

21 June 2004

## MENTAL CAPACITY BILL – FIRST READING BRIEFING

### MDA welcomes new Mental Capacity Bill but warns it will be ‘ineffective’ without more advocates

The Making Decisions Alliance (MDA) – a coalition of 39 disability organisations – has welcomed the Mental Capacity Bill but warned it will be ineffective without more advocacy services.

The Bill, which aims to help millions of people to make more decisions for themselves, was introduced into the House of Commons last Thursday (17 June). It has the potential to transform people’s lives for the better but the MDA believes the Government’s good intentions are at risk if more emphasis is not given to the role played by independent advocates.

Under the Bill, people who may lack capacity – such as those with a learning disability, mental health problems, autism, Alzheimer’s, or severe head injuries – would only have an automatic right of access to an independent advocate in very limited circumstances. This could leave many thousands of vulnerable people without access to independent advocacy services and therefore open to abuse and exploitation. Independent advocacy is particularly vital:

- When life-changing decisions are to be made such as invasive surgery, long-term treatment or where someone should live.
- When other people are to be appointed to make decisions on behalf of the incapacitated person (called a Lasting Power of Attorney or Deputy).
- To help resolve areas of dispute.

The Joint Parliamentary Committee which scrutinised the Mental Capacity Bill when it was in draft form also concluded in its report that independent advocacy services “*play an essential role*” (p80) and that Ministers should “*meet all reasonable requirements for the provision of independent advocacy services to incapacitated adults affected by the Bill’s provisions*” (p82).

The MDA feels that the Bill currently falls well short of the Committee’s recommendation. Richard Kramer, Co-chair of the MDA, said: “*We have been waiting for legislation for 15 years. But this Bill will not achieve its aim of enabling people to take more control of their lives if independent advocates are not given a central role in representing those affected. It will be a huge disappointment if we are left with a law which is toothless and ineffective.*”

### What else will the Bill do?

The MDA is supportive of many of the other measures in the Mental Capacity Bill. In particular, we welcome:

- **Presumption of capacity** – it will be assumed that adults have the legal right to make decisions for themselves. We believe this is vital for the millions of people who are currently, often wrongly, assumed to be incapable of making decisions.
- **‘Best interests’ principle** – the concept of ‘best interests’ must guide all actions taken or decisions made on behalf of a person who lacks capacity.

- **Rights of the carer** – the Bill will give those caring for people who are incapacitated more confidence in their rights to be consulted on the treatment and care of those they look after.
- **Advanced decision-making** – Lasting Powers of Attorney will allow people to appoint a person of their choice to deal with welfare, medical treatment or financial matters in case of future incapacity. They will also be able to write an advance directive (sometimes known as a ‘living will’) setting out what medical treatment they would not want should they lose capacity.
- **A new Court of Protection** – will provide clearer arrangements to allow for specially trained judges to resolve disputes, to make decisions on the most complex matters and appoint a substitute decision-maker (a deputy).

However, in addition to independent advocacy, the MDA has significant concerns about a number of other issues relating to the Bill including:

- **Acts in connection with care and treatment** – the Bill provides legal protection (a defence against liability) for families and professionals when caring for, or treating, someone who lacks capacity. However, there are not enough additional safeguards in place to protect the cared for person when significant decisions are being made – e.g. we feel a person should have access to an independent advocate when a decision on whether to move home is being made.
- **Advance statements** – the Bill does not make any provision for advance statements. These allow people to set out what they would want to happen (as opposed to not want to happen) in the case of future incapacity. For example, it may set out cultural needs that should be respected or a desire to remain at home for as long as possible. We think advance statements should be given a similar status to advance directives.
- **Appointeeship** – the benefit system allows an individual to be appointed to look after the benefits of someone who is considered incapable. This means that the appointee has access to all the state benefits to which someone is entitled but, at present, none of the Mental Capacity Bill’s safeguards would apply.
- **The ‘Bournewood Gap’** – the Bill still does very little to protect those people who receive mental health care and treatment but who lack the capacity either to refuse or consent to that care and treatment. We believe these people would be far better protected by having a similar level of safeguards in the Mental Capacity Bill as were contained in the 2002 draft Mental Health Bill proposals.

### How can you help?

We would like you to support our campaign for more independent advocacy provision and other key revisions during the Mental Capacity Bill’s Second Reading debate. If you intend to speak please let us know so we can brief you in more detail about the MDA’s position on the Bill’s main issues.

### Which organisations make up the Making Decisions Alliance?

Action on Elder Abuse, Addavoice, Age Concern England, Alzheimers Concern Ealing, Alzheimer’s Society, Beth Johnson Foundation, Carers UK, Counsel and Care, The Centre for Policy on Ageing, Cloverleaf Advocacy, Consumer Forum, The Down’s Syndrome Association, Foundation for People with Learning Disabilities, Friends of the Elderly, Help The Aged, Horsham Gateway Club, Kent Autistic Trust, Leonard Cheshire, Mencap, The Mental Health Foundation, Mind, Motor Neurone Disease Association, The National Autistic Society, North Staffordshire Users Group, The Oaklea Trust, PACE, Patient Concern, POPAN, The Relatives and Residents Association, Respond, Rethink, St Clements Patients Council, Scope, Sense, Skills for People, The Stroke Association, Turning Point, United Response.

#### Further information

If you would like to know more about the Making Decisions Alliance, please contact the co-chairs Richard Kramer, Turning Point, on 020 7702 2300 or [Richard.Kramer@turning-point.co.uk](mailto:Richard.Kramer@turning-point.co.uk) or Toby Williamson, Mental Health Foundation, on 020 7802 0332 or [TWilliamson@mhf.org.uk](mailto:TWilliamson@mhf.org.uk). Alternatively, further information is available on the Making Decisions Alliance website at [www.makingdecisions.org.uk](http://www.makingdecisions.org.uk)