



For Quality of Life for
Older People in Care

The Relatives & Residents Association

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**BRIEFING FOR THE PUBLIC BILL COMMITTEE ON THE MENTAL CAPACITY
(AMENDMENT) BILL**

About R&RA

I. The Relatives & Residents Association (R&RA) speaks up and speaks out on behalf of older people needing care. It is the only national charity for older people providing a daily helpline which concentrates entirely on care services for this age group while using the unique perspective of their relatives to improve their quality of life.

II. R&RA was founded to campaign for a better quality of life for older people needing care, including those living at home and those needing or considering residential care settings. By using the day-to-day knowledge and experience of families and friends, we work in harness with others to help improve services and standards. We also try to influence policy and practice by reflecting the experience of our members and callers who use our daily Helpline and thus can make evidence based comments on the case we make, the research and training we carry out and the policies we advocate.

III. We provide support and information through our Helpline and enable older people and their relatives make better informed decisions when seeking or receiving care. We explain their rights under guidance and regulations as well as the benefits and standards they should expect.

IV. We also act as a listening ear to help support families and individuals at what is often a time of crisis and trauma for them, when it becomes apparent that a partner, parent or friend can no longer cope without support. We also help them when there are difficulties and complaints about the standard of care and often act as brokers between the relative or concerned individual and their care service.

V. Our comments are based on our Helpline service and our activities, including training, research and feedback about the reality of life for older people needing or receiving care. Inevitably, our Helpline service is sought by relatives experiencing problems. However, we acknowledge there are many services where very good care is provided and that there are many thousands of frontline staff doing their utmost to provide the best quality of life they can for older people living at home and in care homes.

Background

1. The MCAB introduced in the Lords in July without proper consultation was greeted with virtually unanimous dismay, bordering on despair. This was because most of those involved with the Law Commission's consultation on the topic had expected that the Bill would reflect the Law Commission's draft bill. It was widely assumed that this would provide the basis for the amending legislation and the sector was deeply shocked to find that it differed in a number of crucial respects.

2. In addition, the Mental Capacity (Amendment) Bill (MCAB) as presented to the Lords, included a number of untenable assumptions which produced a strong alliance of providers, users and families, all totally united against both the spirit and the letter of a number of key proposals, including the extraordinary one, which assumed and proposed that the care home manager should have a deciding role in depriving an individual of their liberty. Needless to say, this was unanimously condemned as inappropriate, due to conflicts of interest, lack of knowledge, training and expertise, and a number of other equally cogent reasons.

3. The pressures brought by this coalition of interests plus the valiant efforts of Crossbench and Opposition Lords have ameliorated some of the worst aspects of this ill-thought through Bill.

4. Many, however, remain and there was a last ditch, but failed attempt at Report Stage in the Lords, to pause the Bill so that it could be given the proper consultation process and detailed scrutiny which it had lacked, due to the bizarre haste and manner of its introduction.

5. Although the pivotal role of the care home manager has been reduced, it remains unsatisfactory and there is still major cause for concern the conflicts of interest inherent in the amendments and about a number of major matters.

Existing resource concerns

6. In particular, there has been no proper impact assessment or any indication how the revised proposals will address the 'backlog' One of the major justifications for change was that there exists a large number (c140,000) of uncompleted assessments DHSC estimated that there would be a zero implementation cost, a conclusion which lacks both common sense and credibility.

7. In the light of this, although consulted upon, it seems perverse to extend the remit of the legislation to those in supported living and domiciliary settings, when there is no indication of how the resources will be available for these additional burdens which will largely fall on the 'responsible authority' i.e. the local authority.

8. This is particularly concerning since the proposals now give the responsibility to local authorities at a time when their budgets have suffered major reductions and where it is a well-known and established fact that that statutory responsibilities are not being fulfilled in very many local authorities., We know from our Helpline that vulnerable individuals are not

being assessed and those with pressing and , sometimes, terminal needs are not receiving the services or support to which they are entitled.

9. The Equality Impact Assessment (EIA) has been published belatedly. It again puts forward the erroneous assumption that care plans and best interest assessments are similar in kind and content. Although some aspects of care plans may be relevant, their purpose is different and distinct from those determining the liberty of the individual. They should be designed to inform staff and management about the resident's health, medication, allergies, preferences, hobbies, personal care needs and their family and other contacts. This is a quite different process from what should be involved in best interests assessments. These involve a wide range of professional judgments and interviews including those about mental health and capacity. Apart from its general inadequacy the EIA, it makes no reference at all to the particular needs of the LGBT community. Another sign of haste, perhaps?

Local authority responsibility consultation process and AMCPs

10. Giving the responsibility to the local authority to ensure that those being assessed and those representing them fully understand the consequences of the assessment to deprive someone of their liberty and the right to request an assessment and review by an Approved Mental Capacity Professional (AMCP) (paragraph 13 of the MC(A)B) is an improvement on the original proposal to give this role to the care home manager.

11. However paragraph 13 is at odds with that of paragraph 21, which states that an AMCP will only review the assessments and can, if they feel appropriate and practical, speak to the service user or those referred to in paragraph 20 (family, carers and representatives). This is much weaker than the current system and we are concerned about the ambiguous terminology of "practical and appropriate", particularly as there has been no definition or description of any professional training for AMCP's compared with the specific and rigorous training now mandatory for Best Interest Assessors (BIAs).

15. As indicated above, it is crucial that the qualifications, expertise and training needed for the AMCP role are properly defined. There is a danger that those given this task will not have the training and expertise of current Best Interest Assessors (BIAs) who must have social work training and experience, plus additional rigorous training which must be regularly independently updated and reviewed.

16. The expertise, knowledge and skill required to establish the wishes, feelings and preferences of those who lack capacity and communication skills, due to autism, brain injury, dementia, stroke or other conditions and are consequently unable to verbalise their feelings and objections is a complex and difficult task and not one to be undertaken under pressure of budgets or other stringencies, or without specialist training.

17. The Bill (paragraph 39) does not give the cared for person an absolute right to an Independent Mental Capacity Advocate (IMCA). The right to an IMCA is doubly diluted, as the local authority only have to take 'all reasonable steps' to allocate an IMCA where a person 'should' rather than 'must' be allocated one.

18. It continues to allow the local authority to authorise the newly named 'Liberty Safeguard Protections' without reference to an AMCP. This could mean that concerns unrelated to a person's liberty could sway a decision to deprive someone of their liberty and authorise a

placement on unacceptable grounds: e.g. pressures to remove them from hospital or their own home, restrictions on budgets to short circuit the preferred or better option (a package of care at home or a move to a more expensive area), or lack of personnel to carry out the detailed and specialised assessment required.

19. It needs to be emphasised that no arrangements should be authorised where those with Power of Attorney for Welfare object.

Independence within the local authority crucial

20. Those undertaking the arrangements or authorisation of liberty protection safeguards must and should be totally separate from both commissioning and placement roles within the local authority. Otherwise, they will have clear conflicts of interest with other colleagues, whose actions may be determined by financial or other constraints.

21. Those with these roles should have a separate line management and report directly to the Chief Executive (where not in charge of ASC) or the LA's monitoring officer.

Emphasis throughout the Bill needed on the dangers of 'passive acceptance' and/or tractability and unwillingness to 'make a fuss' exhibited by many without or varying mental capacity.

22. We are in danger of forgetting why the original legislation was introduced. It came about as a result of the experiences of deprivation and the continuing disregard by both health and care professionals of the individual's and their carers' views. P's distress and unhappiness were not taken seriously because he did not actively attempt to leave the hospital (the place of his detention) despite his carers' insistence that he wished to go home. Those who knew him best were also restricted from visiting him in case he tried to leave. This admission was deemed to be 'in his best interests' until the European Court of Human Rights decided he had been unlawfully deprived of his liberty.

23. Under the proposed LPS system, whether or not a person is objecting will be either via a consultation by a staff member of the responsible body, or in the case of care homes, by a care home manager. Many people find themselves compliant or passive when faced with those responsible for their care, or even when showing challenging behaviour may have that behaviour misinterpreted by staff who do not hold sufficient expertise and may not be aware of it.

24. As it stands, those who do not believe that such a placement is in a resident's best interest must make their case to the care home manager or a person appointed by them. It is hard to see how even the most diligent care home manager can fulfil this role without bias. There is a clear conflict of interest and it is unreasonable to assume that they can convey concerns about a placement in their home fairly and fully whether to an AMCP or authorising authority. We cannot see anything within the Bill that allows those consulted to receive a written copy of what is presented of their views.

25. Unfortunately, too often care home managers' dismiss the concerns of relatives and even belittle them for raising them. Two examples follow of where individuals' concerns were undermined and ignored by care home managers, (and in the second case, also by the local authority):

CASE STUDY 1

Mrs P complained that her husband, who could not bear noisy environments, was no longer able to sit in a quiet lounge peacefully. Another resident was regularly placed in the room with him where she would sing at full volume. Mrs P asked that they might share the space so that he may at least be able to sit outside his room peacefully on a few days in the week. After failing to get any satisfactory response from the care home manager, we raised it with CQC who shared the care home manager's response with us by accident. The care home manager had described the wife as a nuisance and stated that there were no issues with his care. Mrs P felt so undermined by the care home manager's response, she no longer felt able to raise any other concerns on his behalf and would not allow us to pursue it on her husband's behalf.

CASE STUDY 2

A daughter, Ms A, was concerned about her father, Mr B. Against all attempts to prevent it, he had been placed in a care home, she felt, against his wishes and against his best interests. However, both the care home manager and her step-mother were content with the placement. His behaviour quickly became increasingly aggressive and he made repeated attempts to leave the home, including climbing out of a window. His daughter's visits were blamed for this behaviour. As a result, the care home manager prevented him from meeting with friends outside of the home and she was asked not to visit by the home. After a complaint by his daughter, he was later moved to a mental health unit where his behavior changed completely and he became much happier. Had she not been there to represent him, his objections might not have been recognised. This highlights how even severe objections can be diagnosed and misinterpreted by those with limited expertise and with vested interests in the current placement.

26. The cases highlight how people who do not have a determined relative or representative to speak out for them may find their placements unquestioned under the new Bill. Even in this case, had Ms A's views needed to be submitted via a consultation with the care home manager, it is difficult to see how the clear clash of interpretations of his behaviour and hostility towards Ms A's role and presence in her father's life would not be influential to the report.

27. It is hard to see how a fair and reasonable interpretation of events could have been established whereby a judgement could have been made in his best interests if the care home had had the discretion to make these consultations.

28. For this reason we support the proposed amendments from Barbara Keeley et al that remove the role of the care home manager from the bill.

Preventing arbitrary decisions

29. In the R&RA we continue to hear from relatives who are restricted or prevented from visiting for spurious reasons, often allegedly 'in the resident's best interests', when it is sometimes in the interests of the home when a relative is considered to be 'too demanding' with little regard to the human rights of the resident to have contact with family and friends.

30. This is too often carried out simply due to the care home's over-defensiveness and unjustified referrals are then made to 'safeguarding' which regularly prolong the unlawful restrictions in the resident's liberty. Two examples of this are:

CASE STUDY 3

The resident had removed his hearing aids and his daughter had had to shout to make herself understood. She was also accused of bullying him and other misdemeanours and was banned from the home, much to her very frail and elderly mother's distress.

She had been a regular visitor and had helped with many personal caring tasks. She was subsequently informed that the matter had been "referred to safeguarding" and that a DoLS referral had been made.

The investigation made it clear that the restrictions had come about because the relative had asked a number of questions about the deterioration in the home's standards of care, which the care home manager found difficult. Visits were resumed after three months.

Meanwhile, the resident in his 90s was unable to understand why his daughter had 'abandoned' him.

CASE STUDY 4

Mrs A was restricted from visiting her husband on the grounds she presented a danger to another resident who had attached herself to him. However, it was this female resident who had a history of disruptive and aggressive behaviour and who was threatening and abusive towards Mrs A. When she sat with Mr A she was easier for the staff to manage.

The home totally missed or ignored Mr A's distress and that he was trying to avoid contact with the female residents and continued to treat his wife as the problem. She could only visit with her son at certain times and this was agreed through mediation with the local council.

This decision failed to take the husband's well-being and preferences into consideration or his right to family life. This was only resolved after we advised her that as his PoA for Welfare, not only did she have a right to visit him but she had a right to be party to his care planning. Even though she had the right to refuse a DOLs and we assume a LPS, it once again highlights how unaware care homes and LA'S can be of the MCA and their duty to protect peoples' rights as well as their inability to assess the resident's behaviour and the deprivation of his wife's visits appropriately.

31. Actions like these can have a major impact on those with dementia who may feel deserted or bereaved without understanding why contact has ceased. Residents may be in a terminal condition and time is not on their side.

CASE STUDY 5

Mrs G visited her husband every day and took a keen interest in his wellbeing, sitting with him for long periods of each day. Mr G had lost the ability to speak and had little mobility. She became concerned that he was still in pain despite being on pain relief and thought the pain was in his mouth as he kept touching his jaw and his facial expression seemed unhappy. She raised this several times with staff who failed to act and dismissed her concerns. She then raised it with the care home manager, who warned her that if she continued to take up staff time she would be banned from visiting her husband who was considered to be at the latter stages of end of life.

Distraught at being parted from her husband at this time, she contacted our Helpline. Working with his GP, the palliative care team and her dentist, a broken tooth cutting into his cheek was found to be the cause of pain. With this filed down and pain relief increased, he became more settled and she was able to continue to visit him, until he passed away a week later.

32. These kinds of banning and restriction should require an automatic notification to the local authority, including an AMCP. This is because we are deeply concerned about the conflicts of interests within local authorities, who wish to have good relationships with care homes and where possible to avoid any conflict with them.

Code of Practice

33. There are also concerns that the Department of Health and Social Care (DHSC) will try to use the Code of Practice to replace what should be in the Bill. The Code, when it is written, should be used to explain and elaborate on the provisions of the Bill, not add what should normally be in it and subject to full scrutiny by Parliament.

NB Please let us know if you require evidence from additional case studies, illustrating restrictions on movement to another placement, restrictions on visiting arrangements and evictions, all resulting in the deprivation of liberty.

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