutiny and expertise will be necessary.

Parental involvement

52. We are concerned about the lack of recognition of parental rights under the LPS system. While parents will fall within the group of people to be consulted about the young person's views about their care arrangements, there is no acknowledgement that parents have the right to make decisions about the young person's placement.
53. Thus, the system for the LPS appears to undermine the Children Act 1989 which provides that parents can object to the young person's placement and can remove their child (unless the young person is under a care order).

Interface with existing legislation

54. We are unsure as to how the new system works alongside existing legislation. There is a complex web of legislation and guidance that relates to those young people who might fall under the LPS system, including Looked After Children and those accessing continuing care, and we do not believe that sufficient consideration has been given to how these fit together.

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