

## Written evidence submitted by the Challenging Behaviour Foundation (MCAB75)

### Executive summary

- The Bill needs to be **strengthened in order to uphold key rights and protections** for people with a learning disability who lack capacity and their families.
- It is essential the Bill ensures people who lack the mental capacity to consent to their care arrangements **receive the least restrictive care possible** and that any restriction of liberty is in the persons **best interest**.
- This Bill is progressing at such a speed that there is **not sufficient time to consult on the important proposals with relevant parties including families, professionals and people with learning disabilities**. This needs to be addressed.
- The Bill needs to consider how it **links to the recommendations in the independent review of the Mental Health Act** (December 2018).
- Amendments to the MCA mean that the liberty protection safeguards (LPS) will be extended to **16 and 17 year olds**. The consequence of this will be to reduce the safeguards in place for an extremely vulnerable group of young people.
- We have outlined some commonly experienced **scenarios** at the end of this submission to help the committee consider how the LPS would be applied in these situations.
- We call on the Government to include **additional safeguards** for young people within the scheme and to **delay their inclusion in order to consult fully** with stakeholders and families with expertise in the group of children.

### The Challenging Behaviour Foundation

The Challenging Behaviour Foundation (CBF) is a charity which exists to demonstrate that individuals with severe learning disabilities who are described as having challenging behaviour can enjoy ordinary life opportunities when their behaviour is properly understood and appropriately supported. The CBF supports families across the UK caring for individuals with severe learning disabilities. Information and support around understanding challenging behaviour and supporting behaviour change is provided through a range of written and DVD resources, email networks, family linking scheme, and through individual telephone support. The CBF supports many families whose relatives lack capacity, as defined by the MCA.

### Appropriate consultation with relevant parties

1. The Bill is progressing at such a speed that there is insufficient time to consult in detail on the important proposals in the bill with relevant parties including families, professionals and people with learning disabilities.

### Interface with the Mental Health Act Review

2. The crossover between recommendations published in Sir Simon Wessely's Independent Review of the Mental Health Act (December 2018) and the MCA needs to be considered. The current confusion in the use of Deprivation of Liberty within the MCA and the MHA often means the needs of people with learning disabilities are not being met in a timely and appropriate fashion. The independent review of the MHA has considered this and made recommendations around when a person should be detained under which act (MHA / MCA) around objection. The Mental Health Act Review makes the recommendation that the Code of Practice for the MHA and for the MCA 'make clear in what circumstances professionals should consider whether or not someone has capacity to make decisions. We also think that both Codes should make clear who should carry out capacity assessments in these situations.' This needs to be explored further and needs to be considered under this Bill to ensure both legislations work together.

### **Conflict of interest in Proposed Responsible Bodies**

#### 3. Care homes

The proposals for care home managers to be responsible for considering the opinions and wishes of the person to make sure the care is provided is what the person needs is inappropriate as represents a conflict of interest. This gives a lot of decision making power to the care home managers who have an interest in keeping people in their care home. The responsible body needs to remain as the local authority.

#### 4. Independent Hospitals

Currently in the Bill the responsible body for an independent hospital is the independent hospital and they can decide if there is a suitable person to be an 'appropriate person'. Families frequently report that they have been excluded from decisions, especially when they raise concerns in independent hospitals. Again this is a conflict of interest as the hospital have an interest in keeping people due to the financial income they provide.

5. Responsibility needs to be with independent people with a specialism in learning disability and autism and community placements. Any decision regarding an individual's care should be fully documented, including the wishes of the individual and family, what inpatient provision provides that cannot be delivered in the community, and why a bespoke package in the community would not be suitable.

### **Strengthening key rights and protections for people who lack capacity and their families and the use of Advocacy**

6. It is reassuring to see that it has been recognised that information on rights will be provided to the individual, their family and advocates. The Mental Capacity Amendment Bill sets out that **once authorisation has been given** there are lots of safeguards put in place including: regular reviews of the authorisation of the responsible body and the right

to challenge the authorisation before the court of protection. However, there needs to be amendment to when this information is provided – people need to know their rights at the **start** of the process **before** arrangements are authorised.

7. There needs to be timely availability of high quality specialised independent advocates. People who lack capacity are reliant on others requesting an advocate for them and therefore advocacy needs to be provided on an opt-out basis rather than an 'opt-in' basis for everyone. Some people, including those with a learning disability may have capacity, but need support to uptake advocacy and recognise how it can help them. People must have the right to object to decisions and have the support and representation to do so.
8. Clarification needs to be given to the role of the Independent Mental Capacity Advocate (IMCA) and appropriate person (usually a family member).

#### **Addressing limitations in access to an Approved Mental Capacity Professional (AMCP)**

9. Currently the Bill enables people who object to the proposed arrangements to have a pre-authorisation review from an AMCP. This needs to be extended and a referral to AMCP made for those:-
  - with significant disabilities who will be unable to express an objection
  - in hospital for assessment and treatment for a mental disorder
  - where treatment includes use of restraint / use of sedating medication
10. People with learning disabilities in inpatient units are at risk of restrictive practice. In October BBC Radio 4 File on 4 broadcast a programme called Transforming Care- is it working?<sup>1</sup> The figures obtained by the File on 4 programme show an alarming 50% rise in the use of restraint in inpatient settings from 15,065 (2016) to 22,620 (2017). Prone (face down) restraint has risen 41% from 2,250 (2016) to 3,170 in 2017. Use of seclusion has risen by 44% and chemical restraint (medication) has risen by 26%.

#### **Adequate Renewals during detention periods**

11. As the Bill is currently drafted there is an increase to 3 years (from 1 year) in the time someone can be detained without renewal. We are concerned this could 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. Families experiences are that even with annual renewing people with a learning disability already remain stuck in units deprived of their liberty for many years. Extending the renewal period could mean this situation is worse and increase the period people are deprived of their liberty.

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<sup>1</sup> BBC Radio 4 File on 4: Transforming Care- is it working?  
<https://www.bbc.co.uk/programmes/m0000mkd>

## **Impact of the Mental Capacity Amendment Bill on 16 and 17 year olds**

12. Amendments to the MCA mean that the liberty protection safeguards (LPS) will be extended to 16 and 17 year olds. We believe this was intended to extend safeguards to this group. Instead, it provides an administratively simpler scheme for depriving this group of their liberty. The consequence of this will be to reduce the safeguards in place for an extremely vulnerable group of young people.

13. It is not clear how the LPS will be applied to the kinds of situations faced by the families we support. We have outlined some commonly experienced scenarios at the end of this submission to help the committee consider how the LPS would be applied in these situations.

### **Suggested changes**

14. We have discussed with other experts and stakeholders and suggest that three additional safeguards should be included for 16 and 17 year olds:

- a) all young people subject to the LPS should have an automatic right to an Independent Mental Capacity Advocate;
- b) all young people subject to the LPS should have their case reviewed by an Approved Mental Capacity Professional; and
- c) there should be a specific duty to consult young people's parents – to establish their views on their child's care arrangements.

15. We believe that by adding 16 and 17 year olds into the scope of the adult LPS scheme late in the process, the Government has failed to sufficiently understand the interaction of this change with the legal system governing children. We suggest that the government should defer the inclusion of 16 and 17-year olds in the LPS system and consult with relevant stakeholders, including a meaningful consultation with families, to consider how it will apply in practice; in particular:

- a) How will the LPS fit with the Court of Protection? Does a lack of use of the Court of Protection by local authorities imply a need for a simpler scheme or is the real need for better safeguarding of vulnerable children?
- b) How will the LPS system work with existing statutory frameworks relevant to looked after children, young people with special education needs and those requiring in-patient psychiatric care; and
- c) What are the human rights and safeguarding implications for including young people within the LPS system.

### **Context**

16. Dame Christine Lenehan's review of children with learning disabilities and autism commissioned by the Department of Health (These are our children, January 2017) set out the evidence for the poor outcomes and denial of basic rights often experienced by this group. She stated that "When the system does not meet children's needs, we know they are at greater risk of social exclusion, prolonged admission to hospital, deprivation, physical harm,

abuse, misdiagnosis, exposure to ineffective interventions, and failure to access evidence-based interventions.” The Transforming Care programme and the NHS 10 year plan have acknowledged how the system is failing this group of children and young people and pledged to improve local support. It is difficult to understand, within this context, why the Government would introduce a legal change which risks **lessening** safeguards for this already vulnerable group of young people. From our discussions with officials, we suspect this is due to a lack of understanding about the children’s system, as the stated intention of extending the scheme to 16 and 17 year olds by the Lords was to increase protections.

17. The bureaucratic challenges faced by local authorities are significant and we recognise that they are struggling with the case load but our experience as a charity supporting this group of vulnerable young people is that some of the worst cases (for example long term detention in Assessment and Treatment Units, repeated restraint and seclusion and neglect) have resulted from actions intended to ease the “burden” on services “caused” by a young person with complex needs. We are concerned that the LPS could make such cases more likely and would argue that safeguarding the rights of young people should be the primary aim here.

### **Assessment of capacity**

18. For those situations in which the LPS system is a proportionate response - (An example may be long term support for young people who may lack capacity but where all needs are being met, families are content with evidence-based care which is being delivered in line with NICE guidelines and there is therefore a low 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 well in advance of their 18th birthday, ideally starting at the year 9 review.

19. 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**

20. We have significant concerns 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 legal right to make decisions about the young person’s placement.

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 or sectioned under the MHA).

### **Interface with existing legislation**

21. It has not been made clear how the new system will work 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 our discussions with officials to date lead us to conclude that there has not been sufficient consideration as to how these will fit together.

### **Conclusion**

22. We believe that further detailed consideration is required to ensure that inclusion of young people in the LPS system 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. 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 call on the government to conduct further public consultation on this area, including with families, to fully understand the implications of these measures on this group.

### **Scenarios**

23. These are scenarios based on real experiences shared with the Challenging Behaviour Foundation family support team. Has the Government given due consideration to how safeguards would be upheld and decisions made about young people in these types of scenarios, which are common experiences among people with severe learning disabilities?

1. John is 16 years old. He has a severe learning disability, a range of health problems and sometimes displays behaviours described as challenging. John attended a local special school and his family are struggling to cope with his full-time care during evenings, weekends and in school holidays. They requested an increase in John's direct payment from the Local Authority to pay for extra support worker time at home. This request was refused, and the Local Authority stated that John should go to an out of area residential college. John's parents are not happy with this proposed arrangement as they consider that with sufficient support they would be able to care for him at home. Despite the objections of John's parents, the local authority wish to proceed with placing John in the residential college.

How would this situation be approached if the proposed Liberty Protection safeguards were in force? In particular, how would the objections by John's parents be addressed?

2. Freya is 16 years old. She has autism and a severe learning disability and displays some behaviours described as challenging. As part of her education, health and care plan,

she attends a special school as a resident during the week and returns to the family home at weekends. Freya finds the transition from home back to school difficult and often becomes challenging during the journey (on the school transport) and when she arrives back at school. In these situations, staff regularly physically restrain her on the school bus, and to stop her leaving her school accommodation.

How would this situation be approached if the proposed Liberty Protection safeguards were in force?

3. Jack is 17 years old. He has severe learning disabilities and his behaviour is becoming increasingly challenging. His family have been informed that in order to access specialist support he will need to be admitted to a private psychiatric hospital for a 6 week assessment and his family have agreed to this. He has not been detained under the Mental Health Act. In the hospital Jack is under constant supervision due to his pica behaviour. "Pica" is a behaviour displayed by some people with severe learning disabilities and means eating inedible objects. Pica can be life threatening if an individual ingests, for example, a battery or a sharp object. A keypad entry system prevents Jack from leaving the building.

How would this situation be approached if the proposed Liberty Protection safeguards were in force?

*January 2019*