

# Making Decisions Alliance

## Submission to the Joint Committee on the Draft Mental Incapacity Bill

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## 1. Summary MDA Response to the Draft Mental Incapacity Bill

1.1 The Making Decisions Alliance (MDA) is a consortium of 28 organisations and groups working with people who may have difficulty making or communicating decisions (see Appendix 6.1; p 30, for our full membership). Our two main aims are:

- To lobby the Government to introduce mental capacity legislation in the Queen's Speech 2003
- To increase awareness of the need for new legislation.

1.2 The MDA is delighted that the Government has published a Mental Incapacity Bill for consultation. After 14 years of Government consultation and the publication of four reports and a draft Bill from the Law Commission, we are very pleased that there are now definite plans to develop a legal framework for decision-making for people who may have difficulties making decisions for themselves. For too long, this has been a fundamental gap in the law.

1.3 The MDA believes that the current law does not provide sufficient protection for those who lack capacity or those who look after them. Currently, the law is confusing and fragmented. The range of people who are let down by the current law is considerable. They include adults with severe learning disabilities, people with autism, people with mental health problems, victims of accident, people who develop brain damage and those who lose mental capacity later in life, including those with dementia.

1.4 The current law is also unclear about the legal rights and obligations of an individual who cares for a person who lacks the capacity to make decisions for themselves. Carers are uncertain about what decisions they can and cannot make.<sup>1</sup> New legislation would give clarity to carers on what they can legally do for the people they look after. Legislation would give carers the legal basis to make informal day-to-day decisions on behalf of someone who lacks capacity provided they exercise their authority in the best interests of that person. Professionals will also be clearer about how to represent the interests of people who lack capacity with whom they are working.

1.5 The current law gives a number of different answers to defining mental capacity. There is no statutory definition of mental capacity. It may not be clear whether an individual lacks capacity in relation to a particular decision. New legislation would ensure that the variety of different tests would be replaced with a single, straightforward statutory definition. This would introduce certainty and clarity. A definition of capacity would relate to a particular decision and would rest on an ability to understand the information relevant to that decision. Legislation should also give people greater rights to have a say in their own lives and to make their own decisions, unless they have been independently assessed as unable to do so.

1.6 The MDA believes that procedures are needed to resolve disputes and difficulties. There is currently no legal mechanism for resolving problems about personal care and welfare. A person who has diminished or fluctuating capacity may not be able to choose a person to make decisions on their behalf. These issues would be addressed in new legislation – for instance, the new Court of Protection would have the power to make decisions about the care or welfare of a person who lacks the capacity. The judicial option would be available where disputes arose and would provide an easy means of appeal if disagreements cannot be resolved.

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<sup>1</sup> In this submission and the appendices, 'carers' is used to refer to friends and relatives who provide unpaid care. Those who are engaged in the provision of care services are referred to variously as 'professionals', 'care workers' or 'paid carers'.

## 1.7 The MDA principles for reform

- People should be treated as individuals and their right to make their own decisions should always be respected. The law should assume that people are capable of making decisions unless the contrary is proved.
- Capacity should be determined in relation to a particular decision at the material time and should avoid generalisations that may unnecessarily restrict a person's right to make their own decisions.
- People who have difficulty making decisions should be supported to make their own decisions rather than having decision-making taken out of their hands.
- Where someone needs support to make a decision or a decision is being made on their behalf, they should have the right to the support of an advocate to help them make the decision and to ensure that they have a say in the decision-making process.

1.8 Although the first three principles are enshrined in the preliminary clauses (2-4), the MDA does not feel that the Bill currently contains sufficient mechanisms to ensure that these principles are implemented in practice. This is why we are continuing to press for the inclusion of advocacy and advance statements on the face of the Bill and for additional safeguards in relation to the General Authority (see Sections 5b: pp 20 – 24; 5a: pp 18 – 19; and 4.5: pp 8 – 12 respectively, for full responses).

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## 2. Summary of MDA key recommendations for additions and amendments to the Bill

### 2.1 General

- Name of the Bill should be amended to the **Mental Capacity Bill** to reflect the presumption of capacity enshrined in the Bill
- Presumption of capacity should be moved from clause 3 to clause 1 to reflect and promote its fundamental importance.

### 2.2 General Authority

- General Authority should be explicitly subject to the presumption of capacity
- Clause 6, subsection (1) - 'or person reasonably believes that P lacks' to be deleted
- Consent in medical treatment to be removed from the remit of the General Authority
- Significant decisions removed from the remit of the General Authority, unless justified by immediate necessity
- The General Authority should not be assumed but should instead be triggered, for instance a case conference involving all those concerned with a person's care
- The continuing need to act under the General Authority should be reviewed as part of a person's care programme.

### 2.3 Restraint

- Throughout the Bill, restraint should always be justified only if risk of serious harm is immediate (for example clause 7 (General Authority), clause 10 (LPAs)).

### 2.4 Monitoring

- The Bill should create a duty on local authorities to intervene in cases of suspected abuse, including abuse of the General Authority.

### 2.5 Lasting Powers of Attorney (LPAs)

- Clarity on the parameters for LPAs is needed, comparable to that given on the powers of Deputies in clauses 17 and 18
- LPAs must be established within a clear hierarchy of decisions, in which they should 'trump' other powers with the exception of Advance Directives and decisions of the Court of Protection.

### 2.6 Deputies

- Deputies should be made subject to Advance Decisions.

### 2.7 Court of Protection

- Court of Protection should be required to investigate potential conflicts of interest on appointment of Deputies and on the activation of LPAs
- The Court of Protection should be made accessible to adults with impaired capacity
- Legal aid and other financial assistance should be given to all such adults to support applications to the Court.

### 2.8 Advocacy

- There should be a legal right to access independent advocacy when formal powers are applied for, and a subsequent duty on the Secretary of State to provide sufficient advocacy services to deliver this
- Advocacy support should be available if required when significant or life-changing decisions are contemplated under any of the powers established in the Bill
- Individuals without other formal or informal networks of support should be prioritised for advocacy support.

### 2.9 Other significant omissions

- Appointeeship system to be regulated under the Mental Incapacity Bill, with appointees subject to the same list of duties as other substitute decision-makers
- Advance statements to have superior status to other expressions of 'wishes and feelings'
- Assessment should defined within the Bill.

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## 3. MDA Response to Specific Committee Questions

### 3.1 *Was the consultation process preceding the publication of the draft Bill adequate and effective?*

**Yes.** As noted above, the proposals set out in the Bill have been the subject of extensive consultation for 14 years. However, the MDA has a particular concern relating to the General Authority (clauses 6 and 7), which during the consultation process was presented as a mechanism for carers to take day-to-day decisions on behalf of a person who lacks capacity. The General Authority as presented in the Bill is far broader and the MDA has several suggestions as to additional safeguards to protect the rights of people with impaired capacity from abuse under the General Authority. See pages 8-12 of this response for the MDA commentary on the General Authority.

### 3.2 *Are the objectives of the draft Bill clear and appropriate?*

**In parts.** The draft Bill is clearly intended to put in place a legal framework to allow decisions to be taken for people who lack capacity. Only in clause 2, subsection (3) does the Bill refer to the need for supported decision-making. The MDA is concerned that the emphasis of the draft Bill is about making decisions on behalf of people who lack capacity rather than maximising decision-making abilities as set out in clause 3 of the Bill. This

misplaced emphasis is reflected in the current title, which the MDA wishes to see changed to the **Mental Capacity Bill** to reflect and reinforce the presumption of capacity.

*3.3 Does the draft Bill meet these objectives adequately?*

**In parts.** In general terms, the mechanisms set out by the Bill meet the objective of allowing people to plan for future incapacity – the major exception to this being the omission of advance statements. The objective of giving carers the right to have a say in decisions made about a person they care for is also met effectively (clause 4). The General Authority and the various formal mechanisms will allow carers and care workers to operate within a comprehensive legal framework. However, our major concern lies with people born with impaired capacity and those who lose capacity without making provisions for this. We feel that this group will not in practice be fully empowered by the Bill to be involved in decisions taken about them or to maximise their ability to make their own decisions.

*3.4 Might lessons be learned from similar legislation already implemented in Scotland or elsewhere?*

**Yes.** Section 1, clause 2 from the Adults with Incapacity (Scotland) Act 2000 would strengthen the protection for adults with impaired capacity in the initial clauses of the English Bill:

*“There shall be no intervention in the affairs of an adult unless the person responsible for authorising or affecting the intervention is satisfied that the intervention will benefit the adult and that such benefit cannot reasonably be achieved without the intervention”.* Please see Appendix 6.3: pp 36 – 39, for a detailed MDA commentary on similar legislation in other countries

*3.5 Are there relevant issues not covered by the draft Bill which it should have addressed?*

The MDA believes that the following issues should have been addressed by the Bill:

- Advance Statements – see Section 5a: pp 18 – 19.
- Advocacy – see Section 5b: pp 20 – 24.
- Appointeeship – see Section 5c: pp 25 – 26.
- Assessment – see Section 5d: pp 27 – 29.
- Public Law Protection for Those at Risk – see Section 5e: p30.

*3.6 In what other ways might the draft Bill be improved?*

The MDA key recommendations for additions and amendments to the Bill are given and summarised in Section 2: pp 3 – 4. All recommendations are **in bold** in the text that follows.

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## 4. MDA Commentary Draft Mental Incapacity Bill

### Clauses 1-5 – Key Principles

#### 4.1 Approach to Capacity

The MDA supports the Government's proposals to create a more coherent approach to mental capacity and is supportive of the new test of capacity, the presumption against lack of capacity and the need for the minimal intervention in people's lives.

4.1.1 A functional approach to capacity will mean that incapacity will be considered in relation to a particular decision or set of decisions, rather than based on a diagnosis of an individual's condition. It is also necessary to take account of the particular needs and values of people from different minority ethnic communities or faith groups.

4.1.2 The Bill should state that religious and cultural factors should be taken into account when making decisions on capacity to consent. Capacity is seldom entirely present or entirely absent. The MDA believes that the intention behind legislation should be to maximise each individual's capacity for decision-making. The emphasis should be on how decisions are made, how the consequences are communicated and how the facts can be broken down to aid decision-making.

4.1.3 Given that the emphasis in the Bill should be on maximising decision-making, **the MDA recommends that the presumption against lack of capacity should be set out in clause 1 of the Bill. The Bill should also be named the Mental Capacity rather than the Mental Incapacity Bill.**

#### 4.2 Definition of Capacity

The definition of capacity in the draft Mental Incapacity Bill drops the diagnostic threshold that was set out in the Law Commission's definition of capacity, namely a 'disability or disorder of the mind or brain...which results in the disturbance of mental functioning.' The MDA supports this approach. This is because we had reservations about the potential for this new legislation to adopt the definitions set out in the Mental Health Act, particular because 'mental disorder' might wrongly be equated with the criteria for compulsion. In addition, it would risk stigmatising or prejudicing people who need support with decision-making. Organisations representing people with a learning disability and older people felt that the term mental disorder would be misleading and not adequately describe their client group. Removing the diagnostic criteria will also mean that all the conditions that result in incapacity would be included within the new definition and ensure that a person will not need to have a prior diagnosis in order to have impaired capacity.

#### 4.3 Inability to make decisions

We are concerned that by not expressly stating that clause 2 relates to the 'material time' the decision is to be made, the functional approach to capacity is watered down. **We therefore think that clause 2 should include the term 'at the material time'**. This would reinforce the functional approach to defining capacity and that the approach is decision-specific. It will also emphasise that giving and obtaining consent is a process and not a one-off event.

4.3.1 Clause 2, subsection (1)(d) envisages that there will be cases in which a person cannot communicate any decision. The clause implies that all forms of communication should first be considered, including sign language or any other means. We agree with this approach but **we think the Bill must make supporting communication an explicit requirement**. This is because an apparent lack of capacity may be, in fact, the result of communication difficulties rather than incapacity. Therefore, the MDA wants legislation to

place an express duty on assessors to support a person to communicate their decision before a finding of incapacity is made. **Mental capacity legislation should create an obligation on assessors to provide more information in order to empower people to make decisions that they are capable of making.** Indeed, provision of information is central to the consent process. People should not be disadvantaged by lack of information or support to make their own decisions or indeed a shortage in resources that prevents this information from otherwise being made available. The parameters around the meaning of ‘all practical steps’ to support decision-making (clause 2, subsection 3) will need to be clearly established.

4.3.2 Health and social care professionals often need help from those in day-to-day contact with the person who can identify and sometimes meet their communication needs. In some cases, specialist staff such as speech therapists may need to be brought in to assist with verbal and non-verbal forms of communication. If at all possible, the person should be assisted to make and communicate their own decision by providing information in non-verbal ways if appropriate. **In addition to clause 2, subsection (1)(d), the MDA believes that clause 2, subsection (3) should state that ‘a person should not be treated as unable to make a decision or unable to communicate his decision unless all practical steps to help him to do so and to assist and support communication have been taken without success.’** Moreover, it should build on the Law Commission’s wording which states that ‘a person should not be regarded as unable to understand information if he is able to understand a simple explanation of that information in broad terms and in simple language’.

4.3.3 The proposed Code of Practice on assessing capacity should promote a person-centred approach to decision-making, which considers how a person communicates, how a decision is made and how can the consequences best be communicated to that individual. It should also consider how a person could be involved where some of the decision-making needs to be done by others. This Code of Practice should also provide guidance on methods of assessment and how different forms of communication, including use of simple language, pictures, audiotape and communication aids, local advocacy support and advance statements, can help decision-making. In other cases, new technology can be used to make the decision and its consequences more visible. The Police Service Guide to Vulnerable Witnesses provides a good example of a person-centred approach to communication with people with learning disabilities.

4.3.4 The MDA supports the recommendation that a decision should not be regarded as invalid because it appears to be an unwise or irrational decision. We remain concerned that it might provoke a more detailed examination of whether an individual has the capacity to make a decision. Many people make unwise decisions but that should not make those decisions invalid.

#### **4.4 Best interests**

The MDA supports the best interests criteria set out in clause 4. The most important factor is the ascertainable past and present wishes and feelings of the person concerned; and the need to permit and encourage the individual to participate as fully as possible in anything done, or any decision, affecting him or her. We support the decision to extend the factors proposed by the Law Commission, to include consideration of whether there is a reasonable expectation of the person recovering capacity to make the decision in the foreseeable future. The MDA understands that it may not be practicable to consult with all family carers, particularly in cases of distant relatives who have not been involved in decision-making, as this may not be regarded as reasonable (clause 4, subsection (d)). However, there should be an expectation on professionals to make proper enquiries to identify all interested parties. Moreover, we are concerned that the views of others may not need to be sought if it is not ‘appropriate’ to consult them (clause 4, subsection (d)).

This may lead to subjective judgements about the appropriateness of a carer to represent a person's views or to challenge the decision of professionals.

4.4.1 We are very concerned about the wording in clause 4, subsection (3)(b) which states that the duty extends to circumstances in which it is 'reasonably believed' that someone lacks capacity. This would allow some people, presumably acting under a General Authority to act, to impose their own views of what is likely to be in the incapacitated person's best interests, rather than effectively applying the best interest criteria, or to impose their views without first taking all practical steps to enable a person to make their own decision.

4.4.2 In relation to decisions made on behalf of a person without capacity, **we support the Law Society's recommendation that decisions must be made in their 'best personal interests'**. This emphasis would stress that priority should be given to identifying those issues most relevant to the individual, rather than to the decision-maker or other people. Without such emphasis there is a risk that the individual's own best interests will not in fact be the paramount consideration.

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#### 4.5 Clauses 6 -7 – The General Authority

The General Authority will give protection to much informal substitute decision-making that currently takes place outside any formal legal framework. This will give a legal context for all day-to-day decisions that are made, such as paying bills and giving medication. In this sense, it codifies the existing legal situation as established in case law.

4.5.1 The MDA acknowledges the need in certain situations to empower carers to take effective decisions on behalf of people with impaired capacity. The General Authority serves this purpose well, and the restrictions set out in clause 7 should prevent the worst abuses of its powers. However, the MDA is concerned that in circumstances where the interests of carers and those they care for are not aligned, the General Authority still offers too little protection for the rights of people who may have difficulty making or communicating decisions.

4.5.2 In these circumstances, the General Authority may tend to undermine the presumption of capacity. With no counterbalance or system of protection for people who may lose the ability to make their own decisions under the General Authority, this may in practice lead to a presumption of incapacity. **To prevent this, the MDA believes that the General Authority should not be assumed but should instead be triggered, for instance at a case conference involving all those concerned with a person's care.** At this point, all the principles of the Bill set out in clauses 2-4, not least the presumption of capacity and the need to take all practicable steps to support decision-making, should be applied. **The decision that the General Authority may be applied to the individual in question should be recorded; and all those using the General Authority should be able to justify its use, if challenged or investigated.**

4.5.3 **The continuing need to act under the General Authority should also be reviewed as part of a person's care programme.** By this means, decision-making mechanisms would be integrated into a person's overall care plan (through the care programme approach, person-centred planning or single assessment process as relevant), reducing the need for additional bureaucratic processes. However, it is important to note that adults with impaired capacity who are not in contact with services will not be able to benefit from this safeguard.



4.5.4 As it stands, the General Authority will enable people to make decisions for others if the person reasonably believes that the other person, P, lacks capacity. We agree that the General Authority should be subject to best interests (clause 6, subsection (6)) but this assumes that a person lacks capacity and that a decision needs to be taken in their best interests. **The MDA argues that the General Authority to act should also expressly state that it is subject to clause 3, the presumption against lack of capacity as well as the best interest criteria in clause 4.**

4.5.5 The Bill should also strengthen the expectation on carers and care workers to take all practical steps to support people to make decisions that they are capable of making, before taking decisions on their behalf. The starting point for carers and care workers should be on maximising decision-making and supported decision-making rather than making a substitute decision under a General Authority. In line with our comments in relation to the 'best interest' criteria, the current wording, 'reasonable belief', runs the risk of allowing the person acting under a General Authority to circumvent the requirement to assess capacity before making decisions on another person's behalf. **The MDA therefore recommends that 'or person reasonably believes that P lacks' in clause 6, subsection (1) is removed from the Bill.**

4.5.6 The MDA's concerns in relation to clause 6 highlights the need for people who have difficulties making or communicating decisions to be able to access support from independent advocates. Without the involvement of an advocate, and with no requirement for capacity to be independently assessed, the General Authority gives statutory recognition to a 'closed relationship' that will not be monitored by any third party, and may therefore be open to abuse. The General Authority was initially presented to stakeholders as a mechanism by which 'day to day' decisions could be taken by carers, without the need to resort to formal processes, so minimising bureaucracy. Yet in the draft Bill, no limitation is placed on the types of decision that can be taken under the General Authority, other than that in all the circumstances it is reasonable. The MDA is concerned that the Bill makes no distinction between a day-to-day decision taken by a parent or carer and bigger one-off decisions such as medical decisions or where a person lives, taken in the best interests of another individual who lacks capacity.

**4.5.7 We therefore recommend that the Bill removes some decisions from the scope of the General Authority. The MDA believes that the Bill should make it explicit that the General Authority does not authorise a carer or professional to make all decisions on medical treatment, in particular to consent to treatment.** The carers' ability to make all decisions on medical treatment should be restricted to the administration of prescribed medication and decisions about whether to provide non-prescriptive medication such as pain killers.

**4.5.8 Other medical treatment decisions should be made by the appropriate health professional under the General Authority but subject to additional safeguards.** The safeguards would include an obligation for the health professional to carry out an assessment which confirms that the person concerned is without capacity to consent, that it is in the best interests of the person concerned for the treatment to be carried out and that the person has the support of an advocate to assist the person to participate in the decision as fully as possible.

**4.5.9 Where it is found that a patient lacks the capacity to make a decision, the health professional, in consultation with the full clinical team and the patient's family, friends and carers, must make a decision in the patient's best interests.** Every effort should be made to reach a consensus between relatives, carers and health professionals. This would include a case conference bringing together all interested parties, which would ensure that all those who know the person would have the chance to

speak for their interests. Where there is a dispute as to whether these interests can be properly defined, the case should be referred to another health professional that is not part of the treating team for a second opinion. In cases where a health professional's view is substantively challenged and agreement cannot be reached it may, as a matter of last resort, be necessary to refer the case to the Court of Protection. These safeguards should be made clear on the face of the Bill. This would strengthen carers' and carer workers' rights through the requirement on health professionals to consult with them before making a decision on a person's best interests.

**4.5.10 The MDA also proposes that other decisions that could potentially have a significant impact on the individual or amount to a significant change in circumstances should not generally be made under a General Authority.** This would cover decisions such as a change in where someone will live, including following hospital discharge, and major financial decisions. Where a person is in contact with services, these decisions should already be taken as part of their care planning process. The new legislation would simply require carers and care workers to obtain a single order from the Court of Protection to legitimately make these decisions.

4.5.11 A significant change in circumstances would need to be assessed on a case-by-case basis, but would include a change of carers, such as a move away from a residential home to supported living. We, therefore, consider that decisions about where someone lives should be subject to similar safeguards as medical treatment, including ensuring that where possible there is a case conference about the proposed change. The MDA would argue that a decision taken under the General Authority in those circumstances would not be reasonable under clause 6, subsection (1)(b). It should instead be subject to the approval of the Court of Protection if an attorney or Deputy had not been appointed. The exception to this would be if a decision had to be made urgently or in an emergency, provided the decision was made for the benefit of the person and in their personal best interests. Similarly, other important decisions, for instance around childcare, should also not generally be taken under the General Authority.

4.5.12 The universal scope of the General Authority also requires a substantial public information campaign to inform all current and future carers of their rights and responsibilities under this legislation. The MDA is concerned that the subtle checks and balances set out in part 1 of the Bill will be lost on many carers if they are not given full guidance and support. The MDA is pleased that a separate Code of Practice will be developed to offer carers guidance in this area. It is important that carers are briefed on their responsibilities and that these responsibilities should only be retained if appropriately discharged.

4.5.13 Practical examples to illustrate the concept of reasonableness might be a useful method of conveying this both to carers and people who may have difficulties making decisions for themselves. **The MDA proposes a duty on the Lord Chancellor or his successor to provide all information to stakeholders on the Bill that he feels necessary, in addition to the requirement to publish Codes of Practice (clause 30).** Supplementary to this, **clause 30, subsection (7)(b) should be amended to that the Codes of Practice must be taken into account where relevant in court cases, particularly in the Court of Protection.** As stated above, carers should be able to demonstrate to the Court or any other investigating agency that their application of the General Authority has conformed to the principles set out in the legislation. This may involve the need to keep notes of why a particular decision was taken, or what steps were taken to enhance the ability to make decisions of a person with impaired capacity.

4.5.14 The MDA supports the concept of the General Authority to act reasonably – the reasonableness relating to the person in that situation. In cases in which the act involves

expenditure, it should be lawful to apply that person's money where the purchase can reasonably be held to be for the benefit of that person. This should be an additional requirement on the face of the Bill. For example, using monies in order to take someone on holiday may be of benefit for the individual but using that money to buy a car for the carer may not be viewed as delivering a direct benefit for the individual.

#### 4.5.15 Restrictions on the General Authority

The MDA supports the proposals in clause 7 that ensure that a person will not be forced to comply with a proposed action to which he or she resists unless it is essential to prevent a substantial risk of significant harm to the person concerned. **However, we believe that this power should be based on an assessment of immediate harm to justify its use.** It will clarify how carers will be accountable and provide protection from abuse where the confinement is justified. We prefer the term used in the Bill 'resists' to the Law Commission's wording 'objects'. An individual may not actively object to confinement, particularly if the person has communication difficulties, but may still resist the proposed course of action. **The Bill should also place a requirement on local authorities to intervene in the General Authority where they do not think that it is being used in the best interest of the individual and to provide a check in cases where a person is detained in order to avert a substantial risk of significant harm to himself, wherever that person lives.**

4.5.16 We agree that a General Authority should not be able to overrule a power of attorney or a decision made by a Deputy appointed by the court. However the borderline between the General Authority and the Deputy system is difficult to draw. e.g. do the informal arrangements cover all medical matters until the decision is challenged? At what point should a matter rest with the court rather than a General Authority to act?

4.5.17 **The MDA is generally inclined towards reserving to the courts decisions on withdraw of medical treatment, such as in cases involving PVS, and other forms of medical treatment such as sterilisation.** This should be made clear on the face of the Bill.

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## Clauses 8-13 – Lasting Powers of Attorney (LPAs)

### 4.6 LPAs - Overall recommendations

One of the major attractions of a Lasting Power of Attorney (LPA) is that it involves the Donor, whilst he or she has capacity, in nominating the person they would wish to make decisions about personal welfare and property and financial affairs. As with all the decision-making powers included in this draft Bill, **the MDA seeks clarification of the parameters of the LPA remit.** We would want these at least covering the same remit as that proposed for the Court of Protection and set out in clauses 17 and 18. **In addition, the Court of Protection / Public Guardian should be required to investigate potential conflicts of interest when LPAs are registered.**

4.6.1 The current approach to informing third parties that an application for an Enduring Power of Attorney (EPA) has been made can be administratively complex and not necessarily wholly reliable. We have some sympathy with the proposal to reduce the numbers of people who are notified, including the limiting of notifications to only the Donor and Donee(s). An important issue here, however, lies in ensuring that the Donor is not subject to any undue influence when creating the LPA. Unless a third party – i.e. someone other than the Donor and Donee(s) – is required to be notified by the Public Guardian that an application has been received, the opportunity would exist for Donee(s) to insist to the Donor that no-one else is informed of the application. **The MDA feels that provision**

**should be made for at least one other party to be notified of the application, beyond the Donor, Donee(s) and the person certificating the Donor's mental capacity.** We suggest that the name(s) of this nominated party is not disclosed to the Donee(s), to further avoid issues of undue influence. Where the application is made by the Donee, we suggest that regulations set out who can and cannot be included as the third party (for example, excluding the Donee(s) partner, children or other immediate family).

4.6.2 Information and training will be needed for Donees to understand the powers that they hold, and the responsibilities placed on them. In particular, this will be needed in respect of understanding that their powers under LPA arrangements are only effective at such times as they are active. At other times, the Donor will be in control of decisions in those areas of life otherwise covered by the relevant LPA(s). The MDA welcomes this principle. **Those holding LPAs should at all times be subject to the Best Interests principle, even when the Donor has capacity.**

4.6.3 We agree with the proposals that a Donor can choose to give to the Donee the power to refuse consent to life-sustaining treatment, and to give or refuse consent to treatment to which an existing advance decision relates. However, we suggest that if an LPA specifies that it is to cover all health and personal welfare decisions, it should be assumed this includes these decisions and the provisions relating to advance decisions; and that the relevant application form should make this clear.

4.6.4 The MDA supports the proposals in clause 10 that the Donee(s) of an LPA will not have the power to force the Donor to comply with a proposed action to which he or she resists. However, we are concerned with the wording of the proviso, 'unless it is essential to prevent a substantial risk of significant harm to the person concerned'. As with our concerns about the General Authority, **the MDA believes this should be changed to 'unless it is essential to prevent an immediate risk of significant harm to the person concerned'.**

4.6.5 It will be critical for Donors to understand that, at times when they have regained capacity, they have the power to revoke a registered LPA. It will also be essential that they are supported to be able to act on this power. This is a specific area where access to advocacy will clearly be of major benefit to individuals.

4.6.6 The proposed LPA arrangements suggest a welcome flexibility in how decisions are made during times of fluctuating or reducing capacity. **The MDA seeks, however, clarification on whether the intention is that those holding a personal welfare LPA cannot take decisions on health matters at times when 'P' has capacity, and whether this would also apply to other, 'personal welfare', aspects held within the LPA.**

4.6.7 **We would also propose the following hierarchy of decision-making**

- If a decision is within the scope of how an individual LPA (or Court-appointed Deputy) has been set up, the LPA (or Deputy) would 'outrank' the General Authority
- If a decision is within the scope of how an individual LPA has been set up, the LPA would 'outrank' a Deputy
- The Court may direct an LPA on decisions on which the LPA has the power to act if P lacks capacity to make those decisions; and can give the consent/authorisation to act which the LPA Donee would have to obtain from P if he had capacity to give it.

4.6.8 Fundamental to this 'hierarchy' is the understanding that it is based on the principles within the draft Bill. In particular, that these powers to act on behalf of 'P' only exist whilst

the person lacks capacity. MDA believes this critical issue will require training, advice and information for all parties.

#### 4.6.9 Capacity in the context of LPAs

The Donor must have capacity when creating the LPA. This is to be assessed by 'a person of a prescribed description' (but this person cannot be a Donee), and a certificate to that effect must accompany the application. In making the application to register the LPA, the Donor must sign to say the prescribed information has been read to him (or he has read it), and that he intends the authority conferred under the LPA to make decisions on his behalf in circumstances where he no longer has capacity.

4.6.10 The MDA is concerned that 'certification' seems to go against the principle, set out in clause 3 of the draft Bill, in which the starting point is always that capacity is assumed to exist. We make a specific recommendation on this matter in the separate section in this paper on Assessment. Our view at present is that, if any such requirement is to be established, this should apply equally to Donors and Donees – not least given that one of the 'qualifying' factors for Donees is that they have mental capacity. (See also 5d.11, pp 28 – 29)

#### 4.6.11 Relationship to Enduring Powers of Attorney

These proposals significantly reform existing arrangements for Enduring Powers of Attorneys in respect of notifying named parties. Currently, a comparatively long list of whole blood and half blood relatives must be informed (where these exist) that an application has been made. It is those 'third parties' who are most likely to lodge an objection over the creation of particular EPAs. As noted above (4.6.1), the MDA believes that a requirement to notify at least one party outside of the LPA arrangement should be retained.

4.6.12 One of the major concerns with current Enduring Power of Attorney (EPA) arrangements lies in the numbers, it is believed, of people acting under EPAs that have not been registered. Many of those holding an EPA for another person appear not to understand that registration is necessary. It will be important for Donees to be able to produce evidence that they hold those powers as near to the material time as possible and for all parties to understand that those powers are only held once registered.

#### 4.6.13 LPA – personal welfare

Although an LPA must be registered whilst the Donor has capacity, it is only effective in terms of personal welfare decisions when the Donor lacks capacity. For people with fluctuating conditions this will be extremely important, as it will mean that decisions about health care should not be taken when the person has the capacity to make their own decisions. It will therefore be essential that guidance and training is in place, especially for Donees of LPAs, in order that they are able to make the distinction; and for health and social care professionals to understand that the creation of a personal welfare LPA does not mean that Donees will necessarily have the authority always to make those decisions. In particular, LPA Donees will need to have sufficient understanding to be able accurately to judge when the Donor has regained capacity in respect of those particular personal welfare questions. Nonetheless, the MDA welcomes the principle that personal welfare LPAs only take effect if at the material time the person lacks capacity, as this illustrates in practical terms that a lack of capacity is not always a permanent situation.

4.6.14 A personal welfare LPA can be set up to include the power to refuse consent to life-sustaining treatment, and to give this explicit authority to the Donee. We support this proposal. With respect to advance decisions, a personal welfare LPA can also be set up such that the Donee can give or refuse consent to the treatment to which an existing advance decision relates. We also agree with this proposal, but suggest that if an LPA

specifies that it is to cover all health and personal welfare decisions, it should be assumed this includes these decisions and the provisions relating to advance decisions, and that the relevant application forms make this clear.

#### 4.6.15 LPA – property and financial affairs

The registration of a property and financial affairs LPA would create a situation where the Donee can act as an ‘ordinary’ power of attorney even when the Donor still has capacity; but, unlike existing arrangements, it will also continue after the person has lost capacity. This suggests that this proposed LPA would mirror both the existing ordinary Powers of Attorney (which tend to relate to a specified, one-off financial event) and those for Enduring Powers of Attorney, whereby once registered a Donee has ongoing authority over the person’s money irrespective of whether or not their capacity fluctuates. It will be important here for Donors to understand that, at times when they have regained capacity, they have the power to revoke an LPA and could choose to do so in respect of financial matters. It will also be essential that they are supported to be able to act on this power.

4.6.16 Banks and other financial institutions may find it easier to know that, once a financial affairs LPA has been registered, they will be dealing consistently with the Donee(s) rather than dealing with the Donor some of the time and the rest of the time with the Donee(s) – especially as it is unlikely they will have sufficient expertise to be able to ascertain whether or not a Donor has capacity at the material time. This has been the arrangement with regards to EPAs for many years, and does not appear to have caused significant problems. Nonetheless it is not consistent with the overall notion of incapacity as a situation that fluctuates for some people.

4.6.17 **The MDA suggests that further consideration be given as to how Donors might regain control over their finances in practical terms during times of capacity other than by revoking the relevant LPA.** Further advice may be needed to banks and other financial institutions if it is possible that they may deal with the Donor of an LPA that is registered for financial affairs at times when the Donor has capacity, and with the Donee(s) at other times. Support to Donors to supervise Donee(s) during times of capacity will also be essential. The MDA believes this would also form an important part of advocacy support.

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### **4.7 Clauses 14-22 – Powers of the Court / Court-Appointed Deputies**

Court Appointed Deputies will replace the current receivership system. As with LPAs, Deputies will be able to take decisions, only if so appointed by the Court of Protection, across the full range of financial, health and welfare issues. Deputies can be appointed to make decisions on one or more strand of decision-making. Additionally, if a trust corporation is appointed Deputy, it can only be in respect of property and affairs. The court will be able to appoint more than one Deputy to act on behalf of an individual who lacks capacity.

4.7.1 The MDA welcomes the extension of powers for Deputies to include personal welfare and property and affairs. We acknowledge the need for this set-up should the person be born with impaired capacity, or lose their capacity without having made previous arrangements to nominate an LPA. However, there need to be full checks and balances to ensure that decisions made by Deputies on behalf of people who lack capacity are in their best interests. Whilst we welcome the restrictions on Deputies set out in clause 20, we feel that they does not go far enough in safeguarding the rights of people who lack the capacity.

4.7.2 We are concerned that the Court of Protection should only appoint a Deputy when an independent assessment of capacity to take a particular decision has been made. Also, the appointment of a Deputy is a key moment when we believe a right to access independent advocacy should be triggered. This also highlights the need for people who have difficulties making or communicating decisions to be able to access support from independent advocates. Without the involvement of an independent third party, assumptions may be inadvertently made about the capacity of that person.

#### 4.7.3 Restrictions on Deputies

We welcome the restrictions laid out in clause 20, particularly those relating to settling property or the execution of a will. However, we feel that there needs to be further restrictions. **The court should be given the power to investigate any conflict of interest, whether professional or personal, before an application for a Deputy is approved.** This will ensure that the applicant for Deputy is a suitable candidate. **Furthermore, the court needs to be given powers to make checks about the competency or capacity of the applicant to carry their functions as a Deputy** – e.g. the Court may decide that a person who is already a Deputy for a number of people may be incapable of taking on additional Deputy responsibilities.

4.7.4 These checks should include liaising with the Criminal Records Bureau (CRB) and local authorities to ensure that the applicant is not on any statutory lists or registers that preclude people from working with vulnerable adults. **Finally, and unlike the MDA's position on LPAs, we do not believe that Deputies should always be able to give consent to the withdrawal of treatment. Rather, we prefer a requirement for a single order of the Court of Protection where circumstances permit.**

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### 4.8 Clauses 23-29, clause 32 – Advance Decisions

The MDA strongly supports the inclusion of Advance Directives to refuse treatment in the draft Bill. This will clarify an existing area of common case law, and will enable an individual's expressed views, regarding withholding or withdrawing of treatment, to be adhered to even when the person concerned has lost capacity. We support the tests of validity and applicability that are detailed in clause 25 and feel they will provide considerable safeguards to prevent advance directives being abused. We particularly welcome the inclusion of clause 32, which will make it a criminal offence, punishable by imprisonment or a fine, to conceal or destroy another person's advance decision as it will validate and strengthen the power and influence of the advance decision.

4.8.1 The MDA welcomes the regulations that require both those acting under the powers of the General Authority and the 'Welfare' Lasting Power of Attorney to be subject to clauses 23 to 25 (advance decisions to refuse treatment). **The MDA, however, feels it is an omission for the Bill not to require court appointed Deputies to also be subject to clauses 23 to 25.** This is particularly important because currently Deputies will be given the power to give or refuse consent to the carrying out or continuation of a treatment. This will provide a legal loophole that could be exploited in order to override a person's advance decision.

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### 4.9 Clauses 34-46 – The Court of Protection

The MDA supports the principle of a unified Court of Protection with High Court status, and the provisions for it to have a regional presence. The MDA welcomes the provision for the Court to make single orders on important decisions. However, the MDA would be concerned if the costs of such orders were so high that it would act as a disincentive. In terms of other costs that might be incurred when making an application with the Court of

Protection, **the MDA seeks an assurance that people who lack the capacity can apply for legal aid to cover their legal costs.** All Court of Protection judges and staff will also need to have detailed training to fully understand the impact of this new legislation. Resources will also need to be found to secure training for Court judges and employees on the needs of the various client groups they will be dealing with.

4.9.1 The Court of Protection must be fully accessible to both carers and adults with impaired capacity. The accessibility of the Court, particularly in relation to single orders, will be particularly important if the Committee accepts the MDA recommendation that certain decisions should be removed from the remit of the General Authority. **Finally, the MDA would like to seek an assurance that the Court of Protection procedures will apply the *Speaking up for Justice* measures, which were set up by the *Youth and Justice Criminal Act 1999*, when necessary.**

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#### **4.10 Clauses 47-49 – The Public Guardian / Lord Chancellor’s Visitors**

The MDA has a general concern that the implementation of any future Mental Incapacity Act will not be effectively monitored. **Our recommendation is that the Public Guardian / Lord Chancellor’s Visitors randomly inspect a given percentage of carers holding formal substitute decision-making powers each year, and then report on the findings of these inspections to Parliament.** Allied to our proposed duty on the Lord Chancellor to provide information as requested, this would increase the likelihood that the principles of the legislation would be respected in practice by carers and care workers.

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## 5a - Omissions from the Bill – Advance Statements

The MDA suggests that the Bill should enshrine in law a person's right to make an advance statement. A person should be able to specify their wishes and plans in advance in case they become unable to make decisions for themselves.

5a.1 An advance statement is a declaration that an adult gives about the care and support they would wish to receive. One of the types of statement that can be given is an advance directive where an adult refuses in advance a specific medical treatment or procedure. At present, this is the only form of advance statement that is legally binding on professionals, as established through case law. Advance directives are also included on the face of the draft Bill.

5a.2 Advance statements and advance directives provide the opportunity for adults with capacity to state their wishes and plans in advance, in case in the future they become temporarily or permanently unable to make decisions or communicate their wishes. Advance statements also protect the principle of consent and ensure that crucial life decisions are not reliant upon the assumptions of professionals involved, particularly with regards to decisions about quality of life. This is why the MDA believes that advance statements should also appear on the face of this Bill.

5a.3 Advance statements 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

- whom they would nominate as a 'nominated person' in future Mental Health legislation.

Furthermore, advance statements provide both additional safeguards and direction for a person acting for someone who has lost capacity.

5a.4 **The MDA proposes a requirement for a person acting under a General Authority, 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.** In Clause 2, subsection (2) the existence of an advance statement would provide guidance around the "practicable steps" to assist those helping someone who is unable to make decisions. In Clause 4, the existence of an advance statement would give a clear indication of all those involved in making decisions on someone else's behalf of the person's 'best interest', especially as an indication of the person's "past and present wishes" (Clause 4, subsection (2)(c)(i)).

5a.5 Advance statements should be subject to the same conditions as advance directives, namely that advance statements meet the criteria of **validity** and **applicability**, and are deemed to be **reasonable** and in the person's **best interests**. **In addition, clause 32, which relates to destroying or concealing an advance decision, could also be extended to include advance statements.**

5a.6 The Explanatory Notes published alongside the draft Bill state that 'Many forms of advance statement will be relevant as the 'past wishes of P' mentioned in the best interests checklist in clause 4.' However, failure to state the legal position of an advance statement on the face of the Bill will undermine its value as a mechanism to plan for impaired capacity.

5a.7 The value of an advance statement is that it is an expression of the individual's views and may be the only means by which the person can communicate this in the future. This gives it, as a document, substantial importance and as such there should be clear guidance about how it fits within the wider powers within the Bill

5a.8 It is possible to legislate for advance statements, indeed it is required, in order to give clear legal guidance on their legal validity, the necessity for and boundaries to which professionals are obliged to follow their requests and the circumstances in which they can be overridden. Furthermore, as the Bill stands, an advance statement will not have the same legal status or validity as an advance directive and thus will not receive the same protection from abuse, undue influence when completed, or destruction.

5a.9 Advance statements would give effect to a person's wishes and act as a safeguard in relation to the other formal powers under the Bill. Consultation of any available record of an advance statement would therefore be one of the 'practicable steps' that must be taken (clause 2(3)) before an assessment of the person's capacity is undertaken. This would reassure people that their views and wishes will be considered irrespective of any future incapacity and could offer concrete protection from neglect. In specific circumstances, it would be a positive opportunity for an individual to record their wish for them to receive life-sustaining treatment.

5a.10 In complex situations, advance statements could act as a vital communication tool, clarifying and informing decisions making for professionals and carers. Around the time of completion of an advance statement they will facilitate further discussion and future planning. This will be beneficial in later decision-making, potentially assisting in avoiding conflict and disputes. It would also prevent the lack of information or representation that can result in decisions being made that are contrary to the person's views or culture.

5a.11 **Advance statements could indicate whom the individual would and would not consider reasonable to act under the General Authority, should they lose capacity at some point in the future.** This would clarify a potential area of conflict and provides a more accessible, less bureaucratic alternative to the 'Welfare' Lasting Power of Attorney. It would act as another process by which an individual's views could be considered; this is particularly important for those who are isolated and do not have someone in their lives who know them well enough to make decisions on their behalf under the powers of the General Authority.

5a.12 It is vital that everyone is aware of the existence of either an advance statement or/and an advance directive. We would hope there would be guidance on the importance of 'registering' them with all the professionals involved, including both the medical and social care team. We suggest that this is clarified in further guidance regarding this area.

## **5b - Omissions from the Bill - Advocacy**

The Making Decisions Alliance believes access to independent advocacy could be a vital mechanism for ensuring the needs and rights of the individual remain at the forefront of this Bill and that its overarching principles are fulfilled. It also strongly believes that access to independent advocacy could help prevent drawn out and distressing disputes and help avoid costly recourse to the Court. **Consequently it believes that Government should take responsibility for providing the resources necessary to ensure that access to independent advocacy is available to those who need it.** Appendix 6.2 details recent Government initiatives that mention advocacy.

### 5b.1 When should independent advocacy support be made available?

Ideally, an individual should have access to independent advocacy whenever they feel they want or need it. However, we appreciate that in a world of limited resources this may not be possible. For the purposes of this Bill, we are particularly concerned that independent advocacy is available in the following situations:-

- When capacity is being assessed in relation to a major life changing decision.
- When a major life changing decision is being made
- When disputes around the above situations arise
- When a court-appointed Deputy is to be appointed, a Lasting Power of Attorney is being set up or activated, or a single order of the Court is being made.

5b.2 In addition, the MDA believes that individuals without other formal or informal networks of support should be prioritised for advocacy support. This should be clarified in a Code of Practice on Advocacy in relation to Mental Incapacity.

### 5b.3 What is advocacy?

There are numerous definitions of advocacy in existence. The Independent Advocacy Consortium defines it as 'taking action to help people to: say what they want; secure their rights; represent their interests; and obtain services they need'.

5b.4 Essentially, advocacy is about empowering people, by enabling them to be more actively involved in the decisions that affect their lives. A good advocate will possess the skills and training not only to help a person speak up for themselves, but also to establish what their preferences are, even when these cannot be communicated in conventional ways. They will also respect the particular needs and values of people from different minority ethnic communities or faith groups. An advocate is not there to express or impose their own views but to act as a facilitator and to support the individual to express themselves. In addition, they should be independent of the organisation that a person is dealing with to avoid potential conflicts of interest.

5b.5 There is a wide range of advocacy models available, including Citizen Advocacy, Peer Advocacy, and paid professional advocacy (see definitions in appendix 6.2: p32, 6.2.3). In some instances a person may need an advocate in relation to a particular decision, while at other times or for other individuals a longer-term relationship is more appropriate. The MDA does not believe that there is only one acceptable model of advocacy. The choice of advocacy used should be based on the individual's own needs and wishes, and take account of what provision is available locally. However, regardless of the chosen model, the independent advocate must be adequately trained for their role.

5b.6 Advocacy is not the only way of ensuring that individuals who may have difficulty making decisions or expressing their views can participate in decision-making. Other support mechanisms such as mediation or interpretation services, service user self-help groups and legal representation at the Court of Protection may also play a valuable role.

However, independent advocacy is an extremely valuable tool in securing an individual's right and preferences.

**5b.7 The potential benefits of Advocacy in the context of mental incapacity legislation**

Ideally an advocate:

- is independent – has no axe to grind, no history, no vested or conflict of interests
- can be a very effective safeguard, flagging up concerns or queries to the appropriate authorities
- understands the abilities of the individual
- is focussed on the needs and views of the individual and ensuring that these are given voice, not the people or institutions around them (person centred)
- is trained not to take a view of their own, only seeking to uncover or communicate the individual's, BUT
- may be able to contribute to the assessment of capacity by highlighting what they know or can glean about the individual's abilities or preferences.

5b.8 An individual may need an independent advocate because of a condition or disability they have, their life experience, their impaired ability to communicate conventionally or some combination of these. Their need may also stem from the type and importance of decision being made: individuals may need assistance to make some types of decision but not others. Even people who are incapable of making a particular decision may be enabled by an independent advocate to express or communicate preferences, which could assist those around them and make them feel sure that they are acting in the best interests of that individual. Such input could also help to develop an individual's capacity to participate in making decisions over time.

5b.9 Alternatively, an individual's life experience (often linked to their experience of how society and institutions have reacted to them and their impairment) may also have an impact on their ability to make certain decisions. An example would include someone who has lived in residential care for all or most of their lives or have lived with family members who have made all the key decisions relating to them. This person may be about to move into independent living and, although their condition may not be directly affecting their mental capacity, they might still need some initial or ongoing support around choices and decisions that affect their lives.

5b.10 Some people may have the ability to make such decisions but may not communicate in conventional ways. There is a risk that people may make inaccurate assumptions about the ability of these individuals to make decisions. Conversely, other people may appear to have highly developed communication skills that may mask difficulties in making certain types of decisions.

**5b.11 When in the Bill should access to advocacy be available?**

The draft Bill sets out a number of ways in which an individual will be able to make decisions on behalf of adults who lack capacity. The MDA feels that access to an independent advocate could be extremely beneficial to the person at the centre of these situations. They could ensure that every effort is made to utilise and accurately assess the capacity the individual has and that the person's viewpoint and preferences is explored and taken account of as far as possible.

**5b.12 - Advocacy as a safeguard for the General Authority**

The draft Bill says very little about the mechanisms by which capacity will be assessed. However, in view of the wide powers under the General Authority, it is likely that in most cases an assessment of capacity will be made by the professional or carer most relevant

to the particular decision to be made, rather than a person who is specifically trained to assess mental capacity.

5b.13 The MDA is concerned that those making assessments of capacity may not understand the wide range of conditions that can affect people's ability to make decisions or communicate their views or have all the skills, knowledge, time or up-to-date awareness of equipment, which may be necessary to accommodate these different impairments. It may also be particularly challenging to assess the capacity of people whose condition fluctuates.

5b.14 This is likely to be particularly important where life changing decision are being contemplated (see below) .The MDA has consequently recommended that certain major decisions be removed from the General Authority and that other arrangements are put in place when such decisions are made (see Section 4.5: pp 8 – 12).

5b.15 The MDA believes the potential involvement of an independent advocate in such circumstances could help ensure the individual's capabilities are being respected and their views included. It could also help others ensure they are optimising the involvement of the individual in the decision-making process, accessing all the relevant information about the person and so helping them fulfil their legal duties. Similarly, when there is a dispute or a desire to appeal against assessment of capacity decision itself, the individual concerned may find the services of an independent advocate an essential safeguard in preventing loss of control over their lives and decisions.

#### **5b.16 — Making major decisions or in important situations**

The MDA is concerned about how the General Authority is defined and where the line should be drawn between informal decisions and more important decisions. For example a decision on how an individual spends their days may not appear to be a major decision, but it could have a major impact on someone's quality of life.

5b.17 The MDA believes it is possible to set out some major life changing decisions or situations where access to an independent advocate will be vital to ensuring that the individual's needs are properly addressed and their preferences taken on board. If the person has been assessed as capable of making the decision, they may need such help to think through their decision or express their views; if not, an advocate can help the individual express their preferences.

5b.18 Among the major life changing decisions or situations the MDA believes access to independent advocacy support should be available are:

- invasive surgery
- long term treatment with significant potential side effects and other major medical treatment
- issues where the individual lives (including independent living options and hospital discharge)
- who they live with
- what work they do or how
- where they spend their day or time
- who provides their personal care, and
- who manages their money.

#### **5b.19 — Disputed decisions**

MDA members and advocacy organisations are often asked for assistance when conflict arises between the individual, their families and professionals involved. Clearly, each of these groups has legitimate needs, pressures and concerns of their own which should be

acknowledged. However, the most important person involved is the individual and their views should usually take precedence. Mediation or Court action might be necessary to resolve this situation, but the involvement of an independent advocate in this process can ensure that the particular views and preferences of the individual are communicated effectively (An opportunity for the individual to challenge the decision reached may also be necessary).

5b.20 Access to independent advocacy may be particularly important in dispute situations when the individual is feeling unable to represent their own views clearly, perhaps due to illness; if their views contrast or conflict with the needs and views of those around them; or if they are unconventional or quirky, as this could be interpreted by others as indicators of a lack of capacity.

**5b.21 — Advocacy Preventing Abuse**

The General Authority envisages a very 'closed relationship' between individual and carer which is not monitored by a third party to prevent or deal with disputes or potential abuse. The involvement of advocacy could reduce the risk of abuse. It could also support those with limited or fluctuating capacity to navigate existing complaints mechanisms such as PALS, ICAS or various Ombudsmen where the problems relate to statutory services.

**5b.22 — Advocacy as a safeguard when a Lasting Power of Attorney, a Deputy or a Single Order occurs**

The MDA believes that access to an independent advocate could be a very valuable safeguard in relation to an appointment of a Lasting Power of Attorney, a Court appointed Deputy or when single orders of the court are being considered.

5b.23 An independent advocate could help explain and support a person through potentially confusing and alienating processes such as court hearings. An advocate could assist in exploring and explaining what the individual feels is in their best interests and support them in continuing to make those decisions they are able to make for themselves.

5b.24 Independent advocates could provide support when an individual is setting up an LPA or revoking it. They could help people with fluctuating capacity to insist that they do have capacity to take decisions and that an attorney or Deputy is not needed to act on their behalf. They could also assist an individual in supervising an Attorney around financial matters.

5b.25 Access to the advocate could be triggered by anyone involved in the case who felt the needs and views of the individual were being ignored or overridden.

**5b.26 Proposals to ensure that independent advocacy is available to all adults with impaired capacity**

**The Government should provide funding to ensure that every local authority area has an independent advocacy service that has the capacity to provide independent advocacy support for people affected by the Bill.** This may mean providing funding to existing services or provide funding for new services.

**5b.27 We would also recommend that each ICAS service has a named person to advise on the new legislation and good practice and to signpost individuals, families and professionals to appropriate sources of advocacy and/or undertake advocacy when there is a crisis e.g. life threatening situation**

**5b.28 There should be a duty on professionals (social workers, medical staff, lawyers, care staff or agencies) responsible for the capacity assessment to involve an advocate where a key life changing decision needs to be taken.**

5b.29 There is much to learn from the experience in Scotland where there is a requirement for local advocacy strategies to be set in every local authority area the creation of an Advocacy Safeguards Agency, which facilitates the development, evaluation, research, and dissemination of good practice around independent advocacy.

See Appendix 6.2: page 32, for answers to frequently asked questions on advocacy.

## **5c - Omissions from the Bill - Appointeeships**

Appointeeships are not included in the draft Bill, but MDA believes this area of welfare provision is also highly pertinent. Appointeeships are arrangements that involve the handling of an individual's state benefits, and are set up through the offices of the Department for Work and Pensions (DWP). There are few statistics on the number of appointeeships held; in 1996, figures provided from the Lord Chancellor's Department suggested that 214,482 older people had such an appointeeship arrangement (many others may also use an agent to collect monies on their behalf, usually from banks, building societies or post offices).

5c.1 Appointee action is normally instigated by an application from the prospective appointee. An officer from the Department for Work and Pensions (or local authority for housing benefit) will then interview the incapacitated person to confirm that they are unable to manage their own affairs. If there is any doubt about the person's capabilities, medical evidence should be obtained. The officer will also interview the applicant to explain the responsibilities of an appointee and confirm that they are suitable to act.

5c.2 Appointees have access to all the state benefits to which someone is entitled to receive (for example, state retirement pension, Disability Living Allowance or Attendance Allowance, Income Support/Pension Credit), but not to other monies (for example, occupational pension or savings other than accrued benefits), which may currently be under the control of an EPA or receiver. Although guidance to DWP staff makes clear that if there is already an EPA or receiver then appointeeship is not appropriate, it is not unknown for an appointee and an EPA to be acting at the same time. For those whose only income is via benefits (for example, those pensioners who do not have an occupational pension) it means that the appointee has control over the whole income if the person has been assessed, on the current 'one-off' occasion by DWP staff, as being mentally incapable of managing their financial affairs. This system does not accord with the principles of the draft Bill. Nor does it give people protection as there are few checks made by the DWP on appointees.

5c.3 While the MDA believes it to be very important that there is a system to enable financial decisions to be made on behalf of people dependent upon welfare benefits who lack capacity it is very concerned that the current system is potentially open to abuse and exploitation. Examples of this, taken from recent Parliamentary Ombudsman's Annual Reports are given in case studies 1 and 2, 5c.5 – 5.c6: p 26.

5c.4 Given that people with impaired capacity who are dependent upon welfare benefits are likely to be even more vulnerable than those with access to independent income/financial assets, as indeed potentially are their carers/family members, loss of control over their personal finances is likely to represent a major event in their life. **The MDA therefore believes that appointeeships should be brought within the scope of the Bill.** Decision-making as to whether someone should be subject to an appointeeship should require a proper assessment of the person's capacity in relation to their ability to make financial decisions. Appointees should be bound to the same 'best interest' principles as those operating as Deputies or Donees of LPAs. A clear system of monitoring and reviewing appointeeships should be put in place to support this.



### **5c.5 Appointeeship Case Study 1 – an example of fluctuating capacity**

*The Pension Service: failure to investigate fully whether to revoke an appointeeship*

5c.5.1 Mrs W complained of events from January 1998 when The Pension Service had received notification that she had been admitted to a residential nursing home for elderly mentally ill people. In June The Pension Service had accepted an application by her daughter, Mrs X, to be her appointee but had failed to investigate fully whether Mrs W remained incapable of managing her own financial affairs when that question arose in May 1999. Had they done so, it was most probable that they would have revoked the appointeeship at an earlier stage.

5c.5.2 The Ombudsman found no evidence of maladministration in the way in which The Pension Service had reached the decision for Mrs X to be Mrs W's appointee. However, they had failed to investigate fully whether Mrs W remained incapable of managing her own financial affairs. The Chief Executive wrote to Mrs W offering her personal apologies. The Pension Service paid Mrs W £317 for loss of personal expenses allowances, £1,750 for loss of disability living allowance and £340 for loss of use of those monies. They also made a consolatory payment of £200 for the gross inconvenience, embarrassment and severe distress Mrs W had suffered as a result of their actions.

5c.5.3 Parliamentary Commissioner for Administration - Annual Report 2002-2003  
Chapter 3 - Investigated cases - The Department for Work and Pensions and its Agencies, including the Appeals Service  
C1560/02

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### **5c.6 Case Study 2 – how those with appointees may be vulnerable to abuse**

*Benefits Agency: alleged improper appointment of an appointee*

5c.6.1 Mr A was unable to handle his own affairs after his discharge from hospital and the Benefits Agency (BA) appointed a neighbour to act for him, and receive his benefit. Mr A subsequently alleged that the neighbour had misappropriated the benefit. The Ombudsman criticised BA for their poor recording of the circumstances surrounding the appointment of the appointee but found no evidence that the decision had been maladministrative. The Chief Executive undertook to remind staff about the importance of good record keeping; and to consider amending the instruction on appointeeship to include a requirement to notify customers on the appointment of an appointee. He apologised for shortcomings in the handling of the case.

5c.6.2 Parliamentary Commissioner for Administration - Annual Report 1999-2000  
Chapter 3 - Investigated cases - The Department for Work and Pensions and its Agencies, including the Appeals Service  
C.176/00

## 5d - Omissions from the Bill - Assessment

The MDA fully supports the presumption of capacity set out in clause 3 of the draft Bill. The MDA does not wish to see the ability for any adult to make their own decisions infringed without an independent assessment of that adult's capacity. **The draft Bill does not explain how assessment will work in the context of this new legislation, and we believe this omission must be addressed.**

5d.1 The nature of capacity in the draft Bill is set out in clauses 1 and 2 (see MDA response on clauses 1-7). In relation to assessment, it is important to highlight that a person only lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself (MDA emphasis). The literal interpretation of this clause would require a continuous assessment of capacity each and every time that person was faced with a similar decision, but this would not be in the interests of the individual concerned, their carers or the relevant professionals.

5d.2 However, the MDA believes it is equally unacceptable for the draft Bill to erode an individual's right to make their own decisions before capacity has been accurately and independently assessed. The MDA would suggest that this would be a gross infringement of article 8 of the European Convention on Human Rights as enshrined in the Human Rights Act:

5d.3 *'Everyone has the right to respect for his private and family life... There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.'*

5d.4 The MDA believes that very few of the vulnerable adults we represent are totally unable to make their own decisions. Instead we view capacity as a sliding scale, with a person's ability to make their own decisions determined by a range of external factors, including time, physical location and the support available to them. Given that most vulnerable adults will fall between absolute capacity and an absolute inability to make decisions, the importance of assessment in underpinning the work of the draft Bill cannot be overstated.

5d.5 Given its fundamental importance, coverage of assessment in the draft Bill is alarmingly sparse. Presentations by officials have made clear that substitute decision-making should always be a last resort (clauses 2-4). Yet nowhere in the draft Bill are mechanisms set out by which the application of this principle of last resort will be monitored and by which abuses of the powers, in particular the General Authority, will be reined in.

5d.6 'Assessment' is not included within the list of expressions defined in the Bill at Clause 50, subsection (3); **the MDA believes that 'assessment' should be clearly defined.** In clause 30, subsection (1)(a), the Lord Chancellor is required on enactment to prepare a code of practice for the guidance of persons assessing whether a person has capacity in relation to any matter. **The MDA seeks clarification as to the legal status of this Code of Practice, and to any sanctions that will be applicable if the Code is breached or ignored.**

5d.7 In Clause 15, subsections (a) and (b), the Court of Protection is empowered to make declarations as to whether:

- A person has or lacks capacity to make a decision specified in the declaration
- A person has or lacks capacity to make decisions on such matters as are described in the declaration.

5d.8 In detailed discussions prior to the drafting of the Bill, officials confirmed that the functional approach to assessing capacity set out in the *Making Decisions* policy paper would be followed in the Bill. *Making Decisions* describes the functional test as, 'whether the individual is able, at the time when a particular decision has to be made, to understand the nature and effect of the decision'. *Making Decisions* explicitly states that the functional approach is designed to prevent unnecessary intrusion into an individual's affairs and to provide the flexibility necessary for individuals whose capacity to make decisions fluctuates, such as some people with mental health problems.

5d.9 The first power of the Court of Protection, to make a declaration as to whether an individual lacks capacity to make a specific decision, is in accordance with the functional approach. However, the second power, to make a declaration as to whether an individual lacks capacity to make decisions, 'on such matters as are described in the declaration' may undermine the functional approach. The MDA believes that 'such matters' in this clause will allow the Court to declare that a person is unable to make a particular type of decision indefinitely. If this interpretation is correct, this power may allow the Court to decide that an individual is unable to make decisions on all matters relating to their finances, their medical treatment or their personal welfare, without regard to the particular circumstances surrounding each decision within these categories.

5d.10 **The MDA would suggest that the second power should be downgraded, so that the Court of Protection may only state that an individual currently lacks capacity in relation to a particular decision, but may also express an opinion that an individual regularly experiences significant difficulty in making decisions on a particular issue and that this incapacity is therefore likely to continue.** A declaration of this nature would then allow carers to claim protection under the revised General Authority proposed by the MDA, which would now require a carer to present evidence that an independent assessment of capacity had been carried out for the person in their care. A declaration from the Court of Protection would be the highest level of evidence necessary for carers to claim protection under the General Authority, and would be appropriate where a person's capacity was contested or regularly fluctuated.

5d.11 The draft Bill sets out two sets of powers that can grant a substitute decision-maker the right to make decisions for an individual across one or more categories. The first type of powers, Lasting Powers of Attorney (LPA), relate to people who wish to plan for future incapacity (see LPA section of MDA response). For these powers, it is clearly necessary for the Donor of an LPA to have capacity at the time the LPA is made. Currently, the Bill deals with this in Schedule 1, 2, (e), which requires a person of 'prescribed description' (similar to requirements around passport applications) to certify that a person has capacity. This requirement appears to contravene the presumption of capacity in clause 3 of the Bill, as the onus should be to demonstrate that an individual who wishes to make an LPA does not have capacity if any doubt exists. **The MDA suggests that Schedule 1, clause 2, subsection (e) should be deleted and replaced with a requirement for a person of prescribed description to sign a statement that, in their opinion, the intended Donor of an LPA has understood the nature and purpose of the LPA.** This would adhere to the functional approach to assessing capacity, as the person of prescribed description is only asked to assess the person's capacity in relation to a particular decision (the making of an LPA) at the material time.

5d.12 The second set of powers relates to individuals who are born with impaired capacity, or who have lost capacity without making an LPA. In these cases, the Court of Protection may appoint a Deputy to manage their personal welfare (including healthcare) or property and affairs, or may make a single order to resolve any dispute on a particular decision (clauses 16-20; clause 38). While the MDA broadly supports the principle of Court-appointed Deputies (see section of response on Deputies), **we believe that Deputies should only be appointed when the court is satisfied that an individual regularly experiences significant difficulties in making a particular type of decision.** This should require a body of expert evidence, potentially including assessments from individuals representing different professional groups. The burden of proof should be higher for Deputies than for a single order of the Court, because as an ongoing power the appointment of a Deputy contravenes the functional approach to assessing capacity. However, a similar duty should apply to single orders of the Court, where a pure functional approach to assessing capacity will be possible.

5d.13 The Bill is silent on which professional groups would be eligible to make an assessment or pronounce on an individual's capacity, for example in providing evidence before a declaration by the Court of Protection. This is particularly important as Ministers and officials rightly wish to minimise bureaucracy in the implementation of the draft Bill, and do not proposed any formal certification of incapacity as applies to medical treatment in the Scottish Act. **Given this, the MDA would emphasise the importance of a holistic approach to determining capacity, with equal weight given to perspectives stemming from a social as from a medical model.** Individual organisations within the MDA can produce a range of evidence that demonstrates a low level of awareness amongst medical practitioners of particular conditions, disabilities and disorders that may impair an individual's capacity.

5d.14 In addition, the draft Bill currently lacks any accessible mechanisms by which an individual may challenge a formal or informal assessment of capacity made about them. Although an individual assessed as lacking capacity can make an application to the Court of Protection to challenge any declaration made by the Court on the basis of this assessment (40, 1, a), the Bill does not explain how Ministers envisage that a person who may have a significant mental disorder can be supported to make such an application. **This is another reason why the MDA believes that any individual assessed as lacking capacity who becomes the subject of the formal powers set out in the draft Bill should have the right to access independent advocacy.**

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## **5.e Omissions from the Bill – Public Law Protection for Those at Risk**

The MDA is disappointed that the Government has decided not to proceed with this issue as part of its review on mental capacity, as proposed in the consultation paper *Who Decides?*. **We believe that the current situation is unacceptable, and the new legislation and in particular the General Authority will make the need for public law protection still more urgent.** We feel that the only way to enable older people, people with a learning disability or mental health problems to receive the most appropriate help when abused is through public law protection. For example, many people with a severe learning disability or older people are unable to care for themselves or are liable to a significant risk of exploitation because of an inability to perceive or assert their rights and interests. There is a need to replace relevant sections of existing legislation such as the *National Assistance Act 1948* that are inadequate and ineffective in respect of protecting people from exploitation and neglect.

**5e.1 The MDA believes that social services should have the duty to investigate cases of neglect or abuse where there is evidence of significant harm or exploitation.** This power would allow the local authority to review existing community care arrangements. The MDA believes that social services should be the lead agency for investigation of abuse but that social services departments should be responsible for co-ordinating responses from other agencies within a prescribed timescale.

5e.2 There is a need to maintain a balance the risk against an individual and respect for an individual's autonomy. Once it has been established that a person has the capacity to refuse the support of the local authority, that choice should be respected.

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## **Appendix 6.1 – Members of the Making Decisions Alliance**

- Add a Voice
  - Action on Elder Abuse
  - Age Concern England
  - Alzheimer's Society
  - Beth Johnson Foundation
  - Carers UK
  - Caring Matters (until 25 July 2003)
  - Counsel and Care
  - Down's Syndrome Association
  - Headway
  - Help the Aged
  - Kent Autistic Trust
  - Leonard Cheshire
  - MIND
  - Manic Depression Fellowship
  - Mencap
  - Mental Health Foundation
  - National Autistic Society
  - Patient Concern
  - POPAN (Prevention of Professional Abuse Network)
  - The Relatives & Residents Association
  - RESPOND
  - Rethink
  - SCOPE
  - Sense (The National Deafblind & Rubella Assoc)
  - The Stroke Association
  - Turning Point
  - United Response
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## **Appendix 6.2 – Background information on Advocacy**

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Successive Governments have highlighted the importance of independent advocacy and showed an appreciation of the valuable role it can play in supporting people to access vital services and ensure their rights are protected. For example, the *Disabled Persons Act 1986* charged local authorities with setting up a formal system of authorised representatives who could make representations about their disabled people's need for services, get a statement of assessed needs and services to be provided and make representations about this. However, this formal system was never implemented.

6.2.1 More recently, the *Health and Social Care Act 2011* (part 1, section 12, clause 19A) empowers the Secretary of State 'to arrange, to such extent as he considers necessary to meet all reasonable requirements, for the provision of independent advocacy services.' This Act also introduced two new mechanisms to deal with health service complaints, PALS and ICAS. A similar clause exists in the draft Mental Health Act in relation to the help to be available from mental health advocates to qualifying patients and to their nominated persons.

6.2.2 In addition, numerous white papers, standards, guidance documents and reports from different Government Departments have drawn attention to the benefits advocacy can bring and emphasised the need for further development and support for such services. However, apart from the limited funding announced in the White Paper *Valuing People* for services aimed at people with learning disabilities over the next 3 years, there has been no indication of any national Government funding or resources for independent advocacy services.

### 6.2.3 Some models of advocacy

**Citizen Advocacy** is a one-to-one ongoing partnership between a trained volunteer advocate and a person who is not in a strong position to exercise or defend their rights and is at risk of being mistreated or excluded.

**Peer Advocacy** is where one person advocates for another who has experience or is experiencing similar difficulties or who has similar life experiences (e.g. service users in a residential facility)

**Professional Advocacy** is where people are employed and paid within an advocacy service. This usually follows a case-work model, focussing on particular issues.

6.2.4 If someone already has a Citizen Advocate they know and trust, they should be able to use this support in this situation if they so wish and if the advocate is willing to do so rather than be required to use a paid professional advocate. Similarly, if someone wanted to have a Citizens Advocate but there are no such schemes in their area but paid professional advocates were available it would be reasonable for them to accept this as an alternative.

### 6.2.5 Advocacy Case Studies

#### **Case Study 1 – advocacy as a safeguard against potential abuse**

A man in his mid-60s has a previous history of long-term institutional admission from his 20s to late 40s. During a hospital admission a neighbour was very active in arguing for him during discharge planning and agreed to provide regular weekly support. At the meeting the gentleman did not challenge this but was still very anxious about going home. It later emerged that the neighbour had encouraged him to sell his family home to move into a bungalow near her so she could 'provide support'. In return, he had invested in an extension for her property.

6.2.6 As time went on, the promised support from the neighbour never emerged. He had been unhappy with the discharge planning at the time, but had never felt comfortable saying anything in front of his neighbour. He didn't want to upset her, as he was still hopeful that she would provide ongoing care. Due to his history of institutionalisation, he was continually scared of getting into trouble for whistle-blowing. Everyone assumed that the neighbour was advocating for him; nobody realised the neighbour wasn't independent. Nobody actually asked the gentleman independently whether he was happy with the arrangements that had been made. An independent advocate would have asked all those important questions.

#### **6.2.7 Case study 2**

The following case study is an example of how someone's condition and their life experience to date have both had an impact on their ability to make decisions.

6.2.7.1 A young woman with Asperger syndrome had many different placements throughout her school life and early adulthood. Her ability to make decisions was affected by these changes in surroundings. She felt was unable to control major decisions in her life, such as her placements, and, because the settings were not appropriate, her reliance on her obsessions (personal hygiene and domestic cleanliness) became more acute. The reassurance she found in her cleaning adversely affected all the other decisions she made — cleanliness was the only thing that mattered to her. As she became more settled in a more suitable supported living arrangement, her obsessions declined and she was able to engage in other activities - college, gym etc.

#### **6.2.8 Case study 3 – advocacy in the communication process**

A non-verbal man with autism attended an autism specific day service in a neighbouring local authority. It had always been assumed that because of his lack of language and his apparent indifference to his surroundings that he was incapable of making certain decisions. When his local authority decided that it would be cheaper for him to attend one of their own generic day centres for disabled people the day centre appointed an advocate. It soon became clear to everyone involved that he had understood what was happening and wanted to stay at his present day service. Through specific questions and his use of symbols the advocate was able to ask him about his current day service and how it helped him.

#### **6.2.9 Case Study 4 – advocacy assisting in the expression of preferences**

A man who suffered a mental breakdown at university is now paranoid about his immediate family, who are doing their best to help him. However, he sees any support they suggest as oppressive and detrimental to his interests. He is very intelligent and can communicate well, but his views are distorted through his delusional beliefs. An independent advocate is needed to help him express his preferences to enable decisions to be made in his best interests.

#### **6.2.10 Case study 5 – advocacy in the process of gaining consent**

A young man with autism and very little language needed a hernia operation and was in a great deal of pain. Because of his autism he hadn't alerted anybody to the pain he was suffering. Staff began to notice his discomfort and he went to a doctor. He lived in an autism specific residential service and the staff, his parents, his psychologist and surgeon agreed he needed the operation. However without the use of an advocate it was agreed that consent could not be assumed. The advocate was able to explain impartially the consequences of an operation. Following access to an advocate he gave consent and the operation was successful.



### 6.2.11 Case study 6 – Advocacy in challenging professional decisions

A lady in her mid 90's was living alone in warden accommodation. She was physically ill but refused on several occasions to go into hospital. It was unknown how serious her illness was due to lack of tests (which could only be done in the hospital) – it may have been a minor blockage that could be easily rectified, but it could also have been something much more sinister. Due to past history the lady was adamant she did not want to leave her home as she was very clear that she wanted to die in her own home. She was aware that she may be shortening her life by this decision but for her the potential benefits of a move into hospital did not outweigh the fear of going there. The GP became very anxious about this and instigated a Mental Health Act assessment, the GP tried to argue there were questions over the lady's capacity but it seemed much more to be a case of 'covering the back' by the GP.

6.2.11.1 The lady was very traumatised by the experience of many strangers entering her home and asking very personal questions. There needed to be someone in this process very clearly advocating for her wishes to stay at home, as her wishes seemed to be totally lost in this process. The concern would be that a GP under the new system would act under the General Authority and remove her into hospital, as the lady herself could express her wishes if given the time and space and when asked appropriately but was too weak to really challenge anyone. An advocate would have clearly been able to challenge the GP's concerns and any 'medical' decisions that he made.

### 6.2.12 Case study 7– advocacy in family disputes

A man's health was deteriorating; and his insight and ability to communicate were severely diminished. There was an on-going dispute between his sister and father and his wife when he became ill, which resulted in a long battle to register an EPA. The family said they were quite happy for his wife to handle all financial and business matters with the EPA not being registered. However, the family then started to take him to meet with solicitors and clerks, seeking revocation of the EPA when he visited them, causing much friction. An independent advocate may have helped to establish and communicate his views.

## 6.2 13 Frequently Asked Questions on Advocacy

### 6.2.13.1 Q. **How can you advocate for someone whose views on the particular issue can't be established?**

A. You can build up a picture of a person's views and preferences from their behaviours and the way they react to different things. From that, it is possible to work out what they may prefer to happen and what makes them happy. It is however very important for advocates to make it clear when it is not possible to ascertain someone's wishes and feelings.

### 6.2.13.2 Q. **How can you get the views of preferences of people who are mentally incapable?**

A. Mental capacity isn't a black and white issue. Someone may be capable of making some decisions and not others, or may not be capable of making many decisions but could be able to express views or preferences that can help guide the actions of the substitute decision-maker. An independent advocate can help explain to someone in a way they are more likely to understand what the decision is about so that as far as possible their views are considered.

### 6.2.13.3 Q. **How would you ensure advocate is independent and accountable?**

A. The independence of the advocate is important to the success of the advocacy. Work needs to be done by organisations providing advocacy to establish how advocates can guarantee independence and accountability for the individual. But we need to make sure

that the possibility of informal advocacy is not removed through any formal process of ensuring independence and accountability.

**6.2.13.4 Q. Who should be responsible for providing and / or resourcing this advocacy input?**

A. Central Government should fund the provision of independent advocacy support needed to make the commitment in the Bill to a presumption of capacity a reality.

**6.2.13.5 Q. How much would this cost?**

A. No accurate figures are available. However, the MDA believes that every local authority area should have an independent advocacy service that is able to support people who are affected by the Bill. For some areas, this will be new provision. For others, existing services would need to be enhanced. It should also be borne in mind, however, that many of recommendations are about providing access to advocacy for those who do not have alternatives. Most people will probably continue to use informal advocates (family, friends, and neighbours) with no substantial cost implications.

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## **Appendix 6.3 – MDA commentary on mental capacity legislation in other countries**

Mental capacity legislation has been the subject of debate and legislative change around the world over the past 20 years. Many countries have made changes to their laws to ensure that they deliver the necessary safeguards for citizens who lack capacity to consent. An ageing population, advances in medical technology enabling people with severe disabilities to live longer, and the move from institutionalisation to community-based living, were cited as the main reasons for reform. These are all issues that are relevant to England, Wales and Northern Ireland.

This paper examines mental capacity legislation in Scotland, Australia and Canada.

### **6.3.1 Scotland**

#### The Adults with Incapacity (Scotland) Act 2000

In March 2000, the Scottish Parliament passed this act, recognising that the existing law was failing to meet the needs of adults unable to make decisions for themselves. The Scottish Law Commission produced a report in 1995 on the subject and, after extensive consultation, the Adults with Incapacity Act was passed in May 2000.

6.3.1.1 Mental capacity legislation takes a functional approach to determining capacity. So, the act makes an assumption that individuals will be able to make their own decision unless it is proved that they are unable to do so. The act states clearly that interventions in the affairs of adults who lack capacity must be in the best interests of that adult; and that the guardian (a spouse, nearest relative, and so on) has a General Authority to act reasonably on day-to-day decisions. The Act creates a new offence for an appointed guardian neglecting his/her duties or failing to act for the benefit of the person who lacks capacity to consent.

6.3.1.2 Under the Act, several agencies supervise those who take decisions on behalf of the adult, ensuring those decisions are in the person's best interests. These agencies include:

- the Public Guardian, which has a supervisory role and keeps registers of attorneys, people who can access an adult's funds, guardians and intervention orders
- local authorities, which can look after the welfare of adults who lack capacity in instances where no guardian can be found (other local authority roles under the Act include investigating circumstances where the personal welfare of an adult is at risk, providing information and advice to those exercising welfare powers and supervising attorneys and guardians)
- the Mental Welfare Commission, which protects the interests of adults who lack capacity as a result of mental disorder.

6.3.1.3 Under the Act, the main ways that other people can make decisions for an adult who lacks capacity are as follows:

- **Power of Attorney**

Individuals can arrange for their welfare to be safeguarded and their affairs to be managed properly. They can do this by giving another person (who could be a relative, carer, professional person or trusted friend) power of attorney to look after some or all of their property and financial affairs and/or to make specified decisions about their personal welfare, including medical treatment.

- **Intervention and guardianship orders**

Individuals can apply to their local sheriff court for an intervention order where a one-off decision or short-term help is required, or a guardianship order, which may be more appropriate in cases where there is a need for the continuous management of affairs or the safeguarding of welfare. Any person claiming an interest in the adult's affairs, or a local authority may make applications for intervention and guardianship orders.

- **Medical treatment and research**

The act allows treatment to be given to safeguard or promote the physical or mental health of an adult unable to consent. Where there is disagreement a second medical opinion can be sought. Medical practitioners have to consult close relatives before administering medical treatment. Cases can also be referred to the Court of Session in certain circumstances. The act also permits research involving an adult incapable of giving consent, but only under strict guidelines.

- **Access to the adult's funds**

Individuals (normally relatives or carers) can apply to the Public Guardian to gain access to the funds. Authorised housing and care services can also manage a limited amount of the funds and property of residents.

### **6.3.2 Australia**

All the Australian States introduced mental capacity legislation between the late 1980s and 1990s. The principal model is the Guardianship and Administration Board Act 1986, in Victoria (recently amended in 1999). Legislation covering different states takes the functional approach to determining capacity. This paper examines South Australia's Guardianship and Administration Act 1993 as an example of the approach used by other states.

#### **6.3.2.1 The Guardianship and Administration Act 1993 - South Australia**

The Guardianship and Administration Act 1993 came into operation in 1995. This set the Guardianship Board, which is responsible for applying the new law, the task of setting out a number of orders. It is assumed that close relatives will make day-to-day decisions, but the Act encourages those who may lack capacity in the future to appoint a guardian. However, guardians can only make welfare and medical decisions on someone's behalf. The act creates a new offence for an appointed guardian neglecting his/her duties or failing to act for the benefit of the person who lacks capacity to consent.

#### **6.3.2.2 Administration Orders**

In terms of welfare and financial affairs, the Guardianship Board may appoint an administrator to look after such affairs. The following can be appointed to act as an administrator:

- The Public Trustee
- A trustee company under the Trustee Companies Act 1988
- A relative appointed by the Board

#### **6.3.2.3 Medical decisions**

There are two laws that deal with the issue of who has the legal authority to consent to medical and dental treatment:

- Consent to Medical Treatment and Palliative Care Act 1995
- Guardianship and Administration Act 1993

6.3.2.4 If a person has not appointed a 'Medical Agent, or has not made an 'Anticipatory Direction' (a living will) under the Consent to Medical Treatment and Palliative Care Act 1995, and mental capacity is lost, then consent to medical or dental treatment for a person with a mental incapacity must be sought from the following:

a) the guardian appointed by a person, prior to mental incapacity, to make medical decisions

b) The guardian appointed by the Guardianship Board under a Guardianship Order. The written order will specify the areas in which the guardian is empowered to make decisions

c) Where there is no guardian or enduring guardian, specified relatives can give consent, including a spouse, a parent, a sister or brother aged 18 years or older, a daughter or son of aged 18 years or older

6.3.2.5 In terms of prescribed treatment such as an operation, where a person is unable to give their consent, the Guardianship Board is the only authority that can give consent. The Guardianship Board is governed by a set of criteria when making decisions about such a treatment or procedure.

6.3.2.6 The Office of the Public Advocate has also been set up as a 'watchdog' with the responsibility of educating the public on issues relating to disability and promoting the interests of people who lack capacity to consent, and in some instances, their carers.

### **6.3.3 Canada**

#### Adult guardianship legislation

The situation in Canada is similar to Australia's in the way that each province has its own legislation. Until recently, mental capacity legislation varied considerably from province to province. There were two main approaches adopted. The traditional system regarded incompetence as absolute (e.g. Ontario's Mental Incompetence Act 1980). This means that legal rights, possessions and decision-making power of the person lacking capacity to consent are transferred to another once the court makes a decision that the person lacks the capacity to consent.

6.3.3.1 This approach was heavily criticised by disability organisations as being paternalistic and open to abuse. Major reform took place in the early 1990's (see Ontario case study).

6.3.3.2 The second approach, adopted in Alberta (the Dependent Adults Act 1976), was one of the earliest attempts to adopt a more functional approach to mental capacity.

#### **6.3.3.3 Ontario – towards reform**

In 1992, Ontario abolished its mental incompetence guardianship regime and enacted three new legislations: the Consent to Treatment Act 1992, the Advocacy Act 1992<sup>2</sup> and the Substitute Decision Act 1992. This legal reform promoted the autonomy of those who lack capacity to consent, and prevented unnecessary legal intervention in their lives. The Act states clearly that interventions in the affairs of adults who lack capacity must be in their best interests. People will be presumed to be able to make their own decisions, unless it is proved otherwise. In all the areas of decision-making, the Act makes clear the need to encourage the individual to participate as fully as possible in any decision affecting him/her. The appointed guardian has a General Authority to act reasonably. As with the legislation in Scotland and Australia described above, the act creates a new offence for an appointed guardian neglecting his/her duties or failing to act for the benefit of the person who lacks capacity to consent.

6.3.3.4 Individuals can arrange for their welfare to be safeguarded and their affairs to be managed properly, by giving another person (who could be a relative, carer, professional person or trusted friend) power of attorney. These include decisions about their property

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<sup>2</sup> In 1996, the Advocacy Act was repealed and the Consent to Treatment Act was replaced by the Health Care Consent Act. This was done under the Advocacy, Consent and Substitute Decision Statute Law Amendment Act 1996.

and financial affairs and/or to make specified decisions about their personal welfare, including medical treatment.

6.3.3.5 Finally, the Health Care Consent Act has created a simple procedure that recognises the social position of family members as natural substitute decision-makers. It provides the legal framework for carers to appeal against medical decisions. It should be noted, however, that if the patient has granted the power of attorney for personal care or if a guardian has been appointed, then the attorney becomes the substitute decision-maker and other family members lose their automatic status.

6.3.3.6 Ontario's legislation has also established the Office of the Public Guardian and Trustee to provide a number of services. Some of these include:

- **Property Guardianship**

This service manages the financial affairs of individuals who lack capacity to consent, when there is no one else who is able, willing and appropriate to provide this service for them. The office may be appointed as guardian of property by a doctor in a psychiatric facility, a designated capacity assessor, or the court.

- **Personal Care Guardianship**

The Personal Care Guardianship is occasionally appointed as guardian of the person to make personal care decisions for a mentally incapable adult, if this is necessary to protect the person from serious personal harm. Only a court can make these appointments. As guardian of the person, it is the office's responsibility to make decisions about things like custody, safety and housing.

- **Decisions about Treatment and Admission to long-term care**

This service is responsible for making decisions about medical treatment and admission to long-term care for those who are mentally incapable of doing so when there is no one else, such as a family member, willing and able to provide this service.

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