

The Making Decisions Alliance brings together a wide range of organisations and groups, working with people who may, for range of different reasons, have difficulty in making or communicating decisions.

Briefing for Chief Executives on the Mental Incapacity Bill and the work of the Making Decisions Alliance (MDA)

1. Overview - Mental Incapacity Bill

The draft Mental Incapacity Bill is the product of extensive consultation stretching back to 1989. Since then there have been a number of Law Commission reports on legislation and incapacity, and two government consultation papers (*Who Decides*, in 1997; *Making Decisions*, in 1999). The Scottish Parliament has already introduced their own legislation to safeguard the rights of people who cannot make decisions for themselves. The Adults with Incapacity (Scotland) Act 2000 introduces a statutory framework for the medical treatment of incapacitated adults in Scotland, as well as a scheme for the management of property and financial affairs.

The government published a draft Mental Incapacity Bill in June 2003, and this has been scrutinised by a Joint Committee of MPs and Peers. Their report was published in November 2003 and the government is expected to publish its response to the Joint Committee's report on 17th February 2004 (see below). Although a Mental Incapacity Bill was not announced in the most recent Queen's Speech, the government has since indicated its intention to introduce legislation before the Summer Recess.

The aim of the Bill is to develop a comprehensive statutory framework to define mental incapacity, help those who lack it to make their own decisions where they can, and enable sound decisions to be made when they cannot. The proposals include:

- A new test of incapacity and a definition of capacity. There will be a statutory presumption that people can make their own decisions unless it is proved that they are unable to do so.
- For those who cannot make a particular decision, there will be statutory guidance on how their best interests should be determined based on the fullest participation of individuals concerned.
- Carers will have a general authority to act reasonably with regards to the personal welfare and healthcare of someone without capacity. This will give a legal context for all day-to-day decisions that are made, such as paying bills and giving medication.
- The government will introduce a Lasting Power of Attorney. This will be wider than the existing Enduring Power of Attorney arrangements, and allow delegation of decision making on healthcare and personal welfare as well as financial matters. It will be available to those with capacity who wish to set up such

arrangements in advance of their becoming unable to make these decisions themselves.

- Those with capacity will be able to make advance decisions to refuse treatment to have these acknowledged and acted on appropriately should they lose capacity.
- A new Court of Protection to deal with all areas of decision making for those without mental capacity. It will be able to appoint a deputy to make some decisions on a person's behalf, or could make a single order on a specific matter.

2. The Formation of the Making Decisions Alliance

The Making Decisions Alliance (MDA) is a consortium of voluntary organisations and groups working with people who may have difficulty making or communicating decisions. Its founding members include Age Concern, the Alzheimer's Society and Mencap. The MDA's two main aims are:

- to lobby the Government to introduce mental capacity legislation as a matter of priority
- to increase awareness of the need for new legislation.

The MDA was formed in January 2002. It has since met on a fortnightly basis over the last two years and continues to grow in membership. We have also set up small action groups to work on campaign actions, media, parliamentary and policy development. The MDA now has thirty members (see Annex One). It is currently co-chaired by Richard Kramer, Head of Policy, Turning Point and Steve Broach, Head of Policy and Campaigns, the National Autistic Society.

The Alliance has successfully brought together organisations with different perspectives. By sharing information we have developed a common understanding of what is needed to support and protect people's ability to make decisions and communicate decisions about their lives. It is seen as the credible voice of the voluntary sector by government.

The MDA has formed strategic alliances with organisations that represent professionals such as the Law Society, the British Medication Association and the Royal College of Psychiatrists, although it has been agreed that they should not be formally invited to become members of the Alliance. We have had regular meeting with these organisations and have shared speakers' platforms, where appropriate.

We have also had close dialogue with some organisations that have expressed concerns or opposition to the Bill, including pro-life groups such as the Society for the Protection of the Unborn Child (SPUC); and with groups of people with a learning disability with whom we have some mutual concerns, in particular over the need for access to advocacy support.

The MDA has its own website page which informs people about the MDA, the rationale for the campaign for new legislation, how people can support the work of the Alliance and provides regular updates of its work (www.makingdecisions.org.uk). This is hosted for MDA by one of our members, the Mental Health Foundation.

3. MDA's campaign for new legislation

The MDA launched a campaign in February 2003, drawing attention to gaps in the current law and calling for new legislation as a matter of priority. We commissioned

a NOP survey that revealed that 92% of people thought that, if they could not make decisions themselves due to a severe head injury from an accident, their partner would have the legal right to be consulted about decisions on their behalf. There is currently no legal right for partners to do this in England and Wales. We used the findings of the poll to help make the case for new mental capacity legislation. The poll findings and the campaign launch generated good media coverage, including reports in the Guardian and on Radio 4's You and Yours.

We also published a campaign pack, which helped to profile the work of the Making Decisions Alliance, set out the case for new legislation and provided support for individuals and groups to take action. Alongside the pack was a summary flyer, which included a detachable postcard to be sent to the then Lord Chancellors Department in support of the campaign. These were distributed through our membership networks including Age Concern, Alzheimer's Society, Help the Aged, the National Autistic Society and Mencap. The Department received nearly 8,000 postcards, which demonstrated the breadth and depth of support for the MDA from individuals and our membership organisations. In response, the Government set up a Consultative Forum drawn from experts from professional groups and voluntary organisations to discuss the framework for future legislation.

4. Draft Bill and Scrutiny Committee

The government's draft bill was published in June 2003. A Joint Committee was then appointed by the House of Commons and House of Lords to scrutinise the Bill. It made 100 recommendations about the draft Bill in its report in November 2003.

The MDA submitted two sets of written evidence to the Committee and gave oral evidence to the Committee over two days. The MDA was represented on the first day by Clive Evers (Alzheimer's Society), Simon Foster (Mind), Roger Goss (Patient Concern), Andrew McCulloch (Mental Health Foundation), Pauline Thompson (Age Concern) and Kathryn Wilmington (Help the Aged). This session covered issues for those who with fluctuating capacity or who may lose capacity in later life.

The MDA was represented on the second day by Steve Broach (National Autistic Society), Caroline Clipson, (Scope), Richard Kramer (Turning Point), Hazel Morgan (Foundation for People with Learning Disabilities), and Susannah Seyman (Down's Syndrome Association). This covered issues for people who may be born with impaired capacity.

The Joint Committee warmly received the MDA's written and oral evidence. We were, by far, the most widely quoted organisation in their report. Many of our recommendations were taken forward and adopted by the Joint Committee. Following the report, we have pursued key agendas around advocacy, appointeeship and advance statements.

The government is expected to respond to the Joint Committee's report on 17th February 2003. The MDA will provide a further briefing for Chief Executives following their response. MDA believes that the Bill must address certain key areas if it is to make a real difference. These are:

- Right to autonomy - The MDA believes that it essential that the Bill maintains the balance between respecting the right to autonomy (presumption of capacity) and the need to ensure adequate protection for those that have difficulty making and communicating decisions and who have been assessed

as unable to make a particular decision (best interests). Currently, the Bill is weighted towards the latter. The MDA is concerned that the emphasis on best interests in the Bill as drafted may lead to a misunderstanding that the overriding aim of the Bill is to impose or restrict a person's own ability to make decisions.

- Advocacy - the MDA wants the government to commit resources to ensure that adults should be able to access an independent advocate to support them to make decisions or to be involved in the decision-making process (particularly in critical situations, such as where there is a dispute, or a major decision is to be taken). We want provision for advocacy to be expressly mentioned in the Bill.
- Assessment - the MDA believes that before important decisions are taken on behalf of an adult, their capacity to make decisions for themselves must be assessed.
- Advance statements - the MDA wants to see advance statements also given proper legal status in the Bill. These provide the opportunity for adults with capacity positively to state their wishes and plans in advance on subjects such as finance, health and care (in case in the future they become temporarily or permanently unable to make decisions or communicate their wishes), and to have these advance statements taken into account in the decision-making process.
- The General Authority – We believe that the general authority as currently set out is too wide and does not distinguish between different types of decisions (eg between day-to-day and major or life-changing decisions). The MDA regards the significance and timing of the decision as the two key factors that determine whether a decision under the general authority is reasonable. We also propose additional safeguards in relation to the general authority to act in relation to medical decision-making and other significant decisions that amount to a material change of circumstances (such as a change of carer).
- Lasting Power of Attorney - More safeguards are needed for the Lasting Powers of Attorney, especially to prevent financial abuse. We also firmly believe that appointeeships, currently handled by the Department for Work and Pensions, should come within the provisions of the Bill.

5. Developing more detailed policy positions

We have successfully built up our abilities to interpret the practical implications of the proposed mechanisms in the draft Bill. We have developed detailed policy positions on a number of issues such as assessment, advance statements, euthanasia and advocacy. We are currently drafting a position paper on research. These position papers have been drawn up by individual members/sub groups before MDA-wide discussion and formal adoption. We have used individual case studies to illustrate these position statements, wherever possible.

In relation to advocacy, we have vigorously maintained that the Bill will not fulfil its intention of supporting and empowering people who have difficulty making decisions if it does not include provisions to enhance the quality and availability of independent advocacy services. We believe that independent advocates are uniquely placed to ensure that the fundamental principles of the legislation, such as the paramount importance of the individual's wishes and feelings, are translated into the practice of substitute decision-making.

However, we recognise that resource constraints will mean that a blanket right to access independent advocacy may not be achievable in the context of this Bill.

Looking solely at the provisions of this Bill, we maintain that a right to support from an independent advocate should apply in situations, in which significant decisions are taken and/or there is a dispute between any parties to the decision or where formal powers created by the Bill are applied for (such as Lasting Powers of Attorney).

Much of the more negative campaigning work and media work against this Bill has been concerned with euthanasia. MDA has developed a detailed position paper in which we reiterate our position that the Bill will not change the law on euthanasia, which is illegal and will remain so. Importantly, this is also the firm conclusion of the Joint Scrutiny Committee. A more detailed parliamentary briefing on this matter has also been shared with all MPs. This was drawn up in response to what we believe strongly is misleading information distributed by SPUC, who continue to claim that the Bill would allow euthanasia by neglect. We have also reiterated our strong position in support of advance statements to be included on the face of the Bill (these could be used by someone to record their wishes that every effort be made to prolong their lives in all circumstances, for example), as well as our support for advance decisions (where someone states in advance what treatment they would wish to refuse under specific circumstances) remaining on the face of the Bill. Both would help to put someone who loses capacity, in terms of expressing personal wishes and having these respected, on a par with people with capacity who are free to refuse medical treatment and able to request that as much help as possible be provided to them.

6. Parliamentary and media coverage

The MDA has had regular meetings with officials from the Department of Constitutional Affairs and with the Minister responsible for the Bill, Lord Filkin. We have regularly contributed to meetings of the DCA's consultative forum and separate meetings held by the Department of Health. We have also had discussions with officials on the Code of Practice and on the implementation of the Bill. We have been praised by the Minister as a serious and well-organised campaigning force

We have briefed MPs regularly in order to inform them of the role of the MDA, the need for new legislation and our concerns in relation to the Bill. A separate briefing on euthanasia was sent out to all MPs (see above) and meetings arranged with key parliamentarians concerned about end of life decision making including Lord Alton and Jim Dobbin, MP. We have also had a number of one-to one meetings with MPs and Peers about the Bill. We have given a number of presentations at Westminster, including a parliamentary seminar to mark the publication of the Bill, and meetings of the All Party Group on Autism and the All Party Group on Learning Disability (which brought together a range of All Party Groups). We organised fringe events at each of the three Party Political Conferences in 2003, which were extremely well attended.

The MDA has formed a separate media group from amongst Alliance members. It was very successful in getting coverage of the campaign pack on national and regional print and broadcast media and in responding to key landmarks such as the publication of the Bill and the report of the Joint Committee. We have also had articles in specialist press, such as Community Care and Third Sector and have used strong case studies to illustrate the importance of legislation and the gaps in government thinking. The MDA has also had articles in our members' newsletters and in other publications such as the Law Society Gazette, RCN newsletter and Mind legal newsletter. We have been effective in selling the story to journalists, despite the complexity of the issue. The MDA have commented specifically on the financial provisions of the Bill, appointeeship and advocacy. The MDA media group has also

developed a media strategy for the forthcoming months. Steve Broach and Richard Kramer have secured speaker platforms to profile the MDA and its work, including the Action on Elder Abuse Conference, Age Concern Conference, Learning Disability Today and forthcoming events organised by Pavilion on Adult Protection and a conference organised by Leeds NHS Trust.

7. Future Challenges for the MDA

- The MDA will need to respond to the Government 's formal response to the Joint Committee's report. We anticipate that we will need to maximise our campaigning activity on issues around the provision of independent advocacy and the general authority to act, if we are unhappy with the government's response.
- There is also a need significantly to step-up our parliamentary activity in anticipation of legislation and to form a separate parliamentary group to work on the forthcoming Bill.
- We want to continue close dialogue with groups concerned about the Bill, including SPUC and People First. We will also need to ensure that members of the Joint Committee are informed about our work, and encourage individual members to continue to exert their influential role with government. It is also critical to ensure that the debate on euthanasia is not used to delay progress on the Bill.
- It is important we maintain links with members, supporters and individuals and we need to consider how to maintain communication.
- We will need to focus our future policy work on informing the Code of Practice that will underpin future legislation and how the Bill will be implemented in practice.

Conclusion

MDA has achieved much over the past two years. It is fast becoming a model of good practice in successful co-working and collaboration across a wide range of voluntary organisations and interests. Our success to date is very much a product of the commitment shown by, and priority given to, this issue and this work by MDA's member organisations - and of the commitment shown by the individuals who attend on behalf of those organisations. Our future success in achieving positive legislative change very much hinges on that existing commitment in order to meet the challenges of the next, critical, stages.

Richard Kramer

Steve Broach

Co-Chairs, Making Decisions Alliance

12th February 2004

Annex One- Members of the Making Decisions Alliance

- Action on Elder Abuse
- Addavoice
- Age Concern England
- Alzheimer's Society
- Beth Johnson Foundation
- Carers UK
- Counsel and Care
- Centre Policy on Ageing
- The Down's Syndrome Association
- Foundation for People with Learning Disabilities
- Headway
- Help the Aged
- Kent Autistic Trust
- Leonard Cheshire
- Mencap
- The Mental Health Foundation
- Mind
- Motor Neurone Disease Association
- The National Autistic Society
- Patient Concern
- POPAN
- The Relatives and Residents Association
- Respond
- Rethink
- Scope
- Sense
- Skills for People
- The Stroke Association
- Turning Point
- United Response