

Mental Capacity Bill

Making Decisions Alliance Briefing for 2nd Reading Debate on Monday 11 October 2004

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1. Executive summary

About the Making Decisions Alliance

The Making Decisions Alliance (MDA) is a consortium of 40 of the leading voluntary organisations which has been campaigning for mental capacity legislation for many years. Members include Age Concern England, Alzheimer's Society, Help the Aged, Mencap, Mental Health Foundation, MIND, National Autistic Society, Rethink, SCOPE, Sense and Turning Point.

What we think about the Bill

The MDA welcomed the Mental Capacity Bill when it was introduced into the House of Commons on 17 June. We feel it has the potential to transform people's lives for the better. However, the Government's good intentions are at risk if more emphasis is not given to the vital role played by independent advocates. Without more independent advocacy services to support and protect more people who may lack capacity there is a danger that this Bill will not be effective.

Key issues

1. General principles (clause 1)

The MDA welcomes the five principles set out at the start of the Mental Capacity Bill. The MDA believes these principles are a considerable improvement on the current legal position which has developed in a piecemeal and confusing manner.

Whether these principles, and hence the Bill more widely, will make a significant difference to the everyday lives of the millions of people potentially affected will depend on how they are implemented, communicated and resourced. The MDA has vigorously maintained that this means greater provision of independent advocacy services to ensure that the principles translate into workable good practice.

The MDA believes that the Bill should also include a non discrimination principle clause to ensure that all people without capacity are treated equally to guard against others making assumptions about their quality of life.

2. Acts in connection with care or treatment (clauses 5-6)

The Bill establishes a legal protection for families and professionals when caring for, or treating, someone who lacks capacity. The MDA recognises the benefits in having such a defence against liability but believes there are not enough additional safeguards in place to protect the cared for person when significant decisions are being made.

We recognise the Government has redrafted and renamed the relevant clause following the draft Bill scrutiny process but its scope still remains too broad. Given this, we feel it is even more important that vulnerable people have access to an independent advocate when significant decisions are to be made

and / or to help resolve disputes over what is in the best interests of a person lacking capacity. For example, we think that there should be a second opinion when moving home when this involves a change of carer.

3. Lasting powers of attorney (clauses 9-14)

The MDA welcomes the Lasting Powers of Attorney (LPA) provisions in the Bill. However, we believe the LPA safeguards could be improved to provide further protection against abuse. In particular, we would like to see:

- More rigorous monitoring of LPAs by the Office of the Public Guardian
- Clearer rules on when a financial LPA can be used and a further notification when LPA is used
- Donees to be checked against the POVA list
- Low registration costs to help promote the use of LPAs
- LPA documents to be as accessible as possible and for there to be clear guidelines about the nature and form of an LPA's content
- Clear provisions to assist the transition from Enduring Powers of Attorney (EPAs) to LPAs.

4. Advance decisions to refuse treatment (clauses 24-26)

There is an urgent need to develop a codified law which supports the right of people to make advance decisions to refuse treatment. The MDA feels such a move is a logical extension of the established principle of autonomy and existing case law. We welcome the additional safeguards which the Government has built into the Bill following pre-legislative scrutiny but feel it should also be a criminal offence to destroy an advance decision.

The MDA strongly recommends that the Mental Capacity Bill also include provision for advance requests for treatment (sometimes called 'advance statements'). Advance requests for treatment are declarations that an adult gives about the care and support they want to receive in the future as opposed to treatment they do not want to receive.

Advance requests for treatment which meet the criteria of validity, applicability and reasonableness would enable an individual to express their views and preferences on a range of issues such as financial and treatment arrangements and dietary requirements. The recent judgment in the case of Leslie Burke, a terminally ill man who was able to enforce his right to receive life-prolonging treatment, would appear to reinforce the case for advance requests for treatment in the Bill and we hope that the Government will now move to codify this decision through the Bill.

5. Research (clauses 30-33)

The MDA believes it is important not to automatically exclude people who lack capacity 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 additional safeguards are needed. In particular, we would like it made absolutely clear that it is not appropriate to carry out research on people who lack capacity where it is possible to carry out the same research on those who can give, or have previously given, their consent.

In addition, we believe that only a family carer or nominated person, a welfare LPA, a registered medical practitioner who is not concerned in P's treatment or care (but only in the most extreme cases as outlined), or a court-appointed deputy (but only for therapeutic research) should be allowed to give permission to undertake research on behalf of an incapacitated person.

6. Independent consultee service (clauses 34-39)

We are disappointed that the Government has chosen not to introduce a right to an independent advocate as it is commonly understood within the social care field but instead has decided to create a new term called an independent consultee which is likely to cause confusion. As the Bill and draft Codes of Practice are currently worded, we do not believe that an independent consultee would provide the same role as an independent advocate currently does.

The Bill says that the function of an independent consultee is to give advice to the body making the decision about the person's best interests. In contrast, the role of an independent advocate is to empower the person to make decisions for themselves. We are concerned that as well as causing unnecessary confusion, independent consultees could have an adverse financial impact on existing independent advocacy services already provided by local authorities and others.

If the Government were to provide assurances that the role of an independent consultee was intended to be that of an independent advocate and make changes to the Bill to reflect this, we would still be concerned that the current provisions:

- Do not act as a sufficient safeguard against possible abuse of the section 5 defence against liability
- Have unsuitable trigger points for when an independent advocate's advice should be sought
- Do not sufficiently reflect the range of significant decision-making situations when an independent advocate is needed to protect particularly vulnerable people
- Do not reflect the need for additional safeguards given the permissive nature of the Bill in relation to the Court of Protection
- Do not successfully close the 'Bournewood Gap'.

The MDA believes there are two major aspects of the Bill where independent advocacy services are vital in supporting people with impaired capacity:

1. To support the proper implementation of the general principles
2. As a safeguard to protect particularly vulnerable people during significant decision-making processes which could lead to a substantial material change. In particular, this should include:
 - When important medical decisions are to be made, such as invasive surgery, investigative examinations, or long-term or open-ended treatment is being considered
 - When a decision might be made about where someone should live involving a change of carer
 - To help resolve disputes.

7. Implementation and evaluation (clauses 40-42)

The Codes of Practice must not just be seen as providing guidance for families, professionals and carers of people who may lack capacity. They are equally there to help empower people to take decisions that they are capable of making and provide protection from abuse and exploitation. As such, the draft Codes must be available in an accessible format and receive as wide a consultation as possible with local authorities under an expectation to ensure that all carers are aware of the codes of practice.

We would also like assurances from the DCA that they will proactively seeking the views of those people who's views may be more difficult to attain – for example those with profound and multiple disabilities or mental health service users.

8. Appointeeship

The MDA feels it is anathema to the overall purposes of this Bill for the appointeeship system to be kept outside of mental capacity legislation. An attempt to have two separate systems for dealing with people's financial affairs will lead to confusion, inconsistency and, in all likelihood, abuse. We are extremely concerned that under the current provisions as they stand, appointees will effectively have more powers than court-appointed deputies and attorneys but will not be subject to any of the Mental Capacity Bill's safeguards.

How can you help?

If you are intending to speak at the Mental Capacity Bill's 2nd Reading debate on Monday 11 October we should be extremely grateful if you would raise one or more of the points raised in this briefing. There is a fuller briefing available for each issue above which outlines the MDA's position and our recommendations for how the Bill can be improved in more detail. If you would like any further information or if you would like a personal briefing from one of the MDA's co-chairs, please do not hesitate to contact us.

For further information please contact the MDA co-chairs:

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2. General principles (clause 1)

What role would the General Principles play?

The MDA welcomes the five principles set out at the start of the Mental Capacity Bill. The principles provide the foundation for the rest of the legislation.

These principles are:

- 1. The presumption of capacity** – *‘A person must be assumed to have capacity unless it is established that he lacks capacity.’*
This principle underpins a key message of the Act – that everyone’s right to make choices and decisions for themselves (the right to autonomy) must be respected.
- 2. Maximising decision-making capacity** – *‘A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.’*
This principle is intended to ensure that individuals who have an illness or disability that might affect their ability to make decisions for themselves should be enabled and encouraged to take as many decisions for themselves as they can
- 3. Freedom to make unwise decisions** – *‘A person is not to be treated as unable to make a decision merely because he makes an unwise decision.’*
This principle reflects the fact that each one of us is an individual with our own values, beliefs, preferences and attitude to risk which may not be the same as other people’s.
- 4. Best interests** – *‘An act done, or decision made, under this Act for a person who lacks capacity must be done, or made, in his best interests.’*
The concept of ‘best interests’ must guide all actions taken or decisions made on behalf of a person who lacks capacity. What will be in a person’s best interests will depend on that particular individual and his or her personal circumstances. However, it is the ‘best interests’ of the person concerned that are relevant, not those of the person making the decision, or anybody else.
- 5. Least restrictive alternative** – *‘Before the act is done, or decision made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person’s rights and freedoms.’*
In many situations there is likely to be more than one possible course of action or a choice of decisions that would achieve the desired outcome. In such cases, those responsible for taking action or making a decision must explore the different alternatives and consider which option would place the least restrictions on the person concerned or allow the person the most freedom.

The MDA's position

The MDA believes these principles are a considerable improvement on the current legal position which has developed in a piecemeal and confusing manner. Although some areas of decision-making in relation to financial matters are governed by legislation, most decisions made on behalf of people who lacked capacity are currently based on common law principles which are often unclear and misunderstood. It is therefore critical that any assessment of a person's capacity take's into account these principles. 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 must take all of these issues into account if they are carrying out an assessment for services or providing services, and 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 matter in question.

Key recommendations

1. **The need for effective implementation and application** – whether these principles, and hence the Bill more widely, will make a significant difference to the everyday lives of the millions of people potentially affected will depend on how they are implemented, communicated and resourced. The five principles make clear that as much as possible must be done to assist a person's ability to make decisions for themselves. The MDA has vigorously maintained that this means greater provision of independent advocacy services to ensure that the principles translate into workable good practice. There must therefore be a significant enhancement of the quality and availability of independent advocacy services in England and Wales. In addition, we do not think that clauses 34-39 which set out specific circumstances when and the manner in which independent consultees should be used goes far enough and does not incorporate the broader range of principles and practice associated with independent advocacy. We are looking to the Government to re-examine this issue during the legislative process.
2. **The need for the five principles to be properly communicated** – the MDA welcomes the Government's commitment to set out the main principles of the Bill at its outset, the decision to change the name of the Bill (from Mental Incapacity to Mental Capacity Bill) and to place greater emphasis on the presumption of capacity. We agree that it will set the tone for the legislation and mean that the Bill is drafted as value-based legislation. The principles will give a valuable yardstick to courts and help non-lawyers to understand the purpose of the legislation and to weigh up difficult decisions. This could increase confidence in the operation of the legislation and its intention that individuals should be supported to make as many decisions as possible. The MDA wants more information on how the Government intends to communicate the five guiding principles in this Bill. The Codes of Practice will be important tool for this. In particular, the Bill's principles must provide clarity and reassurance to those people who

fear they might have decisions taken on their behalf without their consent. For example, people with a learning disability, people with autism and people with mental health problems and others must have absolute confidence that their right to make their own decisions will be adhered to. The challenge for government is to ensure that the five principles are clearly followed, that the safeguards upholding these principles are clearly communicated and, more importantly, that they are monitored and reviewed to ensure that they are workable in practice.

3. **A principle of non-discrimination** – the MDA is concerned that decisions or acts done for people who lack capacity may be effected in more or less favourable ways, depending upon perceptions of other factors affecting the person, such as age or disability. For example, evidence appears to show that people with learning disabilities are treated less favourably when decisions are made about their medical treatment, and groups representing disabled people have expressed the concern that this Bill may inadvertently continue to provide opportunities for these sorts of situations to arise. The MDA therefore proposes that the Bill be amended to include a principle of non-discrimination as regards decisions or acts done involving people who lack capacity to ensure that factors such as age or disability should not result in people being treated more or less favourably.

Summary

- The Bill's effectiveness will depend on how the five principles are implemented, communicated and resourced
- We would like the Government to clarify what role advocacy will play in the implementation of the five guiding principles
- It is vital that the five principles are communicated, that the safeguards to uphold these principles are clearly communicated and, more importantly, that they are monitored and reviewed to ascertain how they work in practice
- A principle of non-discrimination should be added to the Bill.

3. Acts in connection with care or treatment (clauses 5-6)

Why are 'section 5 acts' important?

Clause 5 offers statutory protection against liability for certain acts done in connection with the care or treatment of another person. If an act qualified as a 'section 5 act' then a professional or informal carer could be confident that they would not face civil liability or criminal prosecution when performing that act.

What would the clause mean in practice?

To qualify as a 'section 5 act', the person ('D') must be acting in connection with the care or treatment of another person ('P') and D must have formed a reasonable belief as to P's lack of capacity and best interests.

In addition to these two requirements the following safeguards are in place to protect P when a section 5 act is taken:

- A section 5 act would only be lawful if D met the five guiding principles at the start of the Mental Capacity Bill
- Clause 6 imposes two further safeguards that if the act is intended to restrain P, it must be necessary to prevent harm to P and the act is a proportionate response to the likelihood and seriousness of that harm
- Further clauses 34-39 provide that in situations in which someone does not have any friends or family, an independent consultee must be provided. An NHS body would have a duty to seek advice from an independent consultee about P's best interests when a decision about the provision of serious medical treatment is being made and both an NHS body and local authority have a duty to seek advice about P's best interests from an independent consultee before providing certain types of accommodation
- A new Court of Protection would have the final say on whether someone was acting in the best interests of P if that decision was challenged

Liability for negligence would be unaffected by the new clause. In addition, advance directives would take priority over this clause.

The MDA's position

The clauses on acts in connection with care and treatment would give protection to much informal substitute decision-making and acts that currently takes place outside any formal legal framework. It would give a legal context for all day-to-day decisions that are made and actions that are taken, such as physically helping P to get up and dressed and giving medication. In this sense, it codifies the existing legal situation as established in case law.

The MDA envisaged that these clauses would give statutory recognition to ordinary day-to-day decision-making and actions by family carers and others who have to make decisions for people who are not able to make their own decisions.

Throughout the draft Bill scrutiny process we argued that a 'general authority to act' (as the clause was called in the draft Bill) must be distinguishable from more formal arrangements needed for authorising major decision-making about people's health, welfare and financial affairs. The Joint Parliamentary Committee which scrutinised the draft Bill agreed with the MDA and recommended "a redrafting of the clauses concerning the general authority in order to clarify that its use is intended to be limited to day-to-day decision-making and emergency situations" (p38, Joint Committee Report, published 28 Nov 2003).

The MDA recognises that the Government has redrafted and renamed the clause but we believe that its scope still remains unclear and is too wide. For example, it is not clear whether a paid carer or family carer would be taking an action under a section 5 act, in relation to the case of a person without capacity being moved to a different home, that involved a change of carer, for example, a move from a family home to a residential home.

Similarly, while clause 5 is a defence against reasonable actions already taken, it is unclear whether it is a defence against not acting which, for example, may be the outcome of a medical decision-making process or the decision that an adult with a learning disability should not move from the family home. This highlights our concern with divorcing the 'act' (the doing part) from the decision-making process. We feel that the Government needs to link the decision-making process more closely with the act which follows from that process.

We are extremely concerned that this clause does not:

1. Distinguish between different types of actions taken or set out how the significance and timing of the action should be considered when deciding whether to act under clause 5.
2. Establish a clear hierarchy of safeguards which reflect the seriousness of the action taken and the consequences for that individual. The MDA recommends that some actions taken under section 5 require additional safeguards to counter against its inappropriate use. For example, we think it is important that a person has the support of an independent advocate, when moving home which would involve a change of carer. Similarly, we think that there should be an independent second medical opinion, in relation to serious medical treatment.
3. Relate to the decision to act but rather relates only to the 'act' itself.
4. Require professionals and family carers to justify their decisions in advance and to keep a record of decisions made. Instead, a person will only need to justify decisions retrospectively and then only if that decision is challenged.

5. Establish when authority under a section 5 act ends and at what point and for what decisions an application to the Court of Protection should be triggered. The MDA feels that the Bill should expressly set out which that certain decisions, such as sterilisation, should be excluded from the section 5 altogether and always taken to the Court of Protection.
6. Provide practical assistance for an individual in accessing the Court of Protection
7. Provide the level of clarity needed for families, informal carers and professionals about when they can take a decision on a person's behalf and the type of decision they can take. For example, as outlined above, it remains unclear who would be responsible for acting under section 5 in relation to the decision to move someone lacking capacity and hence who was deciding it was in their best interests.
8. Place a clear duty on health and social care professionals working for statutory authorities to undertake a proper assessment of capacity, in relation to the specific matter in question, when either assessing a person for services or in the provision of services where the person's capacity to take decisions for themselves is unclear.

Key recommendations

1. **Communicating the purpose of section 5 acts effectively** – the Joint Committee set up to scrutinise the draft Bill recommended that it is vital that a “sustained and comprehensive training programme for professionals, and a public information campaign for informal carers is implemented, in order to provide these groups with an accurate understanding of the general authority” (p36). We would add to this Joint Committee recommendation, that it is equally vital that a public information campaign is extended to all those people who believe they may be affected by section 5 acts. The draft Bill's provisions for acts in connection with care and treatment is viewed by suspicion by some people with a learning disability and it is important that the limits of this new clause are clearly communicated to those groups who feel they may be affected by it.
2. **The role of the Codes of Practice** – the MDA feels that there is an opportunity to address the issue of the scope of and safeguards within clause 5 more thoroughly in the Codes of Practice. We look forward to hearing how the Government intends to use these to more clearly define the scope of clause 5.
3. **Access to independent advocacy services** – given that the scope of clause 5 is so broad, we feel it is even more important that there are additional safeguards in place for the most significant decisions for all vulnerable people, and not just those without the support of friends or family. The range of decisions outlined below should involve an assessment of mental capacity if there are concerns that the person may not have capacity in relation to the particular decision in question. We feel access to an independent advocate is particularly important:

- When important decisions are to be made, such as invasive surgery, investigative examinations (such as biopsy or psychiatric assessment), or long-term or open-ended treatment is being considered
 - When a decision might be made about where someone should live involving a change of carer
 - When the process of assessment indicates that it is likely that a person is likely to have a life changing decisions made such as where the person lives, or a change of carer. This should include any assessment made under section 47 NHS and Community Care Act 1990 (this would include section 3 assessments under the Community Care Delayed Discharges Act) or an assessment whether or not to provide section 117 Mental Health Act aftercare, the Care Programme Approach on discharge from a psychiatric hospital, or when reviews of such assessments are to take place which might lead to a change of where the person lives and involve a change of carer.
 - Following an admission to hospital for investigation or assessment, a care plan is made, a diagnosis reached or treatment options are under consideration
 - At the time when a deputy is appointed to make welfare or medical decisions on behalf of a person who lacks capacity
 - To help resolve areas of dispute. The MDA believes that people who have difficulty making decisions are particularly vulnerable when a public body is part of a dispute or aware of a dispute between a family carer or the individual about what is in their best interests. This needs to be clearly recognised on the face of the Bill.
4. **Reasonableness and section 5 acts** – the MDA believes that it is important to consider what is reasonable in the context of decision making under section 5. The MDA believes that a health or social care professional acting under section 5 must have regard to their own professional codes of practice, including a person-centred plan or care management plan and to be able to justify decisions taken on behalf of a person who lacks capacity. It would be reasonable to expect a professional carer to hold a case conference before making significant decisions. It would also be reasonable to expect a family carer to record why a decision was taken to the extent necessary to justify that the decision was reasonable, if challenged at a later date. These safeguards need to be made clear on the face of the Bill and Code of Practice.
5. **Challenging a Section 5 Act** – the MDA proposes an additional mechanism for challenging a decision taken under a section 5 act. We would like to see the jurisdiction of the new Court of Protection extended to include arbitration hearings at a more local level (equivalent to “small claims hearings” in the county court), with appropriately trained and qualified personnel. This could help resolve disputes and prevent more formal applications to the Court of Protection. It would also clarify that formal hearings of the Court of Protection are to decide the most difficult cases and to appoint deputies to make difficult decisions.

6. **Statutory duty to assess capacity** – the MDA proposes an additional limitation on Section 5 acts. We would like to recommend that health and social care professionals working for statutory authorities be required to undertake an assessment of a person’s capacity concerning the specific matter in question, when carrying out an assessment for services or provision of services to the person when the person’s capacity to make decisions for themselves is in doubt.

Summary

- The current clause 5 fails to provide sufficient safeguards or meet the recommendations of the Joint Parliamentary Committee which scrutinised the draft Bill
- A person who may lack capacity is particularly vulnerable when there is a dispute or disagreement between a local authority, family carer and the individual about what is in their best interests and not only when they do not have any friends or family to support them. This needs to be recognised on the face of the Bill.

4. Lasting powers of attorney (clauses 9-14)

Purpose of the provision

The Government intends to extend the current system for delegating decision-making powers on financial affairs – called Enduring Powers of Attorney (EPA) – to include healthcare and personal welfare decisions and rename these delegated powers as Lasting Powers of Attorney (LPA).

What will it mean in practice?

The LPA provisions would allow individuals to plan for the future by granting an LPA to a person (persons) of their choice which could be exercised in the event of future incapacity to make such decisions themselves. Should P lose capacity, the attorney/s would be able to make decisions on their behalf about health, welfare and financial matters. The instrument granting the power will list the extent of the decisions that can be made, so empowering the person firstly by enabling them to choose who they wish to make such decisions and establishing clearly the sorts of decisions they wish to be made.

The intention is that LPAs should be registered soon after they have been made and while the person still has the capacity to make his or her own decisions.

A health and welfare LPA cannot be used if the person still has the capacity to make their own decisions about health and welfare matters. In contrast, a financial LPA can be used at anytime after registration unless the person has specified it is not to be used until they can no longer make financial decisions for themselves.

Under the present system EPAs are not registered until the person loses capacity and it is up to the attorney to decide when registration is necessary. This means that many EPAs are not registered, which in turn, makes it difficult to monitor their use and can leave the person open to financial abuse. Under the new proposals, an LPA could not be used until it is registered. The Bill also allows for the person to choose the third parties (for example family members or friends) to be informed when the LPA is registered. It gives people the opportunity to raise concerns about the appropriateness of the attorney, for example possible conflicts of interest or other concerns before the donor loses capacity to understand those concerns or conflicts of interest.

The MDA's position

The MDA welcomes the LPA provisions and the various safeguards proposed. However, we believe these safeguards could be improved to protect further against abuse.

Key recommendations

1. **Duties imposed on the donee** – currently, a donee is only required to sign that he/she understands the duty imposed on them under section 4 of the Act (best interests). We feel this should be amended so that the

donee is required to take account of the five principles in clause 1, the overriding duty to help the person make their own decisions if they can, and to only use the LPA when the person cannot make their own decisions (unless the LPA specifies otherwise in the case of a financial attorney)

2. **When an LPA is registered** – the Office of the Public Guardian should take extra steps to monitor an LPA where no third parties are listed to be informed of registration or when there are other concerns about the potential for a conflict of interest between the proposed LPA and the person. (see points 4 and 5 below on scrutiny of LPAs and protection of vulnerable adults).
3. **Safeguards against the misuse of a registered LPA** – we are concerned that financial institutions will not know whether a financial LPA is being used for someone who lacks capacity to manage their own financial affairs and this may lead to financial abuse. This is particularly important when an attorney only has authority to manage a person's finances when they lack capacity and that person has fluctuating capacity. It could also mean that banks would need to check themselves whether the LPA is being used in accordance the instructions on the instrument, as registration will no longer give any indication of whether or no the person has capacity. We therefore consider it is essential that there is a further notification made and indicated on the instrument when the LPA is being used because the person can no longer manage their financial affairs. We hope that the guidance to banks and financial institutions will be updated to reflect the changes in the Bill and look forward to hearing from Government how they intend to use the Codes of Practice to ensure everyone is aware of their duties and responsibilities under the Bill.
4. **Scrutiny of LPAs** – we would like to see a mechanism in place to alert the Office of the Public Guardian when an LPA starts to be used and hence needs monitoring. We also recommend random monitoring of a percentage of cases, and/or using risk assessment methods to identify cases which may require additional monitoring by the Office of the Public Guardian. Attorneys should be made aware of such random monitoring.
5. **Protection of vulnerable adults** – under the current Bill, an individual who is bankrupt may not be appointed as a financial attorney. However, there is nothing in the Bill in relation to individuals who may be on the Protection of Vulnerable Adults list. Individuals are referred to, and included on, the POVA list if they have abused, neglected or otherwise harmed vulnerable adults, or placed vulnerable adults at risk of harm. In order to make an informed decision we recommend that before making an LPA an individual should have the right to check the POVA list so that they are aware of whether or not the donee they have chosen is on the list. We further recommend that the Office of the Public Guardian should also check the POVA list in all cases and if the person has chosen a donee who is on the POVA list this should alert the Office to place the LPA on the high risk category for monitoring purposes.
6. **Cost of registering LPAs** – it is vital to encourage as many people as possible to make use of LPAs. If the cost of registering an LPA is

prohibitive (currently the fee to register an EPA is £220) many people will either be deterred from accessing them or will delay registering them. We seek reassurance that costs of registration will be kept to a minimum and that there should be a clear remissions policy.

7. **Design of LPA documents** – the format of the LPA instrument should be designed to ensure that it is clear what welfare decisions the attorney can make and what the individual's wishes are in relation to those decisions. This will help to make sure that there is clarity about how decisions are made. We think that it would be possible to have different sections within the instrument that provide clarity about different issues. For example, one section could set out the individual's wishes and feelings on welfare decisions, one could act as an advance directive about the refusal of treatment (and be subject to the provisions in sections 24 – 26), and another as an advance statement about treatment. This would enable the donor to make it clear on their LPA instrument what their wishes are at the time of making the LPA. For instance they could make it clear in the advance statement section of the LPA that they would be quite happy for their carer to use direct payments instead of services if that is felt by the carer to best meet the needs of the donee. Stating clearly the person's wishes on the LPA would make it much easier for the LPA to prove what the person's past wishes were when they had capacity.
8. **Transitional provisions for EPAs** – there are currently estimated to be about 75-80,000 current registered attorneys and we would be concerned that so many people who lack capacity to make their own financial decisions will have attorneys who are outside of the provisions of section 1 of the legislation. We are very concerned that there is express provision in the Bill (Schedule 4 1(1)) to say that section 1 of the Act does not apply to EPAs. We consider that EPAs should be expected to follow the five principles of the Mental Capacity Act and the Codes of Practice. For people who have not yet needed to register their EPA we recommend that there should be provisions for them either to alter the EPA instrument to add that they wish the EPA to be considered as if it was an LPA, or to be advised of the possible advantages of revoking a current EPA and making an LPA. In the case of registered EPA, we would wish to be reassured that the Office of the Public Guardian would send all attorneys a copy of the Codes of Practice with an indication that this is expected to be followed.

Summary

- The MDA welcomes the LPA provisions and the various safeguards proposed
- We believe these safeguards could be significantly improved to protect further against abuse.

5. Advance decisions to refuse treatment (clauses 24-26)

Why are advance decisions needed?

The clauses on advance decisions to refuse treatment (sometimes called advance directives) seek to codify and clarify the current common law rules and integrate them into the broader purposes of the Bill. An advance decision, as defined in these clauses, represents a decision made by someone with capacity not to be given a clearly specified treatment in the future when they lack capacity. For example, someone with dementia may state that in the later stages of their disease when they are close to death they do not want to be artificially tube fed through a pipe inserted into their stomach. Being able to write down decisions like this in advance enables people to plan for their future and ensure their wishes are carried out. Not everyone will want to set up an advance decision, but it is crucial that when people have taken the decision to state their wishes, those views are acted upon. An advance decision to refuse treatment will be followed in certain circumstances and only if certain safeguards are met.

The MDA's position

There is an urgent need to develop law which supports the right of people to make advance decisions to refuse treatment. The Bill only proposes to regularise the existing status quo and the MDA feels such a move is a logical extension of the established principle of autonomy. We also welcome the additional safeguards which the Government has built into the Bill following pre-legislative scrutiny.

Some groups, such as the Society for the Unborn Child (SPUC), have claimed that the advance decisions clauses change the law in favour of euthanasia. In its report on the draft Bill the Joint Parliamentary Committee refuted this claim. We are also confident that there is nothing in the Bill which promotes euthanasia and welcome the commitment to clause 58. Refusal of medical treatment at the end of life is completely distinct from trying to authorise a doctor to do something that is illegal i.e. undertaking an action with the sole intent of ending someone's life (which someone with capacity could not do either). They cannot authorise a doctor to do anything which is illegal or which a person with capacity could not request a doctor to do.

While we understand and respect the deeply-felt views of anti-euthanasia groups, we feel attempting to link advance directives and euthanasia is wholly misleading and misrepresents the purpose of the Mental Capacity Bill which is to empower people while giving them greater protection when needed.

However, we do have concerns that the Bill will allow the Court of Protection to confer authority on court-appointed Deputies to consent to the withholding or withdrawing of life-sustaining treatment. We cannot envisage a situation where it would be safe and appropriate for a deputy alone to make such a decision. We would therefore recommend that such situations should be

referred back to the Court of Protection and that the Bill be amended to reflect this.

Key recommendations

1. **The need for best practice** – it is very important that the proposals on advance decisions to refuse treatment are not watered down or removed from the Bill. We would also like to see a commitment from the Government to providing clear information to people about advance directives with best practice examples of the format and language which could be used to enable people to make best use of them.
2. **A criminal offence to destroy an advance decision** – the Bill should make it a criminal offence to destroy an advance decision – a provision which was contained in the draft Bill and which had widespread support.

Advance statements

The MDA strongly recommends that the Mental Capacity Bill include provision for advance statements (which are statements of wishes) on the face of the Bill. Advance statements are declarations that an adult gives about the care and support that they want to receive in the future (as opposed to treatment they do not want to receive). We believe the Bill should enshrine advance statements in law. While the explanatory notes to the Bill recognises the importance and relevance of such statements as part of the 'past wishes' of the person for the purposes of the best interests checklist, we do not think this goes far enough.

An advance statement would specify the types of treatment that a person would not find acceptable in certain circumstances but also the kinds of care and treatment that the person would wish to receive, including the provision of life-sustaining treatment. This would not of course oblige doctors to use treatments they considered inappropriate. They could also include decisions about where they want to be cared for whether in their home or in a specialist residential home. The ability to state their wishes in advance can reduce a person's anxiety about the future, and give people reassurances that their wishes will be taken into account.

In summary, advance statements would enable an individual to express their views and preferences on a large range of issues, including:

- domestic arrangements
- treatment preferences
- financial arrangements
- childcare arrangements
- clarification of who to disclose information to, and the limits of what can be discussed
- dietary requirements

Advance statements could provide both additional safeguards and direction for a person acting for someone who has lost capacity. For this reason we

have suggested that there is a section on the LPA instrument to enable people to list their wishes regarding their future care which would be used as an advance statement. The MDA proposes a requirement for a person carrying out section 5 acts, or acting as a 'Welfare' Lasting Power of Attorney or as a Deputy appointed by the Court of Protection to act in accordance with an individual's advance statement providing the advance statement meets the criteria of validity, applicability and reasonableness.

The existence of an advance statement could also provide guidance around the "practicable steps" to assist those helping someone who is unable to make decisions. It should also be noted that legislation in Scotland recognises advance statements.

The recent judgment in the case of Leslie Burke, a terminally ill man, who was able to enforce his right to receive life-prolonging treatment may mean that a patient will have to be asked specifically whether he or she wishes to receive, or refuse life prolonging treatment. The court ruled that if a person demanded treatment, that person was entitled to it and that doctors could withdraw it only if the life it imposed on the patient was intolerable. It reinforces the case for advance statements to have equal value to advance refusals of treatment.

Summary

- The MDA welcomes the provisions on advance directives which propose to regularise the existing common law and provide additional safeguards
- Advance directives will not bring in 'euthanasia by the back-door'
- We would like the Government to establish legal recognition for advance statements under certain circumstances.

6. Research (clauses 30-33)

Purpose

The clauses on research will allow for research to be lawfully carried out on people who lack capacity under certain circumstances.

What will these provisions mean in practice?

The issue of research was not originally considered in the draft Bill. The provisions on allowing incapacitated adults to take part in research were included in the revised Bill following a recommendation by the Joint Parliamentary Committee.

The provisions will mean that research can be carried out on a person who lacks capacity to consent if the research:

- Meets the five guiding principles
- Has been approved by a Research Ethics Committee (REC)
- Is connected with a condition which affects P
- Would not be as effective if carried out on persons with capacity to consent
- Has potential benefits to P without imposing a burden which is disproportionate to the potential benefit
- Is intended to provide knowledge of the causes, treatment, or care of persons affected by the same or similar condition if the risk is negligible and would not be unduly invasive or restrictive
- Has the consent of a family member or friend (in most circumstances but not all)
- Has been approved by the Court of Protection
- Is not contrary to any advance decision which has effect

Clinical trials that are currently regulated under the Medicines for Human Use (Clinical Trials) Regulations 2004 (SI 2004/1031) (or Regulations succeeding or amending them) are excluded from the Bill because the Clinical Trials Regulations already make provision for trials involving participants who lack capacity. Research on anonymised medical data or tissue which the Human Tissue Bill (currently before Parliament) is proposing to cover are also not included.

MDA's position

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 same principles for seeking consent to treatment should apply as the basis for consent to take part in research. The five guiding principles should provide the basis for decision-making for people who may appear to be unable to consent to research. Under this system, many people may consent for themselves and should have the support to enable them to make their own decisions in relation to research.

When consent from the person themselves is not possible through the five guiding principles and/or the use of an independent advocate, we believe that, in all but the most extreme circumstances, consent from a family member, friend or welfare LPA must be obtained whenever research is being considered on an incapacitated adult.

We do not think a doctor or professional carer should be able to make a decision on consent to research except in the most extreme circumstances – i.e. where it is not reasonably practicable in the time available to obtain agreement. In addition, we do not think a court-appointed deputy should be able to consent to non-therapeutic research, unless that deputy is a family member of the person.

How can the provisions be improved?

1. **Tightening the provisions on consent** – it should be made clear on the Bill that:
 - It is not appropriate to carry out research on people who lack capacity where it is possible to carry out the same research on those who can give their consent. We are concerned that having ‘reasonable grounds for believing that the research would not be as effective’ would not meet this criterion and hence seek assurances from Government
 - No other person will be allowed to give permission to research on behalf of the incapacitated person other than a family carer or nominated person, a welfare LPA, a registered medical practitioner who is not concerned in P’s treatment or care (but only in the most extreme cases as outlined), or a court-appointed deputy (but only for therapeutic research). Specifically, we would like to see the removal of Clause 32(7) from the Bill which currently allows 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.
2. **Standards of conduct for researchers** – a specific standard of conduct should be included in the Code of Practice aimed at those carrying out research and the procedure for application approval must be clear and accountable. As part of this, we believe it is important to monitor the number of applications for research and the types of research carried out with different groups. A report should be prepared annually by the Ethics Committee and be opened to public scrutiny.

3. **Developing new areas of expertise** – the Ethics Committee will need to develop new areas of expertise if it is to assume responsibility for social care research. We seek assurances that membership or those bodies specified by regulations made by the Secretary of State should have wide representation, including lay representation, and all members should be required to undertake training in relation to mental capacity issues.

Summary

- The Bill should make it clear that is not appropriate for research to be carried out on people who lack capacity where it is possible to use people who can consent The Bill should clarify who is entitled to give permission on behalf of the incapacitated person
- A standard of conduct for researchers should be included in the Code of Practice.

7. Independent consultee service (clauses 34-39)

The clauses on an independent consultee service aim to provide additional support to particularly vulnerable people during significant decisions. Clauses 34 to 39 set out that an NHS Body or local authority has a duty to seek advice from an independent consultee about what is in a person's best interests when a decision is being made under about serious medical treatment or before providing certain types of accommodation. However, the independent consultee need only be consulted if P does not have any friends or family to consult about a person's best interests.

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. It also states that they are intended to help address concerns raised by the Bournemouth case about safeguards for patients with a mental disorder, who lack capacity and are being treated in hospital.

The MDA's position in relation to independent consultees

We are disappointed that the Government has chosen not to introduce a right to an independent advocate and do not believe that the proposed "independent consultee" is the same as an independent advocate. The Bill makes it clear that the function of an independent consultee is to give advice to the body making the decision about the person's best interests. This is not the role of an advocate.

The role of an advocate is to empower people to make decisions for themselves that they are capable of making with support. Where a person lacks capacity, the role would be to help the person to participate in the decision making process to the fullest extent possible, to help them to speak up for themselves and to make sure that their views are heard. A basic principle of advocacy is that the advocate does not make any judgements, or express any opinions, of their own. They may help to ensure that the person is aware of relevant issues they may not have considered. They may speak on behalf of the person to ensure the person's views are heard and taken account of, but the advocate will not make any decisions or judgements on the person's behalf.

The role of the independent consultee appears to be to support the decision-maker rather than the vulnerable person. It involves making a judgement about a person's best interests and therefore conflicts with the role of an advocate. The MDA believes that the additional resources of £6.5 million to fund independent consultees would be better spent in providing independent advocates.

The MDA recommends that clauses 34-39 should be amended to introduce a right to independent advocacy, rather than an independent consultee.

We are also concerned that prioritising independent consultees in this way may have an adverse impact on advocacy services already provided by local authorities and others. We are extremely concerned that resources will otherwise simply be substituted from one budget to another, to meet the obligation to provide an independent consultee at the expense of advocacy support. We also believe that the situations in which a person should have a right to the support of an advocate need to be much wider than the current situations in which an independent consultee is proposed.

For example, it does not cover situations when there is a dispute or when formal powers are used. Moreover, it does not recognise the fact that the cumulative impact of seemingly less significant decisions, for example about what to eat or wear, can have just as much impact on a person's well being as more serious decisions.

Finally, the provision does not recognise the other serious and significant decisions, which will be made under clause 5. For example, the independent consultees are limited to people moving to or between NHS care and residential care homes and does not appear to include other accommodation options, such as supported living.

Why is advocacy so important for people who may have difficulty making decisions?

Advocates work with individuals to support them to have a say in their lives and to make as many decisions as possible. Where this is not possible, advocates represent the individuals' views and wishes and make sure they are involved as far as possible in the decision-making process. This includes working with individuals to establish what their preferences are, even when these cannot be communicated in conventional ways. This is particularly important where someone may lack capacity. Advocates also ensure that the particular needs and values of people from different minority ethnic communities or faith groups are respected. The independence of the advocate is critical. Being independent means that the advocate has no interest in the outcome of the decision and can focus only on what it means for the individual.

The Joint Committee which scrutinised the draft Bill concluded in its report: "We are convinced that independent advocacy services play an essential role in assisting people with capacity problems to make and communicate decisions; helping them to enforce their rights and guard against unwarranted intrusion into their lives". The Committee recommended that the Government "meet all reasonable requirements for the provision of independent advocacy services to incapacitated adults affected by the Bill's provisions".

The MDA believes there are two major aspects of the Bill where independent advocacy services are vital in supporting people with impaired capacity:

3. To support the proper implementation of the general principles

4. As a safeguard to protect particularly vulnerable people during significant decision-making processes

The MDA believes that the current provisions in the Mental Capacity Bill go some way to meeting these two vital priorities but do not go far enough and certainly fall well short of the recommendation made by the Joint Committee.

The need for advocacy to support the implementation of the general principles

The Mental Capacity Bill provides a statutory framework which aims to empower and protect adults with impaired mental capacity. The Bill starts with five key principles and makes clear that “A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success”.

These guiding principles are reinforced by Clause 4 which sets out the test for best interests and includes the requirement to allow the person participate “so far as reasonably practicable” and involve anyone named by that individual to be consulted on in the decision-making process as far as is “practicable and appropriate”. An individual’s past and present wishes and feelings should also be at the centre of the decision-making process.

The MDA believes access to independent advocacy is a vital mechanism for ensuring that the guiding principles and measures in ascertaining 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. Advocacy can play a more central role in the Bill in ensuring that people can make and communicate decisions that they are capable of making and that they play a part in the decision making process where they cant make a decision for themselves. However, the Bill contains no information on the role that advocacy services could play in this regard.

Moreover, the fact that the government has set out a separate clause designed to identify when independent consultees should be used does not give us confidence that independent advocacy will be at the heart of the implementation process of the five guiding principles and hence of this Bill.

Independent advocacy to support particularly vulnerable people during significant decision-making processes

1. **The most vulnerable people will not be protected for the most significant decisions** – the MDA recognises that resource constraints mean that it would be inappropriate to provide a statutory right to advocacy for all people affected by the Bill and that advocacy should be prioritised for vulnerable people when significant decisions are being made. The key argument is where the threshold of vulnerability should be set to merit access to an independent advocate, and what constitutes a major or significant decision. We feel that the Government’s current

threshold which limits independent consultees to those who are effectively un-befriended misses out a significant group of extremely vulnerable adults and that the Government's analysis of what constitutes a 'significant' decision is too narrow. The range of decisions outlined below should always involve an assessment of mental capacity if there are concerns that the person may not have capacity in relation to the particular decision in question. The MDA believe independent advocacy should be available when any decision is being which may lead to a substantial material change in a vulnerable individual's circumstances. In particular, this should include:

- When important decisions are to be made, such as invasive surgery, investigative examinations (such as biopsy or psychiatric assessment), or long-term or open-ended treatment is being considered
- When a decision might be made about where someone should live and involving a change of carer
- When life-changing decisions are made as part of any process preceding service provision decisions by the responsible authority such as the process of assessment under section 47 NHS and Community Care Act 1990 or whether or not to provide section 117 Mental Health Act aftercare, the Care Programme Approach on discharge from a psychiatric hospital, or when reviews of such assessments are to take place which might lead to a change of where the person lives and involve a change of carer
- Following an admission to hospital for investigation or assessment, a care plan is made, a diagnosis reached or treatment options are under consideration
- At the time when a deputy is appointed to make medical or welfare decisions on behalf of a person who lacks capacity
- To help resolve areas of dispute.

The MDA believes a person is vulnerable not only when they do not have any friends or family to ensure a decision is made in that person's best interests. A person can be equally vulnerable when there is a dispute among people providing them with care, treatment and support (including family and friends, paid carers and professionals. Many legal disputes currently adjudicated under the "best interests" jurisdiction of the High Court have concerned the conflicting views of social workers on one hand, and relatives and carers on the other, about what is genuinely in the "best interests" of the person concerned. Sometimes the dispute can be between the individual and their carers. For instance when someone with a learning disability wishes to move out of the family home, or if they wish to stay at home when their carer can no longer manage to care for them. Although more than one course of action can legitimately be viewed as capable of being in a person's best interests, other parties, however well-meaning, have other interests. Social services and health trusts have concerns about resources, relatives may have to consider the needs of other dependent or vulnerable family members.

Furthermore, it is more often the case that the existence of conflicting interests will be brought to light by relatives and carers when an assessment is being undertaken.

We feel an independent advocate can provide invaluable assistance to resolve such disputes and ensure that P's views are heard. It is vital this is reflected in the legislation.

2. **Does not act as a safeguard for section 5 acts** – given the lack of limitations on the scope of section 5 acts, it is vital that advocacy provides an additional safeguard when significant decisions are taken under acts in connection with care or treatment.
3. **The trigger points for when an advocate's advice must be sought are unsuitable** – the points chosen in the Bill for when an advocate becomes involved are too late in the decision-making process. The trigger point should be:
 - When there is a community care assessment or review under section 47 of the NHS and Community Care Act 1990, including those assessments which are under Continuing Care Directions or section 3 of the Community Care (Delayed Discharges etc) Act 2003
 - An assessment regarding aftercare under section 117 Mental Health Act
 - When a Care Programme Approach is used (on discharge from psychiatric hospital) and in the community
4. **The terms of the Bill are overly permissive** – the clauses fail to reflect the very serious impediments faced by P, carers, donees, advocates and the 'independent consultee' in invoking treatment safeguards and in accessing the Court of Protection. Unlike Section 132 of the Mental Health Act or clause 127 of the draft Mental Health Bill, the Mental Capacity Bill makes no provision to require social services to appoint a nominated person and to inform both the patient and nominated person of help available.
5. **The provisions do not close the 'Bournewood Gap'** – we are extremely concerned that the Bill does not give sufficient protection to mental health in-patients who lack capacity and therefore cannot consent to their treatment. Many such patients are given hospital treatment informally – that is, without being sectioned under the Mental Health Act - because they comply with hospitalisation and treatment (but do not have capacity to explicitly consent). The Bournewood Trust case concerns a learning disabled man who was kept in hospital under sedation, despite the fact that hospital staff knew that he might wish to go home. The case is still before the European Court of Human Rights, on the basis that he was detained unlawfully in breach of human rights. In particular, any person lacking capacity, who is effectively detained in hospital should be given positive rights to:
 - Information about help available from mental health and legal advocates and the right to apply to the Court of Protection

- Automatic access to the Court of Protection together with no-strings legal aid (similar to that available for the Mental Health Review Tribunal)
 - the appointment of a Nominated Person, who would be consulted about treatment and discharge, and who could apply on the patient's behalf to the Court
 - a right to a care plan, which is subject independent review
 - special authorisation for ECT and serious non-emergency treatment before approval of the treatment plan
6. **Application to the Court of Protection** – the Bill should provide that an independent consultee can apply to the Court of Protection as of right rather than having to obtain permission from the court. Section 48 of the Bill should be amended to allow this.
7. The Bill should include provisions to make a complaint if the relevant bodies do not provide advocates in the circumstances listed in the Bill.

Summary

- The 'independent consultee' provision fails to address the needs of many people who may have difficulty making decisions
- A stronger emphasis on advocacy support would provide better protection for those affected by the Bill
- The MDA believes that independent advocacy services are vital in supporting people with impaired capacity- to support the proper implementation of the general principles- as a safeguard to protect particularly vulnerable people for significant decisions.

8. Implementation and evaluation (clauses 40-42)

The need for effective implementation

Past experience shows that unless legislation is implemented properly people do not get the benefit of it. For example, *Missed Opportunities*, a report by Carers UK in 2003 illustrated that only 32% of carers have benefited from the Carers Recognition and Services Act 1995. Whether the Mental Capacity Bill makes a significant difference to the everyday lives of the millions of people who could potentially be affected by this Bill will depend largely on how it is implemented, how it is communicated and how it is resourced.

The Codes of Practice will be key to ensuring this. They are intended to provide practical guidance to all those working with and/or caring for adults who lack capacity, including families, professionals and carers and describes their responsibilities when making decisions with, or on behalf of, individuals who lack the capacity to make decisions for themselves. The Codes are also intended to be of assistance to individuals who are concerned that they may be considered to lack capacity to make decisions for themselves, now and/or in the future and wish to understand this area of law.

The MDA's position

We are extremely pleased that the draft Codes of Practice will be ready for Committee stage and would like to congratulate the Government for meeting this difficult deadline.

Key recommendations

It is vital that the Codes of Practice are not just seen as providing guidance for families, professionals and carers of people who may lack capacity. They are equally there to help empower people to take decisions that they are capable of making and provide protection from abuse and exploitation.

The draft Codes must receive as wide consultation as possible and for this to happen they must be in all accessible formats. We would also like to see the DCA proactively seeking the views of those people whose views may be more difficult to attain – for example those with profound and multiple disabilities or mental health service users.

We would like to see key Government commitments made:

- An awareness campaign to make the public and health and social care professionals aware of the new rights and responsibilities that the Bill brings. This would include publicity through the NHS, social care and voluntary organisations.
- Training of health and social care staff who will be affected by the legislation so that they know what rights people have and those responsible for assessing capacity know how to do so. In particular health

care professionals need to be adequately briefed about authority to treat and consent issues.

- Making information and support available so that people are able to make full use of their new rights. This would include the provision of independent advocacy services.
- Impact studies and a forward research plan to monitor the uptake of new rights so that implementation plans can be adapted to ensure particular groups are not being excluded from using new rights. Also to include evaluation where stakeholders are consulted about how the proposals are working.
- Legal aid available for those seeking a decision of the court of protection on any aspect of their personal welfare without means or merits test and for those who wish to apply to be a court appointed deputy.
- A reasonable costing structure for lasting powers of attorney so that people are not excluded from setting them up for financial reasons.

Summary

- A public and professional awareness campaign is needed
- Health and social care professionals who will be affected by the Bill will need training
- The Government should monitor the impact and uptake of these new rights.

9. Appointeeship

The role of 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. The MDA believes that this is a massive oversight in this piece of legislation.

How appointeeship works currently

Social Security legislation allows an individual to apply to be an 'appointee'. This means they can claim, receive and spend the benefit income on behalf of someone who is considered incapable of managing their own financial affairs. An application to be an appointee is considered by the Department for Work and Pensions (DWP), which normally arranges for the applicant to be interviewed to check whether they are a suitable person to act on behalf of the person without capacity and that they are likely to act in that person's best interests. The benefit claimant is also interviewed by a member of DWP staff to ensure that the benefit claimant is incapable of managing his own affairs. The DWP can seek medical advice to do this. There are similar procedures for Local Authorities, and Inland Revenue to follow for benefits paid by them. When approved, the appointee has access to all the state benefits to which someone is entitled, including housing benefits, administered by local authorities, and tax credits, administered by the Inland Revenue. In some circumstances, for example, where benefits are the only source of income, an appointee will have overall control over someone's financial affairs.

The MDA's position

The MDA feels it is anathema to the overall purposes of this Bill for the appointeeship system, which affects many thousands of people, to be kept outside of legislation and will lead to confusion and inconsistency in the dealings of people's financial affairs.

Key recommendations

1. **The need for one set of rules and comprehensive safeguards** – we are concerned that appointees will effectively have more powers than court-appointed deputies and attorneys without any of the safeguards. As well as not having to adhere to the five principles, appointees are not monitored and an appointeeship is only revoked when concerns are raised by third parties. We think that the same safeguards and monitoring for court-appointed financial deputies, attorneys and appointees should apply given that they may well be undertaking the same role in practice.
2. **Lack of clarity in how both systems will work alongside each other** – if the appointeeship system were to remain outside of the provisions of the Mental Capacity Bill, it is far from clear how the two different systems with

different safeguards and rules would link together and who would have precedence.

Summary

- Bringing appointeeship into the scope of the Bill would help to make sure that vulnerable people are safeguarded against abuse and that appointees act in their best interests
- Such safeguards and principles are particularly important where someone's only income is via benefits as the appointee has control over that person's total income.