

**Mental Capacity Bill, Report Stage Briefing- 14<sup>th</sup> December 2004**

- **We strongly recommend the introduction of a new ‘equal consideration’ clause, to ensure that all options for care and treatment are considered for people who lack capacity irrespective of age, illness or disability, as an addition to the statement of principles on the face of the Bill.**
- **There is insufficient emphasis on supporting communication. We do not want a person to be considered incapable because insufficient time has been taken to understand a person, how they communicate and provide support.**
- **The situations in which a person should have a right to the support of an independent consultee needs to be much wider than the current limited proposals, particularly in relation to people who are “befriended” (e.g. those with families) including where there are disputes among people providing them with treatment, care and support.**
- **We want legal recognition of advance statements in certain circumstances e.g. positive requests for professional care and treatment.**
- **The “Bournewood gap” needs to be addressed in the Mental Capacity Bill, following the recent European Court ruling, with the inclusion of procedural safeguards around assessment and review for people who lack capacity and are informally “detained” in hospital, nursing or residential care without clear legal protection or safeguards.**
- **Protected acts offers statutory protection against liability for certain acts done in connection with the care or treatment of another person. Protected acts would be open to significant misuse if their scope are not better defined. Advocacy would provide a safeguard to inappropriate use of protected acts and a statutory requirement for an independent second medical opinion should be sought in relation to serious medical treatment. Certain medical treatment decisions, such as sterilisation should be taken outside the scope of the protected act.**
- **The system of welfare benefits Appointeeship should be brought within the scope of the Bill to make sure that vulnerable people are safeguarded against abuse and that appointees act in their best interests.**

- **We want to see the power to make a decision about withholding or withdrawing life-sustaining treatment removed from the court-appointed deputies.**
- **In relation to lasting powers of attorney, the Public Guardian should monitor the use of lasting powers of attorney (LPAs) with a view to preventing the abuse and exploitation of a donee's powers.**
- **We would like the Bill to clarify that where public bodies are involved in the formal planning, providing or reviewing of services to someone who may lack capacity, they should ensure that a proper assessment of capacity of the person is carried out in relation to those services. Advocacy should be available to assist the person that is being assessed to express their views.**

## **1. Overriding Principles and maximising decision-making capacity**

The Making Decisions Alliance believes that the emphasis on future legislation should be on supporting people to make their own decisions rather than having decision-making taken out of people's own hands. We must not forget what people can do in our efforts to protect their interests.

The MDA is delighted that the Government has strengthened the Bill in a number of respects. It has re-ordered the opening clauses of the Bill to give greater emphasis to the presumption against the lack of capacity, and honoured its commitment to change the name of the Bill and to set out the main principles of the Bill at its outset. In particular, we are pleased that the principles state that everyone should be encouraged to make their own decisions, be given the support to make and express their views and the right to make what are seen as eccentric or unwise decisions.

The MDA believes that access to independent advocacy is a vital mechanism for ensuring that the guiding principles and measures in ascertaining an individual's best interests are properly fulfilled. We are concerned that without advocacy a person may be wrongly assessed as not being able to make a decision or communicate in the decision making process.

The MDA believes that people have the right to expect that they will be cared for to the highest standards. The MDA would like to see an 'equal consideration' clause incorporated as an addition to the statement of principles on the face of the Bill. The equal consideration clause would ensure that a person who lacks capacity is treated no less favourably than one who has capacity. No assumption should be made that life has less value for people who have difficulty making decisions or need support to make those decisions.

We would hope that the adoption of this new principle would increase confidence in the operation of the legislation and mean that the Bill is strengthened as value-based legislation. Our concerns stem from evidence, anecdotal and otherwise, that prejudices and attitudes about the quality of life of a person with serious learning disabilities, mental health problem or a head injury or another condition that leads to a loss of capacity can get in the way of supporting that person and how they are, what they want, and what they need.

## **2. Supporting Communication**

The MDA does not think that there is enough emphasis on supporting communication. We do not want a person to be considered incapable because insufficient time has been taken to understand a person, how they communicate and provide support. We have also argued that non-verbal methods of communication, such as changes in behaviour should always be recorded and observed. The MDA wants an amendment to the Bill to ensure that specific communication strategies are put in place to maximise the chance that people will have capacity to make decisions and to support them in any best interests decision where a person cannot make a decision for themselves. In particular, we would like an amendment to the best interests provisions (Clause 4). Without these amendments there is no explicit requirement on the decision maker to provide adequate and appropriate communication support to the individual and help them to participate as much as possible in the decision. This would mean that some people, particularly those who have very individual communication methods, are unable to express their wishes and feelings before decisions are made.

## **3. Advocacy**

The Government has indicated in the explanatory notes to the Bill that consultees will act as a form of 'advocate', as they are understood in the social care sector. An NHS Body or local authority will have a duty to seek advice from an "independent consultee" about what is in a person's best interests when a decision is being made about serious medical treatment or before providing certain types of accommodation. The Government has made £6.5 million available to fund independent advocacy. However, the independent consultee need only be consulted if the person does not have any friends or family to consult about a person's best interests (unbefriended).

Following lobbying by the MDA, the Government has confirmed that the overriding function of an independent consultee is to support the individual rather than the decision-maker. The Government has indicated that they want an independent consultee to do more than represent a person's wishes and feelings, but also to give advice to the decision-maker. The Government has called the services as "advocacy plus" It is important for the Government to clarify that this role will be limited to giving advice on best interests, rather than making a decision or judgment on the individual's best interests.

The MDA wants to ensure that the proposals on independent consultees do not undermine the provision of existing advocacy services. Advocacy services are already fulfilling the role of independent consultees and making

representations to decision-makers. We do not think there is a need for a completely new service or a new title (independent consultees) to explain that service.

The MDA understands that it would not be feasible to ask for an open-ended commitment to independent advocacy services in the context of this Bill and it is for this reason that we have not asked for a right to an independent advocate in all circumstances or for all decisions. However, we strongly believe that the situations in which a person should have a right to the support of the consultee are very limited and needs to be wider than the current proposals.

We believe that an individual should have a statutory right to an advocate if that person lacks capacity and a decision is taken on moving home (outside private arrangements) or serious medical treatment. Currently, the Government has agreed to provide limited support to people who are “unbefriended”, namely people without a network of family carers or relatives. This would mean that an independent advocate would not be available in wider situations, effectively in relation to people who are “befriended” (e.g. those with families) and in cases of disputes between the individual, family and health or social services. The MDA wants these provisions to be made available on the face of the Bill.

The MDA sees the role of a family carer and the role of an independent consultee/advocate as complementary. Whereas the family carer is likely to know their parent, son or daughter and want to safeguard their best interests, the independent advocate is likely to know how to navigate the system better, including what treatments and services are available and what has worked most successfully for other clients. It is often the case, particularly for the most significant decisions, that both a family carer and an independent advocate are needed to support someone who lacks capacity. An independent consultee/advocate would only be involved in decisions around moving home where the NHS or local authority is arranging that accommodation.

Given that the Government has talked about independent consultees as providing an “advocacy plus” role (and that people will need to have a high levels of skills, experience and training to fulfill that role), it is important that the befriended and their families are not at a major disadvantage, as compared to the unbefriended who will get the advocate

An independent consultee is only available once it is established that the person lacks capacity, which means that those who could make a decision if they had the support of a consultee may be denied this and so be wrongly deemed to lack capacity. An advocate/independent consultee would be vital to someone where there is significant doubt about their capacity, as well as helping potential decision-makers, rather than being limited only to someone who clearly lacks capacity. The MDA believes access to independent advocacy is a vital mechanism for ensuring that the guiding principles and measures in ascertaining an individual’s best interests are properly fulfilled

and that the Bill should be strengthened to reflect this. The MDA would like the Code of Practice to be strengthened, with worked examples of how advocacy could support an individual where there is doubt that a person has capacity.

#### **4. Advance Decisions**

An advance decision contains a person's instructions as to which medical treatment or professional care intervention that person would or would not be prepared to accept if he or she should subsequently lose the capacity to decide for himself or herself. Advance decisions are simply a method whereby a person can exercise his or her right to accept or reject professional care interventions or medical treatment.

The MDA strongly recommends that the Mental Capacity Bill include provision for advance decision-making. Advance statements (which are statements of wishes) and advance directives (which are advance refusals of treatments) should both be provided for on the face of the Mental Capacity Bill. The Bill currently only makes provision for advance refusals of treatment.

The MDA has argued strongly that the Mental Capacity Bill will need to be amended to take account of the ruling in the recent Leslie Burke court case. In that case, a man with a terminal illness, who feared doctors would withdraw artificial nutrition and hydration from him when he deteriorates, launched a right to life campaign. He rightly won his landmark ruling requiring medical staff to honour his wish for life prolonging treatment. This marks a major and welcome shift in power between patient and doctor and in favour of prolonging life rather than ending it. In the future, the case suggests that a patient will have to be asked specifically, whether he wishes to receive or refuse life-prolonging treatment

The court ruled that if Mr Burke or anybody in a similar position demanded treatment he was entitled to it, and that doctors could only withdraw it if the life imposed on the patient was intolerable. The ruling gives advance directives - written when a patient is competent - greater authority over treatment when mental incapacity intervenes. Many advance decisions are made by people specifying they don't want forms of treatment. Demand for treatment has previously carried less weight but the court has given equal value to both demands. There is also considerable research evidence to show that unless advance statements have substantive legal status the experience of patients and professionals is that they may well be ignored. We also believe it to be anomalous that people with mental disorders in Scotland will have advance statements recognised in new Scottish mental health legislation but there is no legal recognition of advance statements in England and Wales in either the Mental Capacity Bill or the Draft Mental Health Bill.

Building on our support for the Leslie Burke case and in line with the position of the Disability Rights Commission, the MDA has drafted an amendment that would allow people to make advance statements and therefore have much more choice and control over their lives. An advance statement would specify

the types of professional care intervention or medical treatment that a person would find acceptable in certain circumstances.

The MDA also believes that advance statements and advance refusals must be recorded in writing and witnessed unless there are particular circumstances e.g. the person's illness or disability prevents them from doing this.

The MDA recognises that the ruling in Leslie Burke has been appealed and that advance statements would still be subject to a test of reasonableness but we feel that this is an ideal opportunity to make law which is both progressive and empowering for those likely to be most affected by it, and may also go some way to allay the concerns around euthanasia.

## **5. Protected Acts and Treatment Safeguards**

This offers statutory protection against liability for certain acts done in connection with the care or treatment of another person. If an act qualifies as a "protected act" then a carer can be confident that he will not face civil liability or criminal prosecution. A qualifying protected act may be performed by a range of people on any one day. The key requirements are that the person acts in connection with the care or treatment of a person who lacks capacity and that the person has formed a reasonable belief as to the person's lack of capacity and best interests.

The MDA supports the objective of providing clarity about what action can be taken by informal and professional carers when someone does not have capacity to make the decision themselves, without formal procedures or intervention by the court. However, we do not think that the section on protected acts provides sufficient protection for people who may have difficulty making decisions for themselves and could undermine the enabling ethos of the Bill. The major concern is the lack of guidance on the face of the Bill as to the full scope of the protected act – the two key factors determining whether an act is reasonable should be its significance and length of time in which it must be undertaken. We are concerned that a protected act would be open to significant misuse if its scope is not better defined. The MDA has argued that advocacy would provide a safeguard to the potential of inappropriate use and a statutory requirement for an independent second medical opinion should be sought in relation to serious medical treatment. Certain medical treatment decisions, such as sterilisation should be taken out of scope of the protected act altogether.

## **6. The Bournemouth Case**

The MDA is concerned about the implications of the European's Court's ruling on the Bournemouth case, concerning people who lack capacity and are informally "detained" in hospital, nursing or residential care without clear legal protection or safeguards, and the recent announcement that the Government will be carrying out a consultation on how best to address this issue. While the MDA fully supports the principle of a consultation process, we are very concerned that the timing of this may prevent the Bournemouth ruling being addressed in the Mental Capacity Bill. The MDA believes that the Mental Capacity Bill is the more appropriate Bill for the safeguards to address the Bournemouth ruling to be placed. This is because the European Court's ruling primarily concerned the unlawful detention of Mr L, as opposed to the treatment he received. We believe that the safeguards proposed in Part V of the draft Mental Health Bill in 2002 provide an excellent blueprint, which could be adapted appropriately for the Mental Capacity Bill. It is critical that the Bill provides procedural safeguards around admission and review. This should include a treatment plan, a review process, a second opinion, advocacy services, a nominated person and a clear process for appeal. The Government has argued that there is no need for safeguards around review because the Human Rights Act 1998 allows a person access to the court.

## **7. Research**

The MDA believes it is important not to automatically exclude people with a learning disability, autism, mental health problems or dementia from research in the same way that these groups should not be excluded from services and medical treatment. However, research in this area raises a number of difficult ethical issues and hence the most stringent safeguards must be in place. Issues of dignity and privacy and the need to protect people from harm or exploitation must be paramount. We feel the current provisions are a good start but do not provide sufficient safeguards.

The MDA does not think that a court-appointed deputy should be able to consent to non-therapeutic research, unless that deputy is a family member of the person. In addition, we do not support proposals which currently allow a researcher to apply to the Court of Protection to carry out research even if the person consulted, such as a family member, does not give their permission to the research. The Government has promised to review these clauses in the light of discussions at Committee Stage.

## **8. Court of Protection**

The Bill establishes a new superior court of record called the Court of Protection which will be able to sit anywhere in England and Wales. It is intended that the Court of Protection will have a regional presence but the court will have a central office and registry as designated by the Lord Chancellor. The MDA wants assurances that public funds will be made available to ensure that the Court of Protection is sufficiently accessible. It is proposed that deputies would only be appointed by a newly created Court of Protection in limited circumstances. We want to see the power to make a

decision about withholding or withdrawing life-sustaining treatment removed from the court-appointed deputies. These concerns were echoed in the Joint Committee's report and we hope that the Government will now reconsider this issue.

## **9. Lasting Powers of Attorney (LPAs)**

The Bill creates a new statutory form of power of attorney, the "lasting power of attorney" or LPA. It can be extended to personal welfare matters as well as to property and affairs.

The MDA are very concerned that there appears to be no attempt to monitor the registered LPAs to ensure that there is no abuse, but to leave it to people to raise concerns with the Public Guardian. In the response to the Scrutiny Committee the Government stated that 'All financial LPAs will be under the scrutiny of Public Guardian in any case. It might be possible for a higher level of monitoring of an LPA to be offered to donors who are concerned about the potential for a conflict of interest or who foresee other difficulties.' This appears to conflict with statement made by the Minister in committee 'there is not an undertaking to look over the shoulder of individuals who have the power of attorney, unless things are going wrong.' This implies there will be no monitoring after registration, instead it will be left for people to check the register if they have concerns. We recommend the inclusion of an additional safeguard mechanism by which the Court of Protection or the Public Guardian could monitor the use of LPAs with a view to preventing the abuse and exploitation of a donee's powers.

The MDA further recommends that guidance should be provided to assist financial institutions to deal with the operational realities of LPAs. We believe there needs to be a duty on the donee to keep changes of circumstances, such as name change on marriage and changes of address up to date when an LPA is in use. If a person had a concern and wished to check the register it may be impossible to match the person they are concerned about to the register.

## **10. Appointeeship**

Appointeeship is when someone is appointed to look after the benefits of someone who is considered incapable of managing their benefit entitlement. Estimates show that well over 200,000 people have their benefits looked after through this system and yet under the current proposals they would not be under the principles, protections and safeguards within the Mental Capacity Bill. All people who are authorised to manage the person's finances should come under all of the provisions of the Mental Capacity Bill. The Government has promised to review this area following Committee Stage. The MDA recommends:

- people managing the persons' benefit income should be on a par with deputies and monitored on the basis that the choice of the appointee was not made by the individual;



- they should be required to follow the codes of practice in particular the principles of enabling the person to make their own decisions about how they spend their benefit wherever possible; and
- come within the remit of clause 42 (criminal offence of ill-treatment or neglect).

### **11. Duty to assess capacity**

It is critical that any assessment of a person's capacity takes into account the principles at the beginning of the Bill. The Bill also makes it clear that an assessment, as well as decisions or acts done on behalf of someone who lacks capacity, must be specific to the matter in question e.g. someone may lack the capacity to make complex decisions about medical treatment but still have the capacity to decide what they would like to eat. It is therefore particularly important that health and social care professionals take all of these issues into account if they are carrying out an assessment for services or providing services through formal care procedures e.g a community care assessment under Section 47 of the NHS & Community Care Act 1990 or the Care Programme Approach. A duty should be placed upon professionals to carry out a proper assessment of capacity if there is any doubt about the person's ability to make decisions for themselves, in relation to the specific care or treatment being proposed or provided. The person should also have a right to an advocate and any other communication assistance necessary to assist them in expressing their view, as part of this assessment.

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