The Mental Capacity Act and People with Learning Disabilities: Practical Implications

Steve Hardy
Consultant Nurse in Learning Disabilities, Oxleas NHS Foundation Trust
Honorary Tutor, Institute of Psychiatry
Aim of the presentation

- To gain a better understanding of the practical implications of the Mental Capacity Act in,
  - how it relates to people with learning disabilities
  - Assessing capacity
  - Making best interest decisions
  - A focus on behaviour described as challenging
Mental Capacity Act (2005)

- The Mental Capacity Act (2005)
  - Department of Constitutional Affairs (2005)

- The law applies to adults over the age of 16 years in England and Wales.
Mental Capacity

- Mental capacity is the ability to make a decision

- Includes decisions about day to day life, such as when to get up, what to wear or whether to visit the doctor if you’re feeling unwell or more serious decisions

- Also refers to decisions that may have legal consequences, such as agreeing to have medical treatment, buying goods or making a will
Why follow the MCA?

1. Impacts on large numbers of people using services – and therefore on those who provide, commission and inspect them
2. Implementation is a statutory requirement – not a choice!
3. Following the Mental Capacity Act and being able to justify your actions is a valid basis for defence against any litigation
4. The MCA promotes autonomy and choice of individuals
5. Offers protection to people who are vulnerable
6. To ensure that people who lack capacity are offered the same range of interventions as they able to make decisions for themselves
7. Services need to be able to demonstrate that they have followed these principles
Principles of the MCA

- A presumption of capacity - every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise;
- The right for individuals to be supported to make their own decisions - people must be given all appropriate help before anyone concludes that they cannot make their own decisions;
Principles of the MCA

- That individuals must retain the right to make what might be seen as eccentric or unwise decisions;
- Best interests – anything done for or on behalf of people without capacity must be in their best interests; and
- Least restrictive intervention – anything done for or on behalf of people without capacity should be the least restrictive of their basic rights and freedoms.
When you might question capacity

- The person has a mental disorder
- Person has made several unwise decisions
- You believe that the person is being coerced
- The person is suggestible/acquiesces
- Personal knowledge of the individual
Common scenarios in practice

- Medical treatment
- Where to live & contact with family/others
- Managing money
- Sexual relationships
- Engage in a tenancy agreement
Capacity

- Should be decision specific.
- A person may lack the capacity to make a decision about one issue but not about others.
- A person can lack the capacity to make a decision at the time it needs to be made, the loss of capacity may:
  - Be partial
  - Temporary
  - It can change over time
Who assesses capacity?

- The person who would normally assess capacity is the person who will implement the decision if the person had capacity and agrees. E.g. a surgeon would assess an individual's capacity with regards to surgery.

- It would be best practice to involve those who know the person well and/or with experience and/or training in working with people with learning disabilities.
Enhancing Capacity

- We have a responsibility to enhance capacity by providing enough support and information in a way that is accessible to the individual, i.e. psychological intervention or medication.
- You must be able to demonstrate that you took all reasonable efforts to enhance capacity when making a decision as whether someone has or lacks capacity.
Outdated approaches to assessing capacity

- **Status**
  - Your status determines your ability to make a decision e.g. gender

- **Outcome**
  - Judgement of capacity based on societal values
Developing an objective method of assessing capacity

- **Re C; considered whether a person who had schizophrenia, whilst detained in a high security hospital had capacity to refuse the amputation of a gangrenous foot**

  - Capacity requires that the person can:
    - understand and retain the information relating to the decision in question
    - weigh that information in the balance to arrive at a choice
Developing an objective method of assessing capacity

Re: MB pregnant woman’s refusal to consent to medical procedures necessary for a Caesarean section (venepuncture) due to phobia to needles.

- Found that inability to make a decision occurs when:
  - The patient is unable to comprehend and retain information which is material to the decision, especially as to the consequences of having or not having the treatment in question; or
  - The patient is unable to use the information and weigh it in the balance as part of the process of arriving at a decision.
The functional test

- The person must have impairment, or disturbance in functioning of the mind or brain
- The person is unable to make a decision for himself if he is unable
  - To understand the information relevant to the decision
  - To retain information
  - To use or way that information as part of the process of making the decision or
  - To communicate his decision
Medical Treatment

- Understand in simple language what the medical treatment is, its nature and purpose, and why it is being proposed
- Understand the principal benefits, risks, and alternatives of the treatment
- Understand in broad terms what will be the consequences of not receiving the proposed treatment
- Retain the information for long enough to use it and weigh it in the balance in order to arrive at a decision
Medical treatment – assessing capacity

- Need to give information (get information from treating doctor, translate into an accessible format)
- Ask what they remember – “can you tell me about the treatment….
- What are the good things about having treatment? – “will it make the cancer go away” “will make me better”
- What are the bad things “it might not work” “I will feel very sick”...
- What if you don’t have the treatment “I won’t get better” “I might die”
- What do you want to do? (communicating choice)
- What reasons? (weighing up)
Where to live

- Questions (as a conversation!)
- What is it like living here? (i.e. supported living)
- What do you do here?
- What are the good things/bad things?
- When/if you lived with Mum/Dad – what was it like?
- What did you do?
- What were the good things/bad things.
- Living with friends or living with Mum/Dad?
Engage in a tenancy agreement (1)

- Information that the person should be given:
  - You will be living in x house
  - You will be paying rent – that means you have to pay “y” amount every month to be able to stay living in “x” house
  - You will have to pay for food, for light, for heating the house. For example, every time you turn on the light, it uses electricity. You have to pay for using electricity. (Electricity is what makes the light work.....) The more electricity you use, the more you have to pay.... This is called “paying the bills”
  - You have to take care of the house – that means you have to make sure you look after the things in the house. The only things that are yours are......
Engage in a tenancy agreement (2)

- If you don’t pay the rent, or pay for the electricity, or for heating the house then you might be told that you can’t live here any more and you will have to move to another house.
- The person who owns the house (you pay the rent to them) is xx housing association. Because you live there and pay rent, they have to do things for you.
- They have to let you live here
- They have to make sure that things you use in the house (like the washing machine) work properly
- They have to look after the house as well......
Understanding a tenancy contract

- Possible questions for assessing capacity to engage in a tenancy agreement
- Open questions:
  - I have said you will be paying money (called rent). Can you tell me how much you will be paying?
  - Can you tell me why you have to pay it?
  - What else do you have to pay for?
  - What happens if you don’t pay?
  - What happens if you cause a lot of trouble?.....
Assessing capacity

It’s a conversation, not an exam!
Deciding on capacity

- There is no prescribed amount of knowledge etc. that a person has to demonstrate.
- It is a judgement based on the balance of probability.
Models of decision making

- Making your own decision
  - Having capacity and making a decision for yourself
- Advance decisions
  - To refuse (but not demand) medical treatment
- Substituted judgment
  - “standing in the other person’s shoes” – acting as if you were them, trying to decide what they would have wanted
- Best interests
  - More objective test – what is the “best course of action” for this person, and not the personal views of the decision-maker
Best Interests: Cases

- The following court cases involved people with learning disabilities and helping shape best interest

  - *Re A (Male sterilisation)* [2000] 1 FLR 549 CA
  - A Hospital NHS Trust *v* S [2003] EWHC 365 (Fam)
  - *Re S* (Adults Lack of Capacity: Carer and Residence [2003] EWHC 1909 (Fam)
  - *Re Y* (Mental Incapacity: Bone Marrow Transplant) [1996] 2 FLR 787
Male Sterilisation

Re A (Male sterilisation)[2000] 1 FLR 549 CA

- Advantages of a vasectomy were not clear
- Would his freedom be restricted if he retained his fertility (i.e. likely to have similar level of supervision in care as at home)?
- Unlikely to reduce the risk of exploitation or STIs?
- Unlikely to enter into a casual sexual relationship
- It would not enhance his quality of life?
- Issue of the impact on his mother, or of any woman who might get pregnant by him, not relevant, as mother will continue to care
- Birth of a child or disapproval of his conduct unlikely to impinge on him
- Benefit of foolproof contraception
- Dis-benefit of apprehension, risk and discomfort of the operation
- Decision: operation not essential to A's future well-being
Kidney Transplantation

A Hospital NHS Trust v S [2003] EWHC 365 (Fam)

- “just because a person cannot understand treatment, does not mean they cannot have it – the inability to understand must make the treatment intolerable. If there is a quality of life then, even if it is necessary to go through a traumatic period, it would be worthwhile in the long term.”

- The court thought that specialist preparation would overcome these problems to a significant extent.

- There were other methods of treatment currently available, but a kidney transplantation should not be excluded on non-medical grounds.
Removal from family home

*Re S (Adults Lack of Capacity: Carer and Residence [2003] EWHC 1909 (Fam))*

- S’s welfare was the prime concern, and the relative suitability of each party’s plans for her future.
- S had no contact with her siblings.
- S’s father did not co-operate with the local authority.
- S’s father was unable to meet her needs for 24-hour care and to respond appropriately to her challenging behaviour. He was also getting older.
- S’s father loved his daughter and felt a strong sense of duty towards her.
- The local authority could offer purpose-built accommodation, appropriate staffing, more social living amongst people of her own age and the opportunity for her family to visit.
- The judge held that, on balance, S’s best interests would be served by following the Local Authority care plan.
Bone Marrow

Re Y (Mental Incapacity: Bone Marrow Transplant) [1996] 2 FLR 787

• Considerations
  • Continue to enjoy visits from mother and sister
  • Good relationship with mother and sister
  • If sister became unwell, visits from mother would reduce
  • Strong possibility sister would die without the transplant, resulting in end of relationship and visits
  • If sister died, Y’s mother would have to look after sisters child and thus visits would reduce
  • Sister more likely to recover with Y’s bone marrow, though sisters best interests not the issue, sisters survival is in Y’s best interests
  • Operation would be traumatic and uncomfortable
  • General anaesthetic without problems, but Y at no greater risk than rest of the population
  • Family could support Y through procedure
  • Y could have pain killers following operation
  • Permission granted for transplant to occur
Balance sheet approach

From these cases it has been recommended decision makers should use a ‘balance sheet approach, which should include:

- Benefits of the procedure
- Disbenefits of the procedure
- Possible gains and losses and likelihood of them occurring
- Strike a balance between possible gains and losses
- Only if the benefits out weight the disbenefits should the procedure be viewed as in the persons best interests
# Balance sheet approach

<table>
<thead>
<tr>
<th></th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Welfare</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Relevant circumstances

- Relevant decisions will vary from case to case
- Medical – not just the outcome, but what will be the burden and benefit of the treatment?
- Social Welfare – how will this impact (for better or worse) on the way the person lives their life? What will this do to the person’s relationships etc?
- Emotional – How will the person feel, react?
Please Check!

- Before that a best interest decision is made, ensure that an assessment of capacity has been completed and it was concluded that the person lacked capacity at this time in relation to this particular decision.
Best interest decisions

- If a person has been assessed as lacking capacity then any action taken, or any decision made for, on behalf of that person, must be made in his or her best interests.

- The person who is to make the decision is known as the ‘decision maker’ and will normally be the carer responsible for the persons day to day care. In regards of treatment, the ‘decision maker’ is the clinician responsible for giving the treatment.
Best interests - for those who lack capacity

- MCA provides a statutory checklist of factors to be considered when making a decision on behalf of someone unable to make it for themselves.
- These include:
  - Anti-discriminatory practice
  - Considering whether person might regain capacity
  - Do everything possible to encourage participation
  - Consider any wishes or beliefs the person themselves might have had
  - Consulting others (including family and carers)
  - Consider all relevant circumstances
  - NOT be motivated by a desire to bring about the person’s death, if the decision involves life-sustaining treatment.
Least restrictive

- People whose behaviour is described as challenging are at risk of being in receipt of aversive interventions, being placed in restrictive environments and having limited opportunities.
- The decision made in the best interests of the individual should be done in a way that is less restrictive of the person’s rights and freedom of action.
- Medical treatment:
  - The treatment has to be in accordance with that which would be given by a responsible body or other medical practitioners.
Deprivation of Liberty Safeguards
Deprivation of Liberty Safeguards

- In response to the Bournewood case
- The Mental Health Act 2007 amended the Mental Capacity Act 2005 by introducing DoLS.
- DoLS provides a process to which individuals are assessed as to whether their liberty is being deprived and due legal process to safeguard their rights and ensure appropriate review.
- DoLS follows the five principles of the Mental Capacity Act 2005.
Deprivation of Liberty

- Currently 3 ways to authorise deprivation of liberty:
  1. Detention under the MHA.
  2. Authorisation under DOLS.
  3. Order from the Court of Protection
Case example: Least restrictive

- Re C; C v Wigan Borough Council (2011) EWHC 1539 (Admin) (‘The Blue Room’)
  - C – 18 year old man
  - Severe learning disabilities, autism
  - Sensory impairments, significant communication needs
  - Severe behavioural challenges
  - Residential special school
    - Individual education plan
    - Timetabled activities
    - Behavioural support plan
    - 2:1 staffing 24 hours day
    - Own flat, with some shared facilities with another young man
Case example: Least Restrictive

- Behavioural plan since 2007 included use of the ‘blue room’ specially constructed room, padded, 10 feet square, secure door (impaired line of sight), window and door cannot be locked

- Rationale
  - Calming influence
  - Prevent injury
  - Seen at time as in his best interests

- Though door could not be locked staff could prevent exit if C continued with aggressive behaviour, and if undressed would be encouraged to stay in the room
Case example: Least restrictive

- June 2010, 2090 instances of challenging behaviour, average 70 per day. ‘Blue room’ door held to confine C on 192 occasions, average 6.4 times a day and C was confined for many hours a day.
- September 2010 claim made for judicial review by C mother, which Inc.;
  - Appropriate care plans
  - Disclosure of behavioural support plan, incidents of restraint, qualifications and training of staff
  - Transition plan
  - Breach of ECHR articles
    - 3 - Inhumane or degrading treatment or punishment
    - 5 - Right to liberty and security
    - 8 - Right to respect for private and family life
- C as assessed as lacking capacity to conduct litigation and did not have the capacity to make decisions about residence or care.
Case example: Least restrictive

- Agreement to make formal assessments and implementation of existing sensory interventions
- Outcome
  - Since C turned 16 the MCA was more relevant to his situation, but this was not applied.
  - As DoLS does not apply to C, as not residing in a hospital or care home, an application should have been made to the COP before any deprivation of liberty occurred.
  - There was no lawful authority to deprive C of his liberty.
Case example: Least restrictive

- COP when making a best interest decision in C case will have regards to the same material as contained in the DoLS Code of Practice.
- CoP sought views of 9 expert witnesses
- Courts view in relation to situations where secluding was lawful:
  - When used to control aggressive behaviour, but only so long as was necessary and proportionate and it had to be the least restrictive option. In accordance with an intervention and prevention care plan. Use of blue room written as part of a protocol, in which staff trained specifically in relation to C.
Case example: Least restrictive

- Not lawful to seclude C solely for nakedness, is not proportionate to any risk or least restrictive option. Staff training for strategies.
- Not lawful to seclude C as a punishment, as part of a behaviour management plan.
- Not lawful to seclude C solely for reason of him self-harming. Could be used where C’s self-harm was coupled with aggressive behaviour.
  - (Thirty Nine Essex, CoP Update, Issue 10, June 2011)
It would not be right to leave this tragic case without noting that there are many very dedicated people, professionals and trained carers alike who are involved in the care of those with complex needs like C: they deserve the court’s and society’s sincere thanks. Despite this and despite the plethora of Government guidance and regulation, the court is left with a worrying impression that urban myth and so called ‘common sense’ rather than expert advice and multi-disciplinary working practices continues to be influential in some residential settings. Inquiries long ago established the need for specialist, qualified care and treatment for pupils and patients with special needs and likewise in the management of the establishments which provide that care and treatment: whether they are schools, children homes, care homes or hospitals. Until this court’s intervention, that multi-disciplinary environment with access to high quality inter-disciplinary advice did not exist for C. That was unacceptable.
Positive steps

- Transforming Care: A National Response to Winterbourne View Hospital
  - The Department of Health will work with CQC to agree how best to raise awareness of and ensure compliance with Deprivation of Liberty Safeguards (DOLS) provisions to protect individuals and their human rights and will report by Spring 2014.
  - Physical restraint should only ever be used as a last resort and never used to punish or humiliate.
  - The Department of Health will, together with CQC, consider what further action may be needed to check how providers record and monitor restraint.
Positive steps

- WV Concordat:
  - With external partners, DH will publish by the end of 2013 guidance on best practice around positive behavioural support so that physical restraint is only ever used as a last resort where the safety of individuals would otherwise be at risk and never to punish or humiliate.
  - We will explore with the Royal College of Psychiatrists and others whether there is a need to commission an audit of use of medication for this group. As the first stage of this, DH will commission by summer 2013 a wider review of the prescribing of antipsychotic and anti-depressant medicines for people with challenging behaviour to report.
  - As the British Psychological Society, to provide leadership to promote training in, and appropriate implementation of, Positive Behavioural Support across the full range of care settings.
Key points

- The MCA is every body’s business
- A clear framework that promotes autonomy and on how best interest decisions should be made.
- However it does not provide a tick box/threshold assessment, practitioners and carers are required to make decisions on capacity and best interests.
- Families and carers are central to the MCA process and should not be overlooked.
Key points

- There is no justification to use overly restrictive practices, practitioners should always seek to use the least restrictive option and be able to justify what they are doing is the best course of action for the individual at that particular time.
- Positive behaviour support is key in developing high quality, ethical interventions
- We need to be mindful of where the line is drawn, and where something may become a deprivation of liberty.
- If we think that line has been/will be crossed then legal processes need to be adhered to.
References

- Joyce T and Hardy S (2012) Mental Capacity Act and People with Learning Disabilities: A training pack to develop good practice in assessing capacity and making best interest decisions
- Re C; C v Wigan Borough Council (2011) EWHC 1539 (Admin) Re A (Male sterilisation)[2000] 1 FLR 549 CA
- A Hospital NHS Trust v S [2003] EWHC 365 (Fam)
- Re S (Adults Lack of Capacity: Carer and Residence [2003] EWHC 1909 (Fam)
- Re Y ( Mental Incapacity: Bone Marrow Transplant) [ 1996] 2 FLR 787