

Changes to the MCA Code of Practice and implementation of the LPS

Response from the Challenging Behaviour Foundation

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Introduction

The Challenging Behaviour Foundation (CBF) is a UK charity focused on the needs of people with severe learning disabilities whose behaviour challenges, and their families. The CBF 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.

For more information about the CBF go to our website: [Homepage for the Challenging Behaviour Foundation](#)

Our response has been informed by meetings with members of our legal panel¹, family carers of young people and adults with severe learning disabilities, and conversations with other third sector organisations.

On the 22nd of June 2022 the CBF and Mencap² facilitated a virtual focus group to gather feedback from family carers whose relatives have a severe learning disability. All the families had experience of DOLS or felt that their relative may be at risk of being placed under the LPS in the future. Family carers unable to attend shared their feedback in separate meetings or via email.

The Code of Practice

Q4: Are the principles of the MCA fully explained in the revised Code? Yes/No If you responded No, please specify the relevant paragraph and what you think it should say (up to 250 words).

No

We support the inclusion in the code of practical steps to gathering the views of individuals who do not communicate verbally. It would be even more helpful if the scenario on page 88 of the draft MCA Code of Practice includes an individual who does not communicate verbally to demonstrate how some of the approaches suggested work in practice.

There are also some specific sections of the draft MCA Code of Practice that we have concerns around:

¹ [National Strategy Group - Challenging Behaviour Foundation](#)

² [The Voice of Learning Disability - Who We Are | Mencap](#)

- Para 5.43 – In addition to the individual being informed about the result of the best interests decision, family members and advocates involved in the decision should also be consulted.

Para 5.61-5.80 - In the Best Interests checklist, the point - the person's past and present wishes and feelings, beliefs, values and any relevant cultural factors should be taken into account (paragraphs 5.61-5.80) - must be moved to the top. We are pleased this is included in the checklist, but it must be moved to the top to highlight that it must be central to all best interests decisions

*Q7: Do you have any other comments on the proposed updates to the existing Code guidance? **Yes**/No If you responded Yes, please specify the paragraph which your comments relate to, and your views on this (up to 500 words)*

Yes

The focus throughout the Code of Practice must be on improving the quality of life for individuals who may lack capacity, including young people and adults with severe learning disabilities whose behaviour challenges. This is not currently the case. Families have told us there must be a focus throughout the Code on improving quality of care and support and reducing restrictions on a person where possible. However, currently the main focus appears to be reducing the burden on the system.

Despite talking about 'putting the person at the centre', the focus on reducing 'the burden on the system' is the exact opposite of person-centredness. There needs to be a far greater focus on outcomes, skills, and maximising capacity. LPS mustn't allow people to be cared for in overly restrictive ways just because they meet overarching criteria for LPS. Any statutory scheme which permits the state to deprive someone of their liberty for the purpose of providing care and treatment must be robust and comprehensible. Without substantial changes, the current proposals to replace DoLS with LPS will result in weakened safeguards for vulnerable people.

Best Interests

We support the inclusion in the code of practical steps to gathering the views of individuals who do not communicate verbally. It would be even more helpful if the scenario on page 88 of the draft MCA Code of Practice includes an individual who does not communicate verbally to demonstrate how some of the approaches suggested work in practice.

There are also some specific sections of the draft MCA Code of Practice that we have concerns around:

- Para 5.43 – In addition to the individual being informed about the result of the best interests decision, family members and advocates involved in the decision should also be consulted.
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Q20: From your perspective, how clear is the LPS guidance in the Code and is there anything that you feel is missing (up to 1,000 words)? Please reference specific groups of people

Together with multiple other stakeholders, including family carers, we feel that the current proposals to replace Deprivation of Liberty Safeguards with LPS will result in weakened safeguards for individuals, including young people and adults with severe learning disabilities whose behaviour challenges.

Currently there is a significant gap in the collection of qualitative data. A focus on quantitative data will mean the data will record the processes taking place but not impact on quality of life for individuals who lack capacity/ under LPS.

In addition, there is no monitoring of Section 4B. This is very concerning, as people will be deprived of their liberty potentially with no safeguards in place. There will be no record of how many individuals are restricted under Section 4B or for how long.

Overall, there is a lack of detail on how LPS will work within the family home. Families supporting relatives with learning disabilities at home have raised concerns around this, particularly in regard to the extension to 16 and 17 year olds.

We have further concerns around implementation, specifically whether timescales for implementation of the code allow for the development of necessary training courses for qualification of AMCPs?

The Code of Practice is not clear:

Families shared with us that the Easy read format is not accessible for everyone and some individuals will need different resources and communication styles in order to understand these processes and frameworks. Therefore, we would suggest creating a number of short clips to supplement easy read, for instance. Furthermore, families felt that LPS as a scheme is very hard to understand, and the apparent focus on reducing the 'burdens' of the system is concerning.

Scenarios

Q21: Is there any part of the Code where an existing scenario requires updating or a new scenario or best practice example is required to help illustrate the policy? (1,000 words

We have some broad concerns across the scenarios presented. Throughout the scenarios 'learning difficulty' and 'learning disability' are used interchangeably. These terms have different definitions (as highlighted below) and are likely to cause misunderstanding if used incorrectly within scenarios in the code of practice. It must be clear in each scenario if the person has a learning disability or a learning difficulty. It may be helpful to include definitions in the code.

A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life. A learning difficulty does not affect general intellect. There are many different types of learning difficulty including dyslexia, attention deficit-hyperactivity disorder (ADHD), dyspraxia and dyscalculia. A person can have one, or a combination (<https://www.mencap.org.uk/learning-disability-explained/learning-difficulties>).

Additionally, there are some specific parts of the draft Code where the scenarios are inadequate. The following examples have been informed by our discussions with a range of stakeholders about the legal concerns held around the draft Code.

- In Chapter 12 of the draft Code there is failure to apply case law around the definition of a DoL and that this is inconsistent with the law decided in key cases including *Cheshire West*. The scenarios in this chapter fail to identify where a person might be deprived of their liberty, and therefore, miss that LPS should be triggered where arrangements may amount to a deprivation of liberty. We suggest that DHSC and MoJ should consult with legal experts within the field of learning disability to improve these examples.
- In Chapter 5 of the draft Code it discusses best interest scenarios. We support the inclusion in the Code of practical steps to gathering the views of individuals who do not communicate verbally. However, it would be even more helpful if the scenario on page 88 includes an individual who does not communicate verbally to demonstrate how some of the approaches suggested work in practice.

Assessment and Authorisation

Q3: How clear is the guidance in chapter 24 at explaining how challenges relating to the LPS can be made, including deciding when to make an application to the Court? (300 words)

- Routes to challenge must be clear, including for family members who are not acting in the Appropriate Person role. There must be robust mechanisms in place to challenge if your input as Appropriate person and/ or family carer is dismissed by the AMCP or IMCA.
- Code of Practice says that anything an AMCP says that isn't followed then has to be recorded so it can be challenged – but need to have the views of all involved recorded, and not in a tokenistic way. Deputy opinions have often been disregarded in prior experience, and clinicians have ridiculed families, who are already vulnerable to blame in these situations.

Q9: [LPS completed in 21 days, Responsible Body acknowledgement in 5 days] Do you think the timeframes set out in the Code are (too long/about right/too short) (300)

Families shared their concerns with us around the timeframes set out in the Code. Specifically, that the timeframes for acknowledgement and authorisation need to have a statutory basis and should be accountable.

- The 21 days figure must have consequences for failure to comply. Although this may be seen as an additional administrative burden, the consequences of an individual being detained, without the necessary acknowledgement and authorisation is a significant breach of their human rights, specifically the right to liberty. Therefore, there must be accountability to ensure that there are not delays in this process.
- Furthermore, the proposed 21 day timeframe means that for this period any deprivation of liberty could be authorised on the basis of a single Section 4B decision, thus leaving providers at risk and potentially exposing the individual to harm. This risk is even greater if the Responsible Body does not make a decision

within the 21 days further highlighting the necessity for accountability within this process.

Q11: Is the guidance in chapter 13 on the authorisation, reviews and renewals processes clear? (300)

- Our concerns around the 3 year timeframe for authorisation have been shared by families we have consulted as part of this response. For individuals with a severe learning disability, the 3 year timeframe could mean individuals remain under restrictions which could potentially cause detriment to their physical or mental health for much longer than is required. The provisions that a review can be requested at any point might not be a sufficient mechanism for challenge if reviews are not accessible and robust – for instance, due to shortages of social workers or relevant skills, it is very difficult to get reviews under the Care Act.

Q18: Do the assessments, determinations, and pre-authorisation reviews regulations enable the right professionals to carry out assessments and determinations? (300)

- Paras 13.44 & 13.46 of the draft Code must be clearer about who the individual carrying out pre-authorisation reviews will be. We are concerned that if the individual carrying out the pre-authorisation review is not a health or social care professional, there may be no professional registration, regulation, or accountability.
- One family with experience of DoLS for their relative told us that one advantage of the current system is that the Best Interests Assessor had experience and a firm understanding of capacity. Concern has been expressed by families in relation to the new code that those who are carrying out the assessments, because it will be an additional aspect of an existing role, will not be sufficiently qualified and experienced to make an accurate assessment.
- Reviews must involve the person, Appropriate Person and/or IMCA and the views of family members must be sought where appropriate.

General Comments:

- There must be a clear focus throughout the code on improving the quality of care and support for individuals, including how it will make lives better and reduce restrictions.
- Information in the code must also be clearly and effectively shared with individuals and their families if it is to be effective. Families have told us that under existing DoLS, they have not been well informed, for example of the option for conditions to be placed on restrictions.
- Families told us they lacked confidence that the Responsible Bodies would complete reviews properly, and felt they might become a tick box exercise. One family shared that in their prior experience of DoLS, the Local Authority had been uninterested in a lot of information that was in fact relevant to the care provided for their relative. When they reached the Court of Protection, the Judge was asking where this information was – he took an interest in the paperwork in a way that the LA assumed he wouldn't be.
- There is little mention of conditions on authorisation despite the important role these have had in improving outcomes under DoLS. Conditions should have consequences for failure to follow them.
- Families we consulted around the draft code told us they were confused by what the medical assessment will include in comparison with other frameworks e.g. whether autism counts as a 'medical disorder', and how the system will work by applying to 'any medical disorder of the mind' in lieu of specific definitions.

AMCP

Q17: The purpose of the AMCP regulations is to ensure that there are an adequate number of trained AMCPs with the required skills and knowledge to carry out this role. Will the AMCP regulations achieve this? (300)

Families, organisations and legal experts we have spoken to have shared concerns around the effectiveness of the role of AMCP in the pre-authorisation review process.

Additionally, there is some uncertainty that the different professionals who will be required to take on these responsibilities will have the time or in-depth knowledge of the individual to be effective in the role of AMCP. There are additional issues to consider if professionals take up this role such as:

- How will the professionals remain independent if they continue their other role as well as being an AMCP?
- Many of these professions operate closely with those using a medical model of disability, for instance is it appropriate for a hospital nurse to make assessments in the community?
- Given that the current workforce is understaffed, will these professionals have sufficient capacity?

Given these concerns, we recommend that AMCP team and Responsible Body consider the impartiality of the AMCP and Article 5 human rights of the person when deciding whether AMCP will also give the authorisation. AMCP should not work on cases referred by their employer. Para 18.35 of the draft Code suggests incorrectly that a person's objection must be frequent and consistent before it is considered.

IMCAs

Q19: Do the IMCA regulations allow for IMCAs to carry out their full functions effectively under the LPS? (300)

Families shared a number of concerns about the role of IMCAs informed by their previous experiences including:

- They have limited independence and effectiveness
- Families had experience of losing the ability to input and being removed from Nearest Relative role once an IMCA had been put in place – these safeguards need to work alongside families not against them.

- There is a lack of good practice examples of IMCAs across the country, the lack of examples of where IMCAs have been effective limits trust in them as many families have had negative experiences.

In order for IMCAs to work effectively these concerns must be addressed. The IMCA regulations must also address practical concerns such as how will IMCAs be commissioned successfully if there is no knowledge of how many are needed, and there is insufficient knowledge of the population with learning disabilities and autism.

Additionally, it is important that the IMCA supports the Appropriate Person (AP) in participating in decisions, ascertaining wishes and feelings, finding alternative (less restrictive) courses of action, reviews etc. It should be clear that the AP can request an IMCA at any point and the code must be clear about what reasonable steps will be taken to appoint an IMCA (It is not sufficient to say 'reasonable steps' will be taken given the known gaps in advocacy provision). Examples of reasonable steps may include finding an IMCA from a neighbouring area.

The right to independent advocacy under LPS and the MCA Act 2005 are weaker than proposed by law commission recommendations e.g. it isn't opt-out, there is a best interests test for people who lack capacity to access an IMCA and key issues of availability/resourcing which are already recognised as problems for IMCAs are not addressed.

Appropriate person

General comments:

- Due to the complexities of the Appropriate Person role, it would be useful to have more accessible and comprehensive information on the role. Attention should also be given to not only the person themselves but the complex scenarios they might face, and thus the additional support they may require. There should be improvements to the information provided (E.G. with flowcharts) detailing the pathways to challenging decisions. We recommend a formal appointing letter

defining the role, with practical checklists, training, legal information etc (including as easy read).

- We are concerned by the suggestion that family carers who are already appointed as Health and Welfare deputies might not be suitable for the appropriate person role due to conflict of interest. Family carers we have been in touch with while developing our response to the consultation have shared this concern and suggested families who are already appointed as Health and Welfare deputies would rather be more suitable to the Appropriate Person role as they are already monitored and report to the Office of the Public Guardian, and have been judged fit to make best interests decisions for the individual.
- Appropriate Persons must receive proper support and supervision, as is given to appointed Health and welfare deputies
- Flexibility is required within the Appropriate Person role to recognise the multiple responsibilities that family carers have and to avoid creating an unnecessary barrier to families taking on this position.
 - It should be possible for the role to be held jointly e.g. by two parents
 - There must be flexibility within the role to enable a family member to be the appropriate person for some decisions but not necessarily all decisions.
- We are concerned that the Appropriate Person role will not be sufficiently robust as IMCAs (who may not know the individual well at all) will have greater rights to access relevant information (15.72).
- Families have also expressed concern over a potential conflict of interest if the Responsible Body appointing the appropriate person are also commissioning the person's care and support.

Advance consent

General comments:

- Advance consent may limit the safeguards in place for an individual

- The scope of LPS is so broad that the potential impact cannot necessarily be envisaged several years in advance
- Advance consent in the code is not aligned with the Mental Health Act where the statutory ability to consent in advance to informal admission has been removed.

Vital Acts/ Section 4B

Q15: Do you agree with the position set out in the Code, or do you think Responsible Bodies should be notified every time section 4B is relied upon? (300)

Disagree

- Responsible bodies should be notified every time section 4B is relied upon.
- The limited mechanisms and governance of Section 4B are not satisfactory compared to holding powers under the Mental Health Act. This is a concern we have also heard shared by other stakeholders during the consultation period.
- There is insufficient detail on when Section 4B could be applied and the ‘vital acts’ could be too broad.
- We strongly recommend the introduction of time limits and accountability frameworks
- Mechanisms must be put in place to prevent the inappropriate use of Section 4B.

Children and Young People

Q2: How clear is the guidance in the Code at explaining the interaction between the LPS and other relevant legislation and planning for 16 and 17 year olds? (300)

- We are very concerned by the proposal to allow use of the LPS, rather than section 25 of the Children Act or Section 119 of the Social Services and Wellbeing Act (Wales) to authorise deprivation of liberty of young people in secure children’s homes. Section 25 of the Children Act provides significantly

more safeguards than the LPS, including provision of legal representation and requirement to seek authorisation of the court.

- Further clarity is needed on the interaction between EHCPs and LPS for 16 and 17 year olds.

Capacity and Funding

Q12: Do you agree that the care home manager role should not be implemented?

Yes, agree

Q16: To what extent will chapter 20 and the Monitoring and Reporting regulations help ensure the monitoring bodies deliver effective oversight of the LPS? (300)

- All data recorded should be analysed and publicly reported. This will help ensure accountability and drive ongoing improvement in practice

Q22: Do you agree with the estimated impact of the LPS, as set out in the Assessment? (300)

Strongly disagree

- Lack of information provided to families about MCA and LPS will mean a significant burden on families of individuals with severe learning disabilities remains. Lack of IMCAs with the relevant knowledge and experience to support individuals and their families will further add to the burden.
- We support previous equivalent assessments, but it is unclear what measures will be implemented to ensure these are used correctly.
- Consultation will be tokenistic unless the person consulting has relevant expertise to consult individuals with severe learning disabilities who do not communicate verbally.

- Based on the current experience of families, we are not confident a 'regular programme of reviews' will be implemented. In circumstances where a new authorisation might require an increase in support, the potential increase in costs might be a disincentive for reviews to take place.
- The assessment assumes IMCAs will always be available when required. However, the reality is advocacy is not commissioned sufficiently to provide support wherever needed. Where advocates are available, they often do not have the skills to support children and adults with severe learning disabilities or enough time to get to know the individual or their family: we are not confident the '*additional support and representation*' will protect and uphold the person's Article 5 rights under the ECHR
- Safeguards must be strengthened in order for neither LPS or MHA to cause significant disadvantage. Children and adults with learning disabilities must not be detained in inpatient settings under either LPS or MHA unless they have a serious mental illness.
- Steps to prevent a potential conflict of interest if the same organisation who is arranging care is also organising the LPS assessment and authorising arrangements must be included in the code. If additional support is required, this could come at an extra cost to the organisation arranging the person's care.

Q24: Does the Training Framework cover the right learning outcomes? (300)

- In order for LPS to be effective, there must be significant investment in advocacy, including training for advocates specifically around young people and adults with severe learning disabilities who do not communicate verbally. Supply/ provision

of high-quality effective advocacy has been one of the greatest concerns raised by families we have consulted around the draft code of practice.

- Additional requirements in the guidance for Wales on eligibility to carry out assessments should be copied across to the guidance for England:
 - *(iii) the ability to communicate effectively with a view to identifying characteristics and attributes of a person (“P”) that are relevant to P’s needs, and*
 - *(iv) the ability to act independently of any person who appoints them to carry out an assessment and of any person who is providing care or treatment to P;*
- The training framework must cover the above skills as they are essential to ensuring improvement in quality of life for individuals with severe learning disabilities.

Q25: Are there further data items needed in the National Minimum Data Set to provide effective oversight of the LPS? (300)

- Data must be collected on emergency restrictions made using section 4b. Without consistent data collection on section 4b it will not be possible to know how many individuals are restricted with reduced safeguards.
- The current data set is too focused on quantitative data. Although this is important, qualitative data is essential to understanding the impact on the quality of life of individuals who are deprived of their liberty through the LPS. Currently the data collection focuses too much on process.
- Including data collection around outcomes for individuals, including young people and adults with learning disabilities whose behaviour challenges, will help drive practice towards using LPS to improve quality of life.

Interface with MHA and other legislation

Q10: How clear is the guidance in chapter 13 at explaining the interface between the LPS and other health and care assessments and planning? (300)

- Families we have consulted as part of this consultation response have expressed serious concern about the interaction between LPS and other health and care assessments, particularly with the extension to 16 and 17 year olds and into the family home.
- There is an existing lack of join-up between assessments including EHCPs, SEND reviews and adult CHC reviews.
- Families are not currently informed about deprivation of liberty and the MCA ahead of their relative becoming an adult.
- The draft guidance does not provide sufficient reassurance that this will change in practice.

General comments:

Improvements are needed to the guidance for professionals in chapter 22 when deciding whether to use the Mental Health Act or Liberty Protection Safeguards. Acknowledgment is needed in the guidance that the least restrictive option should be taken, but this should be balanced against safeguards and effective legal rights.