

Mental capacity – who is affected and why

Millions of people in the UK may at some point have difficulty making and communicating decisions, in other words they may be deemed not to have mental capacity. This may affect people who have disabilities or impairments, health conditions such as dementia, injury (such as brain injury) or mental health problems. Groups of people who are likely to have difficulty making decisions include approximately:

700,000 people in the UK with dementia. These numbers are expected to rise significantly over the next 25 years as the population ages. (Source: Alzheimer's Society website)

One in six adults aged between 16 and 64 have severe and enduring mental health problems (i.e. mainly schizophrenia and bi-polar affective disorder). (Source: *ONS*).

145,000 adults with severe and profound learning disabilities in England, including 120,000 adults of working age and 25,000 older people. (Source: *Valuing People*, DOH, 2001)

310,000 adults in the UK with an autism spectrum disorder whose IQ is greater than 70. They will not be included in the population with a learning disability, but all of them may experience difficulties in making and communicating decisions. (Source: National Autistic Society information centre)

135,000 people in the UK requiring round the clock care after surviving severe head injury. (Source: Headway, the brain injury association website)

300,000 people disabled following a stroke, the largest single cause of severe disability in England and Wales. About one-third of those who suffer a stroke will experience communication difficulties. (Source: Geddes, 1996 and ONS Mid year estimates 1994 cited by the Stroke Association website)

Only a tiny minority of those who may have difficulty making decisions have accessed the current legal provisions relating to mental incapacity. 20,000 people currently have a receiver appointed by the Court of Protection, and a further 25,000 have a registered Enduring Power of Attorney. **Please see *Frequently asked questions factsheet 10* for further information on Enduring Power of Attorney.**

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Case studies

Example One

Elizabeth was the sole carer for her aunt with dementia who was living in a care home. She experienced great problems in looking after her aunt's interests "because 'the authorities' seem to think that because she has no close relation [i.e. daughter/son/husband] they can manage her life as they see fit." Elizabeth or her aunt have not been consulted on any matters throughout most of her aunt's stay at the home. With her aunt's doctor, Elizabeth repeatedly has to argue the need for her to have access to information or involvement in medical care. She finds that "it is a waste of all our time when I am told to make appointments with various people, who are unable to give me any information. There is also a problem when I am not kept informed about my aunt's medication. I try to keep involved in her taking the medication regularly and I need to know about changes in the dose and when new prescriptions are issued."

How legislation would help

Elizabeth thinks that her aunt has some capacity which is not recognised, therefore disempowering her aunt. Currently, the law suggests that a person either has full

capacity or no capacity. By recognising that capacity is not a 'black and white' issue, new legislation will allow the aunt to be involved in her own care as far as possible. Legislation will also help by allowing her aunt to delegate her decision making powers by way of a health and welfare power of attorney. Elizabeth will be able to fully participate in decision making, and represent her aunt's needs and preferences.

Example Two

Mark and Andrew are 19 and 23 and live in a residential home. They have profound and multiple learning disabilities and can not communicate their preferences. Mark and Andrew's parents are unhappy with a service provided by Social Services and consider that it is inadequate and inappropriate to meet their needs. Social Services have made it clear to the parents that they have no right in law to make any decisions on behalf of their two sons.

How legislation would help

The family would have a legal basis to make informal day to day decisions on behalf of Mark and Andrew. This would be regarded in law as "a general authority to act." An application could also be made to a Court of Protection for a manager to be

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appointed. The manager may be a friend or paid professional and would be accountable to the Court of Protection. The Court selects the manager by considering the person's wishes, the nature or complexity of the person's affairs, and what would be in the person's best interests.

Example Three

Sarah is 33 and was born with a condition that left her unable to walk or talk. At 18 she was admitted to hospital with pneumonia. While in hospital her consultants suggest to her mother that she should not be given life saving antibiotics. Her mother wants to refuse, but the doctor says that there is no absolute duty to take account of her views with regard to her daughter's treatment.

How legislation would help

Although relatives may currently be consulted, Sarah's mother cannot legally consent or refuse treatment on Sarah's behalf. Where 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. Where there is a dispute as to whether these interests can be properly defined, the case would be referred to another health professional who is not part of the treating team for a second opinion. Reform would ensure that

the health professional would have a legal duty enshrined in law to try to reach a consensus between relatives, carers and health professionals. In cases where a health professional's view is seriously challenged and agreement cannot be reached it may, as a matter of last resort, be necessary to refer the case to the courts.

Example four

Janice is 27 years old and was diagnosed as suffering from schizophrenia 4 years ago. She has been admitted into psychiatric hospital on three separate occasions. Two of these admissions involved her being compulsorily detained under the Mental Health Act 1983. Currently she lives at home with her mother and is dependent upon welfare benefits. Janice is on strong medication which makes her very drowsy a lot of the time so she spends a lot of time in bed although likes going to the pub to see friends. She has two children, one of whom is in care, the other who lives with her but is looked after mainly by her mother. At present Janice's mother makes her hand over all her money to her because she says that Janice does not have the capacity to handle it herself and will spend it on alcohol and non-essential items. Janice is visited by a social worker who has concerns about how Janice's money is handled but Janice's mother refuses to discuss the issue with them.

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How legislation would help

Legislation would enable a clear assessment of Janice's mental capacity to be made, particularly regarding her ability to handle money. This would result in either protecting Janice's rights to handle her financial affairs herself, confirm that her mother is acting in Janice's 'best interest', or indicate that other arrangements (e.g. via the social worker) need to be considered in order that decisions about her money are based upon Janice's 'best interest', even if she is unable to make the decisions herself. Whichever way, legislation would clarify Janice's capacity to make decisions and remove the possibility of financial mismanagement or exploitation.

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