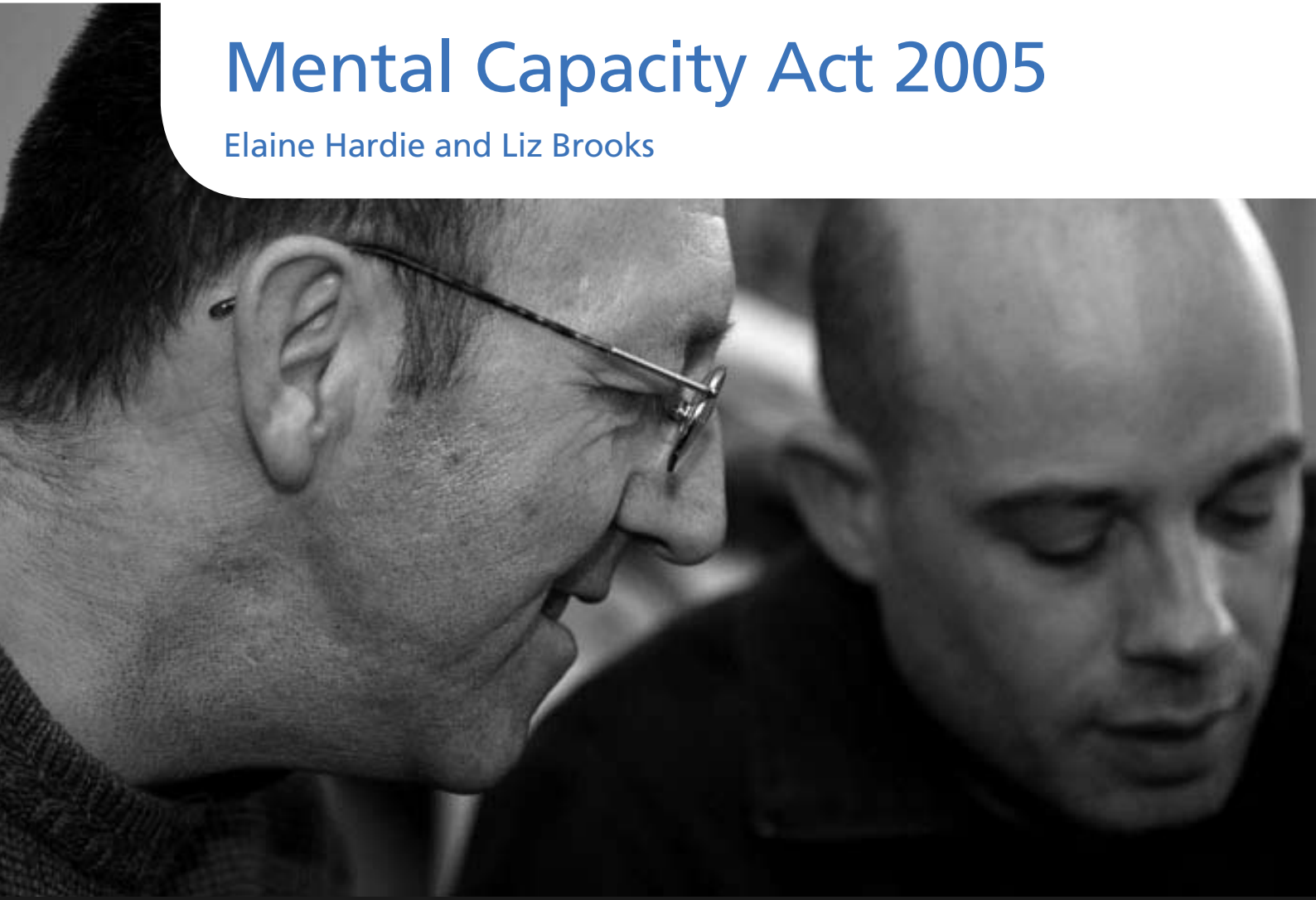


Mental Capacity Act 2005

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**Implications for people
with learning disabilities**

Brief guide to the
Mental Capacity Act 2005

Implications for people with learning disabilities

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About the British Institute of Learning Disabilities

The British Institute of Learning Disabilities is committed to improving the quality of life for people with a learning disability by involving them and their families in all aspects of our work, working with government and public bodies to achieve full citizenship, undertaking beneficial research and development projects and helping service providers to develop and share good practice.

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About this guide

The Mental Capacity Act 2005 came into force during 2007. It affects people who are not able to make some or all of the decisions that affect their lives. This could be now, or at any time in the future.



There are approximately two million people in England and Wales who lack mental capacity to make some decisions for themselves, for example people with:

- learning disabilities
- dementia
- mental health problems
- stroke and brain injuries

In addition to this there are up to six million family and unpaid carers and people involved in health and social care who may provide care, support or treatment for them.

If you work with people who have a learning disability, this guide is for you. We also hope it will be read by:

- parents and carers
- friends
- advocates and self-advocacy groups
- anyone wanting to know more about the Mental Capacity Act 2005 and how it applies to people with a learning disability

We want people with a learning disability to be aware of their choices and decisions, and talk to those around them about how they feel.

The guide aims to:

- explain the key points of the Mental Capacity Act 2005
- explain what some of the choices and decisions might be
- help you to support someone with a learning disability to plan ahead and talk about their future

The guide also provides case studies to demonstrate the key points of the Act. These are practical examples to explain how the Act might be applied in a real life situation. However, they are not intended to be a model answer, as each situation must be taken on an individual basis.

The guide is accompanied by a poster that highlights the 5 Principles of the Act.

How does the Mental Capacity Act 2005 affect people with a learning disability?

Prior to the Mental Capacity Act 2005 there was no clear legislation on mental capacity in England and Wales. It was therefore dependent on pockets of good practice or common law. This meant that people with a learning disability in one service or part of the country may have been treated very differently to those in another service or geographical location.

There was no legal protection for people who provided care and treatment for people who lacked capacity, no legal rights for carers or family members to be consulted and only limited options for people who wanted to plan ahead for any future loss of mental capacity.

The right of people with a learning disability to make their own decisions has not always been respected. Many people have been viewed as incapable because of their label or diagnosis, or were 'allowed' to make decisions by those around them so long as they were seen by others as making the 'right' decision. If someone with a learning disability made a decision that was considered to be unwise by their family or people who support them they were often seen as lacking capacity.

Some professionals have made decisions on behalf of a person with a learning disability who lacks capacity without considering their wishes and feelings. They have made assumptions about their level of capacity and taken decisions on their behalf without including them or their family in the process.

The Mental Capacity Act 2005 aims to change this and encourages a consistent approach across England and Wales.

The only parts of the Mental Capacity Act 2005 that apply to children are the criminal offences of wilful neglect and ill treatment of an individual who lacks capacity. However, this is only for children who have an 'impairment or disturbance of the brain' and who lack capacity, not those who may lack capacity because of their age or stage of development. There are other pieces of legislation and guidance, such as the Children Act 1989 and the Fraser Guidelines, that cover children.

Most of the Act covers young people aged 16 and 17 although it will be decided on a case-by-case basis which is the best piece of legislation to use with each individual. The only parts of the Act that do not apply to young people are Lasting Power of Attorney, advance decisions to refuse treatment and statutory wills.

What is mental capacity?

'Mental capacity' simply means our ability to be able to make decisions.

These may be everyday decisions about the food we choose to eat or the clothes we wear. They may be bigger decisions, for example where we live, who we live with, what health care treatment we need or what we spend our money on.

Some people have the capacity to make some decisions, such as what to have for breakfast, but cannot make more complex decisions, for example how much of different foods to eat to stay healthy.

Some people have 'fluctuating capacity'. This means that they can make decisions some of the time or at certain times of the day but not at other times.

Case study

Tom is a 25-year-old man who has Down's syndrome and has lived in a care home for six years. He is able to express what he wants, and make decisions about day-to-day choices, but has difficulty understanding the long-term implications of his choices. Tom's favourite foods are pies, chips and fry-ups and it is difficult to persuade him to eat his 'five-a-day'. He hates all forms of exercise and has become seriously overweight. His doctor is concerned that without a strict calorie-controlled diet and exercise programme he is at high risk of a heart attack.

In this situation Tom's staff decided that all the residents (and the staff) would benefit from a healthy eating regime. This was useful as Tom did not feel that he was being 'picked on'.

The staff involved Tom in the menus for the house and wherever possible tried to substitute high calorie food for 'low calorie' options. They

worked with him in a way that he understood to enable him to understand the food choices available to him.

They looked at alternative forms of exercise such as line dancing and walking, which Tom did not consider to be 'real' exercise, and encouraged him to choose a keep fit DVD by a celebrity he liked.

Tom was not denied his favourite steak pies but was encouraged to have them on a Saturday, after he had done his shopping, as a treat.

This way Tom was included within the decision-making process and was not completely restricted from having some of the things he liked to eat.

The 5 Principles

Five principles underpin the Mental Capacity Act 2005 and we have a *legal obligation* to ensure that *every time* we work with someone with a learning disability we work within the framework of these principles.

Principle 1: Assume a person has capacity unless proved otherwise.

Previously, we have made many assumptions about people with a learning disability. We may have assumed that because they have a learning disability they do not have the capacity to make their own decisions.

Under the Mental Capacity Act 2005 we have a duty to assume that a person with a learning disability *has* the capacity to make their own decisions. The process of assessment will confirm this or show that the individual may not be able to make decisions on their own.

Principle 2: Do not treat people as incapable of making a decision unless all practicable steps have been tried to help them.

It has been common practice to give information to the person with a learning disability and assume that they lack capacity if they cannot make a decision immediately. Often this has not been the case at all.

We now have a *duty* to ensure that we take every practicable step to support the individual to make their own decisions. This includes:

- presenting information in an accessible format and helping the individual to communicate their decision to you, for example using symbols, pictures, signs, assistive technology, clear jargon-free text or a translator if the person does not speak English
- spending time identifying the preferred communication methods and, if this information is not known, finding out from those who know the individual well
- allowing time for the person to process the information or being aware that certain times of the day might be better than others because an individual may need time to reflect on the information and we cannot assume that a decision and choices can be made in a single session – they may need to discuss with those around them
- ensuring the environment is comfortable, private and does not have any distractions
- using calendars and diaries or objects of reference





Principle 3: A person should not be treated as incapable of making a decision because their decision may seem unwise.

People with a learning disability have been 'allowed' to make decisions as long as they have made the 'right' decisions. If the

person made an unwise decision, the people who supported them would assume that they lacked the capacity to understand the decision and take the decision away from them.

However, most of us have made an unwise decision or two in our lives. As citizens we have the right to make our own decisions, even if sometimes we make an unwise one. This is what helps us to learn and develop as individuals. We are all who we are today because of the decisions we have made along the way and any mistakes that may have resulted. We all learn from the risks we take and the mistakes that may have resulted.

This principle recognises that people with a learning disability are citizens with the same rights as everyone else, including being able to take risks, and that if they understand the consequences of their decision it is their decision to make.

Principle 4: Always do things or take decisions for people without capacity in their best interests.

This principle applies when we are working with people who lack the capacity to make their own decisions. It may seem an obvious statement, but decisions have often been made because it was in the interests of those who support the person with a learning disability or their family.

We can only apply 'best interests' when a person lacks capacity. If a person has the capacity to make their own decisions – even if it is an unwise decision – we cannot overrule that decision by saying that we are acting in their best interests.

Principle 5: Before doing something to someone or making a decision on their behalf, consider whether the outcome could be achieved in a less restrictive way.

If you are the decision-maker for someone who lacks capacity you must consider the options available and decide which option will be the least restrictive for the person.

Assessment of capacity

As a result of the Mental Capacity Act 2005 the assessment of capacity has to be done on a 'decision-by-decision' basis. Previously, it had been quite common to make 'blanket' assessments of the person's capacity. This meant that an individual could be assessed and labelled as 'lacking capacity', a label that stayed with them always and for all decisions.

While there will obviously be some people with learning disabilities who lack capacity to make decisions and who are unlikely to acquire this capacity, there are also many people with learning disabilities who can make day-to-day decisions, but who are unable to make bigger life-changing decisions. Other people have fluctuating capacity and can make decisions on some occasions but not at other times. What to wear and what to eat are examples of day-to-day decisions, while moving home or an operation in hospital are examples of bigger life-changing decisions.

By specifying that people are assessed on a decision-by-decision basis, the Mental Capacity Act 2005 recognises that people with learning disabilities can be encouraged to make whatever decisions they have the capacity to make, and that if they are unable to make a particular decision someone will make it for them in their best interests.

However, it will not always mean that they lack capacity because next time a decision needs to be made they will have another opportunity to be assessed. It also means that anyone could be responsible for assessing the individual at any given time. Front-line workers will use the decision-by-decision criteria on a day-to-day basis to make a range of decisions about an individual's support and welfare and it is good practice to ensure that the issue of choice and decision-making is addressed in people's support plans.



Assessing capacity

The Mental Capacity Act 2005 Code of Practice tells us that the assessment of capacity is a two-stage test.

Stage 1: The diagnostic approach

1. Does the person have an impairment or disturbance of the functioning of the mind or brain?

This can include people:

- with a learning disability
- with dementia
- with mental health problems
- suffering from a stroke or brain injuries
- who have a temporary impairment or disturbance of the brain, for example people who are in a coma or unconscious or under the influence of drugs or alcohol

If the answer is 'yes' then the Mental Capacity Act 2005 can be used and we can move on to the second part of assessment.

Stage 2: The decision-making process

1. Does the person understand the information regarding the decision?

We should have taken *all* practical steps to support the person with learning disabilities to make the decision themselves.

It is important, at this stage, to identify the preferred communication methods and to ensure that information is given in an easy to understand and accessible way, using symbols, pictures, signs, assistive technology, interpreters or whatever the person needs to help them understand what is involved in the decision they have to make.

2. Can the individual retain the information for long enough to make a decision?

This is about the individual's short-term memory and whether it is possible for them to retain information for long enough to be able to make a decision.



There are many strategies that can be used to help the person:

- Give information in more than one way, for example words and pictures.
- Ensure that the individual is given information in small 'chunks' rather than bombarded with lots of information all at once.
- Use prompts, cues or objects of reference to help the individual remember, and put these in places the person will see, for example hanging up a blue dress and a red dress on the wardrobe door for the person to choose which one to wear.
- Repetition helps the memory, so the more the information is repeated the better the chance that the person will remember it and that it will become part of their long-term memory.

Just because the person is able to retain the information relevant to the decision for a short amount of time only *does not* prevent them from being considered as able to make the decision.



Case study

Beth is a 19-year-old woman who has learning disabilities and limited short-term memory. She is in hospital because of her epilepsy.

Doctors have identified worrying signs in her recent brain scan and feel that an operation is needed but, as with any operation involving the brain, the risks are high.

That Beth has difficulty with her short-term memory does not mean she cannot make the decision about whether to go ahead with the operation. She just needs to retain the information for long enough to make a decision and understand the consequences of her decision.

The surgeon is the person who has most insight into Beth's condition and is therefore best placed to consider what practicable steps will help Beth understand the decision she needs to make. The surgeon presents the information

in an accessible format, they give her small amounts of information at a time and repeat the information for her, as this may help her retain the information in her long-term memory. Staff working with Beth visit her a number of times over the several days that Beth needs to make the decision.

In this scenario Beth is unable to make the decision because she cannot retain the information for long enough to make it. The surgeon must act in Beth's best interests.

If Beth could retain the information, even for just a short period of time, to enable her to make the decision, the decision would be hers to make.

3. Does the individual understand the implications of their decision?

Many people with learning disabilities can make day-to-day choices. Some, however, have difficulties with bigger, life-changing decisions. This may be because they do not understand the implications of those bigger choices. Sometimes the bigger decisions are 'abstract' (things that may or may not happen in the distant future) and are not 'concrete', (happening in the here and now) which can make it difficult for the person to understand. Sometimes it may be difficult to weigh up the pros and cons of the options available.

Taking *every practicable step* should help the person to understand the long-term consequences of their decision and include information about the foreseeable consequences of:

- deciding one way or another
- failing to make the decision

This is the area we need to pay particular attention to, however, as people have the right to make unwise decisions as long as they understand the implications for their decisions.

Case study

Alfie is a 46-year-old man who has moderate learning disabilities and communicates using signs and symbols. He has lived in a care home for seven years. He can make day-to-day decisions but has difficulty understanding the implications of bigger decisions. Alfie needs to have an operation but says he does not want to have it as he is afraid of hospitals.

Those working with Alfie assume that he has the capacity to make this decision himself. As part of the assessment process, and working, in line with the 5 Principles, to take 'all practicable

steps', staff work with Alfie to try to understand his fear of hospitals. They find out that he used to live in a long-stay hospital and had an awful time there. Staff realise that Alfie's fears are quite natural.

They involve a speech and language therapist who explains the implications of the operation to Alfie. He is shown round the hospital, introduced to the staff and given time to familiarise himself with the ward he would be on. It is agreed that Alfie would only need to stay in as a day patient – if all goes to plan –



4. Can the person communicate their decision to you?

The Act recognises that most people can communicate even if it is through finger tapping or some other form of intensive interaction such as symbols, pictures, signs, assistive technology, interpreters or whatever else the person needs to help them to express themselves.

We must identify an individual's communication methods and if we do not know this information, find out from those who know the person well.

The person *has the capacity* to make a decision themselves if the answer to these statements is yes:

- they understand the information about the decision that needs to be made
- they can retain the information for long enough to make a decision
- they can weigh up the pros and cons of the options available to them and understand the long-term implications of the decision
- they can communicate their decision to you



and that his key worker, who uses signs and symbols and understands how he communicates, would stay in with him to help reassure him.

Alfie decides that he will have the operation.

If Alfie understands the implications of not having the operation, it is his decision to make even if he decides not to go ahead. Those who work with Alfie need to ensure that they have evidence of the assessment process they have gone through with him and that they have adhered to the 5 Principles of the Act. Where

major decisions such as these are made, a multi-disciplinary team should be involved with Alfie.

Alternatively, if he does not understand the implications of not having the operation, those around him should decide what course of action would be in his best interests.

The person *lacks the capacity* to make a decision themselves if, despite our best endeavours and taking every practicable step to support them to make the decision, the answer to these statements is no:

- they cannot understand the information about the decision that needs to be made
- they cannot retain the information for long enough to make a decision
- they cannot understand the long-term implications of their decision or weigh up the pros and cons

The Mental Capacity Act 2005 is an important factor for the person with learning disabilities to have control over the outcomes of their decisions and their lives. For support workers the important part is supporting people with learning disabilities through the decision-making process in line with the 5 Principles.

If the decision is a 'big' decision or one that might involve some risk it is crucial to involve other people, such as family and friends who know the person well, in the process. It is also important to document the process to determine if the person has capacity to make the decision in hand.

Case study

Shahbaz is a 50-year-old man who has a learning disability. Shahbaz grew up in the Punjab and for the past 15 years has said he would like to return there for a holiday. His older brother has recently died and left him a small amount of money, so Shahbaz is planning a holiday there.

Shahbaz's doctor says that as he has heart problems there is a high risk of him having a heart attack which could prove fatal. Shahbaz says that at least he would die a happy man and

is determined to go. The staff at the residential home are trying to stop him going as they say that making such an unwise decision shows that he lacks capacity.

Although Shahbaz has a learning disability, the difficulty with this situation concerns his physical ill health. Shahbaz has wanted to go to the Punjab for a long time. An advocate who is brought in to work with Shahbaz feels that he has the capacity to make the decision as he



Best interest decisions

The Act does not define what is meant by 'best interests'. This is because we are all individuals and what might be in one person's best interests might not be in another person's best interests. The government knows that it cannot legislate for every individual, so instead provides a Best Interests Checklist.

The person who takes on the role of decision-maker for someone who cannot make their own decisions, has a legal obligation to ensure that the Best Interests Checklist is used as a guide.

Best Interests Checklist

- 1. The decision-maker must consider whether it is likely that the person will at some time have capacity and when that is likely to be.**

It may be that the person has undergone recent hospital treatment, changes in medication or has been unwell. So it may be that the decision can be postponed until the person may be in a position to make that decision themselves.

- 2. The decision-maker must involve the person who lacks capacity in the decision-making process.**

Previously, when people lacked capacity to make decisions, professionals would make the decision separately without involving them. In terms of the Best Interests Checklist we now have a legal duty to involve and encourage the person with a learning disability in the process as far as they are able or to improve their ability to participate, as fully as possible in any decision affecting them. Even if a person is assessed as lacking capacity they must be involved in the decision-making process.



clearly understands the potential consequences, even if it seems unwise to those around him.

Even if it were felt that Shahbaz lacks capacity to make this decision, it may be that he could still go, as it is part of his wishes and feelings. The decision-maker would have to weigh up the pros and cons of the decision to go or not to go, working their way through the Best Interests Checklist and making a decision in the best interests of Shahbaz.

While the obvious choice may be to prevent Shahbaz going on holiday as it presents a risk to his physical health, this needs to be balanced with the risk to his psychological/mental health if he was refused the opportunity to go.



3. The decision-maker must have regard for past and present wishes and feelings, especially written statements.

Some people who now lack capacity may have previously been able to make decisions for themselves and may have shared their wishes and feelings with others. They may still be able to share their wishes and feelings on a particular decision and the decision-maker has an obligation to consider these wishes and feelings as part of the decision-making process. So far as possible the decision-maker will need to consider:

- the person's past and present wishes and feelings
- the beliefs and values that would be likely to influence the person's decision if they had capacity to make the decision for themselves
- the factors the individual would be likely to consider if they were able to do so

4. The decision-maker must consult with others who are involved in the care of the person.

There is now a legal obligation to consult family or friends when making a decision on behalf of a person who lacks capacity. Previously, although many support workers had involved family members or colleagues, it was only as part of good practice. The legal obligation is to involve anyone who may have an interest in the person or responsibility for their care or support, if it is practicable and appropriate to consult them.

Case study

Yasmine is a 19-year-old woman with learning disabilities and limited communication skills. She can make everyday decisions about things like what to eat or wear, but does not have any understanding of long-term consequences.

When she began attending the day centre three months ago her family made it clear to staff that she is a Muslim and spent time explaining what this means. However, Yasmine has shown that she likes bacon sandwiches and staff have not prevented her from eating them. The family found out and turned up demanding to take

Yasmine home on the basis that her cultural needs were not being met.

In this situation the professionals considered a number of things. They assumed that Yasmine has the capacity to make this decision herself. However, during the process of assessing Yasmine's capacity to make the decision the professionals felt that Yasmine did not understand the implications of eating bacon sandwiches. The consequences may include her family preventing her from attending the day centre or deciding that they do not want her to



5. The decision-maker must not make assumptions based solely on the person's age, appearance, condition or behaviour.

It should not be assumed that a person's tastes are the same as those generally associated with people of the same age. For example, just because someone is 65 does not mean that they necessarily like watching daytime television or because a person is 20 they like going to the pub at the weekend. Nor should assumptions be made based on a person's appearance (for example because they come from a particular cultural background) or on a particular condition (for example because they have a label such as learning disability) or because they present 'challenging behaviour'.

6. Where a decision relates to life-sustaining treatment the decision-maker must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his or her death.

All reasonable steps that are in a person's best interests should be taken to prolong their life. In a limited number of cases where treatment would be futile, overly burdensome to the patient or where there is no prospect of recovery, the medical decision may be to withdraw treatment. However, this decision cannot be motivated by a desire to bring about death for whatever reason, even if from a sense of compassion. The decision-maker must consider the range of treatment options available and whether the individual has made previous statements about life-sustaining treatment.

live with them any more as she has not followed their religious observances.

The people who supported Yasmine decided that they had to do so in her best interests. They did this by working with her to include her in the process of finding alternatives such as salt beef, vegetarian bacon, etc. which Yasmine might find equally enjoyable and which are acceptable in the Muslim faith. Yasmine's family was consulted, as was the Imam of the local mosque who explained that there may be some exceptions to the adherence to

certain religious observances, due to Yasmine's disability. This ensured that all the options available were considered to ensure that the least restrictive alternative was found.

If Yasmine had understood the implications of continuing to eat bacon and still wanted to eat it, then it would have been Yasmine's decision to make – even if it was considered by some of the people around her to be an 'unwise decision'.

Communication

by Sue Thurman

Effective communication is the key to the Mental Capacity Act. Addressing the communication issues faced by people with learning disabilities **and** those communicating with them is vital both in order to assess somebody's capacity and to act in somebody's best interest.

It is important to remember that

- **Communication is both verbal and non verbal.** For many people with learning disabilities spoken or written words are not their strongest way of either understanding or expressing themselves. Non verbal communication must be valued and promoted as a valid means of communication. Making 'reasonable adjustments' for people's communication includes being familiar with a variety of communication approaches including **signing, symbols, objects of reference, communication aids** and approaches such as **Intensive Interaction**.
- **Communication is a two-way activity – understanding as well as expressing.** Research and experience shows that people with learning disabilities' levels of understanding are routinely over (or under) estimated by others. It is important to establish clearly how much somebody understands and how they can be best supported to understand the information they need (including non verbal means). It is always vital to remember that expression and understanding may be 'mismatched' (ie somebody may understand a lot more than they can say or vice versa.)
- **Communication is a shared activity – dependent on both partners.** It is not enough to focus on the communication skills or difficulties of the person with learning disabilities. Communication partners must also examine their own communication abilities and if necessary develop new styles and skills of interaction relevant for the people they support.
- **Communication is always potentially ambiguous.** Anyone's communication can easily be misinterpreted by others. This is even more likely with the use of individualised non verbal ways of communication. It is important to try to establish clear 'yes' and 'no' signals from the person. Ways to validate ambiguous communication should be sought and any remaining ambiguity acknowledged, particularly in important life-changing decisions. It is important in evidencing decisions about capacity for example, that you are specific about what you see or hear somebody 'tell' you as opposed to what you and others conclude this means. Opinion and fact should be clearly distinguished as they are not the same!

Everyone supporting people with learning disabilities should acknowledge the importance of communication as a human right and know how to support people to understand and express their decisions as far as they are able. The use of a **Total Communication approach** where all means of communication are valued and promoted as appropriate is an important principle for all decision-making. Two essential ingredients in all of this are **preparation and time**.



- **Prepare by being person-centred and take time to get to know people well.** It is essential to know the person and their communication as well as possible. Do they have a **communication passport** that tells you about their communication? What is important to them as well as for them? Who already knows and communicates well with them? What are their preferred ways to communicate? How do they best understand information? What communication and other skills will you need to communicate well with them?
- **Prepare to explain the decision and take time to do this before you meet with the person.** What decision are you asking the person to make? What is their previous experience of such decisions? What information do they need to know and how will this best be expressed? It helps to prepare materials beforehand to support this (eg pictures, objects, photos or DVDs). How much spoken language is appropriate to the individual? Think about the amount and complexity of the language you plan to use. What vocabulary will they understand? Take care to avoid jargon and non-literal language which is easily misunderstood by many. Break information into manageable chunks for the person. Some people may need information presenting in very specific ways to suit their needs such as through **Social Stories™** for some people on the autistic spectrum. Who is the best person to discuss the decision with them? Will you need any special communication aids or the advice and support of a specialist such as a Speech and Language Therapist? Where, when and how would be best to talk to them (bearing in mind that whilst there are benefits to including a familiar person, there is also the risk that they may have conflicting agendas, misplaced beliefs or an undue influence over the person)?



- **Prepare to support the person to express their views and give them enough time to do this.** Be prepared to accept and encourage all forms of communication. Offer a variety of ways in which the person can express themselves and provide any communication aids needed. There are many communication tools that can be useful to support decision-making. Check which ones the person already uses before considering introducing new ones. For some people the use of **Talking Mats™** has proved a helpful way for them to express their views. Interactive approaches such as **Intensive Interaction** and **Story Sharing™** may help people with more profound difficulties to be included in decisions even when they lack the capacity for independent decision-making. Always ask for support from family, carers or Speech and Language Therapists if you are unfamiliar with any of these. Be aware of fatigue as it can be very tiring for people who face difficulties with communication to hold conversations. Allow plenty of breaks and always remember a number of short discussions are often better than one long one for many people.

The Code of Practice tells us that 'To help someone make a decision for themselves, all possible and appropriate means of communication should be tried' (p32). Any communication approaches you use should be based on a person's **individual** needs and circumstances – what is **important** to the person as well as what is **important for them**. **Total or Inclusive Communication** is required for this, alongside careful preparation. To check that you have made the necessary preparation the following questions are a helpful checklist.

- How will I support the person to understand the information? How will I know if they have?
- How will I support the person to retain the information? How will I know if they have?
- How will I support the person to weigh up the information? How will I know they have done?
- How will I support them to communicate their decision? What means are they likely to use?
- How will I know I have understood their decision? How will I check this out?

Some terms that may need further explanation

Communication Passports are guides to communicating with and supporting somebody effectively. Some passports contain a wide range of information about the person. Others (particularly those called communication dictionaries) focus entirely on how the person can best be supported with their communication.

Talking Mats™ help people with communication difficulties think about issues discussed with them and to express their opinions using sets of picture symbols which can be attached to a mat. The finished mat can be photographed as a permanent record of the person's feelings about the topic.

Intensive Interaction is a practical approach to interacting with people through sharing their own language. It helps the people to relate better and enjoy each other's company. It uses body, voice and another person's presence to develop communicative exchanges in ways suited to each person.

Object of reference is the use of an object as a means of communication where it is used to represent ideas just like words, signs or symbols.

Total or Inclusive Communication uses all possible different ways of communicating according to each situation and person. It depends on people without communication disabilities making adjustments to their communication to include the other person rather than expecting change from them.

Communication aids range from simple boards or books to more sophisticated pieces of computer equipment which can have voice output within them so the person can 'speak'. There are a number of ways to use these aids via eye gaze, switches or touch screens to trigger a spoken word or message.

Symbols are pictorial representations used in a standard formalised way to convey meaning. They can be in the form of photographs, drawings or one of many commercially available symbol sets.

Signing is using a series of hand gestures in an agreed way to communicate information with another person. Signs from British Sign Language (BSL) have been developed into several vocabularies specifically to help people with learning disabilities.

Story Sharing™ involves the shared remembering and telling of an experience (an event, outing, something new or out of the ordinary) by a person with the support of a story-sharing partner. The story can then become a way in which the person can be included in conversations.

Social Stories™ consider and respect the perspective of the person with an autistic spectrum condition in the writing of a short story, defined by specific characteristics in an effort to provide them with the social information they lack.

Decision-making and risk

Life involves risk. Without taking risks, people would not grow and develop. Everyone has the right to take risks and the right to make choices and decisions about their lifestyle, which can involve risk-taking.

The role of professionals and those who support people with a learning disability is to reach an appropriate balance between supporting choice, independence and appropriate risk-taking with ensuring that vulnerable people are protected from abuse, neglect and exploitation.

Decision-making can present risks for any of us and making the right decision can be a very difficult thing to do.

To help us to make the right decision, we need to have information and skills for using and weighing up that information; having the ability to think abstractly about all the potential 'what ifs' and to consider what would happen if a decision did not work out the way we would like.

However, even with skills and information we can sometimes get it wrong and whilst all decisions can present a degree of risk, some decisions can place us at serious risk emotionally, financially or physically.

Many people with learning disabilities have not been given the opportunity to make decisions on a regular basis. This can be due to a family or staff member thinking that they know what is best for the person or wanting to protect the individual from failure.

Alternatively, the person with a learning disability may have been 'allowed' to make decisions – just as long as they make the 'right' decision. If the individual makes a decision which is seen as 'wrong', 'unwise' or presents some kind of risk, then their choice has often been taken away from them and they have been seen as 'lacking capacity'.

The only way to develop decision-making skill is by practicing – the more we practice at making decisions the better we get. Making the wrong decision can also be an opportunity to learn and develop.

As citizens, we have the right to make unwise decisions even if they may seem like the wrong choices and even if there is the potential that we are placed in some kind of risk.

Some people are 'risk-takers' by nature whilst other people prefer predictability and consistency – people with learning disabilities are no different. That is why it is difficult to make decisions for others as we all have our own views, values and feelings about what is right, even if others may not agree with our decision-making.

In relation to the Mental Capacity Act, one of the key points is about the individual understanding the long-term implications of their decision. If they do then the decision is theirs to make. However, if the individual cannot understand the implications of their decision, then this is where we need to act in the person's best interests and exercise our duty of care.

It can be a very fine balance between our duty of care and supporting people to make decisions.

This is why professionals need to ensure comprehensive processes and documentation is in place which supports the decision-making process; ensuring that we evidence the process and decision that the individual has made, including the information that supports the assessment process and the conclusions that identify that the individual knew the implication of the decision that they were making.

Following on from this we need to consider risk-assessing the decision – not to prevent it from happening but to identify mechanisms to support the individual with their decision and devise strategies to support this to happen and to cover all eventualities if things do not work out as planned.



Independent Mental Capacity Advocates

Local authority and NHS agencies have a statutory duty to involve an Independent Mental Capacity Advocate (IMCA) in specific decisions.

An IMCA's role is to:

- support and represent the person in the decision-making process
- meet the person in private if required
- find out the person's past and present wishes, feelings and values
- evaluate information, including accessing and copying relevant social and medical records
- evaluate alternative courses of action
- consult with others involved in the person's life
- establish the support given to the person in the decision-making process
- seek a further medical opinion if necessary
- check that the Mental Capacity Act 2005 5 Principles and Best Interests Checklist are being followed
- prepare a report, which the decision-maker has a legal duty to consider
- challenge the decision (including capacity) if necessary, informally first and through the Court of Protection as a last resort

The IMCA service is available to people aged 16 years or older who have been formally assessed to be lacking mental capacity and have no appropriate friends or family to consult.

An IMCA *must* be instructed when:

- a decision must be made on behalf of an individual regarding either the provision, withdrawal, or withholding, of serious medical treatment
- a decision must be made on behalf of an individual regarding long-term accommodation in a hospital, residential, nursing or other supported care environment

An IMCA *may* be instructed when:

- a review of the qualifying arrangements which have been made by a responsible body as to the individual's accommodation is proposed or in progress
- it is proposed to take protective measures under adult protection procedures, irrespective of whether they have appropriate family or close friends

Local authorities and NHS agencies can also involve an IMCA in care reviews of people who lack capacity and have no family or friends to consult with.

Court Appointed Deputies

The Court of Protection has been set up under the Act. In some situations the Court of Protection may appoint someone called a Court Appointed Deputy to make decisions on behalf of an individual who lacks capacity if it is felt that it would be in the individual's best interests to do so.

The Court of Protection will decide on the extent of the Court Appointed Deputy's decision-making responsibility, which can be any of the following:

- financial decisions
- welfare (including healthcare) decisions
- financial and welfare decisions

A Court Appointed Deputy can be a family member, a friend or a professional.

Anyone who previously had the role of Local Authority Receiver will have become a Court Appointed Deputy from 1 October 2007.

Two new criminal offences

Safeguarding adults has been high on everyone's agenda for the past ten years or so. Previously, however, many forms of abuse did not constitute a criminal offence, so the person with learning disabilities did not receive any justice.

On 1 April 2007 the Mental Capacity Act 2005 introduced two new criminal offences which are intended to protect the most vulnerable people within our society:

1. Wilful neglect of an individual who lacks capacity
2. Ill-treatment of an individual who lacks capacity

If found guilty, the abuser can face up to five years in prison and up to £2,000 in fines.

Case study

Sally lives on her own in a large house and has savings in her bank. Sally is struggling to cope with the stairs in her house and has recently had a fall.

She has been assessed as lacking capacity to make a decision about moving home. She did not make any plans for her future while she had capacity to make this decision.

The court decide to appoint a Deputy, Sally's son Adam. The court feel that future decisions are likely to be needed regarding Sally's property and affairs and that she has a level of income that a Deputy needs to manage.

Future planning

Before the Mental Capacity Act 2005 people could not be confident that any wishes and feelings they had about their future care and treatment would be carried out. The Act has introduced several ways in which a person can plan ahead for a time when they might lack capacity. These were introduced from 1 October 2007.

Lasting Power of Attorney

Under the Act a person can appoint someone who they know and trust, for example a family member or friend, to make decisions on their behalf for a time when they lack capacity. This is called a Lasting Power of Attorney (LPA).

There are two types of LPA:

1. The **Properties and Affairs LPA** replaced the Enduring Power of Attorney (EPA) on 1 October 2007. The Properties and Affairs LPA covers issues of finances and decisions regarding the property of the person and offers greater safeguards. However, although the EPA had often been considered to be open to abuse, anyone who has an EPA can still use it if it is registered with the Office of the Public Guardian. The LPA enables someone to take decisions on behalf of an individual who lacks capacity but must still be drawn up when the person has the capacity to make decisions themselves.
2. The **Personal Welfare LPA** is a new way for an individual to appoint someone to make health and welfare decisions on their behalf at a time when they think they might lack capacity. It covers issues of health and welfare. The LPA *must* be made when the individual *has* capacity, and comes into force when the individual *lacks* capacity. The LPA must be registered with the Office of the Public Guardian for it to be used by the person appointed attorney.

Advance decisions to refuse treatment

The advance decision is a way of refusing specified medical treatment in advance. The individual must *have* capacity when the advance decision is drawn up. It comes into effect only when the individual *lacks* capacity.

If the advance decision is about life-sustaining treatment it must be signed in front of a witness. It is a legally binding contract so if a medical professional, for example a doctor or paramedic, is aware of the advance decision and still chooses to give that treatment they can face both civil and criminal charges. Doctors can provide treatment when a person has an advance decision if the doctor feels that there is evidence to suggest that the advance decision is not valid and applicable, for example if:

- the individual has been coerced into making the advance decision
- the individual has not regularly reviewed the advance decision
- an LPA has been appointed since the advance decision has been in place

It may be advisable for the doctor to take the case to the Court of Protection. As the advance decision is a legally binding contract the Court of Protection *cannot* overrule it, but can decide whether it is valid and applicable or not. If the advance decision is clearly drawn up and regularly reviewed, it will be seen to be valid and applicable.

Making your wishes and feelings known

When acting as decision-maker for a person who lacks capacity there is an obligation to consider both their past and present wishes and feelings. These can be about any area of the person's life, such as health and welfare or where someone might want to live.

While the decision-maker has an obligation to consider these wishes and feelings when working out what is in the person's best interests, they are not legally binding as with the advance decision, so the decision-maker can choose not to abide by the wishes and feelings of the individual if it is felt that it would not be in the person's best interests to do so.

Acts in connection with care and treatment (Section 5 Acts)

Provision of care and treatment

The Mental Capacity Act 2005 sets out a provision of care and treatment. If a person has no personal welfare LPA or advance decision to refuse treatment they can still be provided with the care or treatment they need. The person providing the care or treatment decides what is in their best interests. This is the same as it has always been but the decision-maker must follow the principles of the Act.

Section 5 Acts can include pledging the incapable person's credit, applying money in their possession and reimbursement for costs incurred. Therefore, anyone who provides care or treatment for a person who lacks capacity must have a 'reasonable belief' that the person lacks capacity to make the decision for themselves, for example on personal care, what to eat, or what clothes to wear. However, it is still important for the person providing the care or treatment to act in the person's best interests by following the 5 Principles of the Act and the Best Interests Checklist. As long as they do this they can be confident they will not face civil liability or criminal prosecution.

However, the Act does not authorise people providing care and treatment to do things that conflict with decisions made by attorneys and court appointed deputies.

Case study

Mrs Ford's daughter Terri, aged 21, has severe learning disabilities. Mrs Ford has always provided a wide range of care for her daughter such as personal care, supporting her to eat her food, access to health appointments and so on. Mrs Ford has heard about the Mental Capacity Act 2005 and is concerned about what this means for her in her role. She also wants to make sure she is 'doing the right thing' for her daughter.

So long as Mrs Ford is reasonably certain that Terri lacks capacity she can carry on doing what she has always done. However, she will need to make sure that she follows the 5 Principles of the Act, and in particular the Best Interests Checklist, to make sure that she is acting lawfully.

What is not permitted

There are certain limitations to Section 5 Acts and these include acts of restraint that are *not* permitted, *except* where:

- it is reasonably believed that the action is necessary to prevent harm
- the act is a proportionate response

Restraint includes use of force or threatening to use force to make someone do something that they may resist. Restraint can also include restricting a person's liberty of movement whether or not the person resists, for example a front door being locked to prevent the individual who lacks capacity from going wandering off.

However, restraint does not include depriving the person of liberty within the meaning of the European Convention on Human Rights.

Case study

John is a young man with a learning disability who can make most day-to-day decisions. However, he lacks capacity to understand the implications of long-term decisions. John has had health problems for several months. The doctor has serious concerns about his health and would like to take some blood tests to rule out certain conditions, but knowing John well realises that he may resist the tests.

As decision-maker the doctor needs to involve John in the decision-making process. The doctor has 'reasonable belief' that John lacks the capacity to understand the tests. The doctor must consider if there are any alternatives that could be tried first, in terms of the 'least restrictive alternative', for example urine tests, etc.

If the doctor feels that it would be in John's best interests to have the tests and has taken all steps under the Best Interests Checklist he could take the blood from John if he felt that any distress caused to John by him being held down was outweighed by the benefits of having his condition correctly diagnosed and having the appropriate treatment.

It must be reasonably believed that the action is necessary to prevent harm and that the act is a proportionate response.

Frequently asked questions

1: Issues for a person with a learning disability

What decisions can I make?

The Mental Capacity Act is a law passed by the Government. This says you should be able to make a decision unless someone can prove that you can't.

When you need to make a decision your family carers or those who support you will work with you to see if you are able to make that decision.

Some people with a learning disability find they can make some decisions, or understand some choices, sometimes but not all the time. It may depend on how they are feeling or what the decision is.

Each decision you make will be looked at in its own way to make sure that those decisions you can make, you do make.

When you might not be able to make a decision because you do not understand or you are not feeling well, people around you will make a decision for you. They must make the choice that is best for you. But they will still need to involve you in the decision and listen to your wishes and feelings about what you want.

What information and support is available to help me make decisions?

It is the job of the people who support you to help you to make your own decisions.

They have to make sure that they think of all the different ways to help you to do this.

This could mean making sure that information comes in ways that help you understand, or using signs, symbols or other ways to make sure you understand everything about the decision you need to make.

The Court of Protection was set up by the Government to protect your interests. You can ask the Court of Protection to look at decisions made on your behalf if you disagree. There may be money available to help you do this if you can't afford to do it yourself.



What if I make a decision that others do not like?

If you make a decision that others do not like or agree with, as long as you understand what could happen or go wrong, then it is your decision to make.

Others around you have to accept you can make this decision even if they do not like it.

But if you do not understand what could go wrong for you and those who support you have tried to explain the problems to you and you still do not understand, then those who support you may make the best choice for you.

What if I don't agree with a decision made for me by other people?

If those who support you make a decision on your behalf and you are unhappy about the decision they have made, you can:

- talk to the person making that decision or talk to their manager
- ask someone in your family to speak to them for you
- ask an advocate to speak to them for you

If this still does not sort the problem out you can contact the Court of Protection who will deal with decisions about your money or care.



2: Issues for family carers

I have always made decisions in my son's best interests, so how will this make a difference?

Much of what we do under the Act will be the same, however the Act gives us a new framework.

The Act was introduced to ensure that people who have an 'impairment or disturbance of the brain', have the same rights as other citizens to make decisions about their own lives. For many people with a learning disability this opportunity has not been available as others have made decisions on their behalf 'in their best interests', overruling the individual's choice or decision.

There will be some people who do not have the capacity to make some decisions for themselves, like your son. As 'best interests' only applies if the individual cannot make the decision for themselves, it is useful to look at the two stage assessment to see what this means in more detail. The Act provides a Best Interests Checklist, and as decision-maker this will help you to support your son, ensuring that his wishes and feelings about the decision is considered and that he is involved in the process.

How do I make sure that I support my daughter to make decisions in line with the Act?

The Act provides several things to help people who support others to make decisions.

These are the 5 Principles, the two-stage assessment of capacity and the Best Interests Checklist.

More information can be found in this brief guide.

What if I disagree with a decision that is made about my son?

If someone else is acting as the decision-maker for your son (for example a social worker) then they have a responsibility to consult with others who are important to your son as part of the decision-making process. This will include yourself and other members of your family involved in his life.

If you disagree with the decision it is best to try to sort it out with the person concerned. If this does not work, you can then speak with their manager; ask for a second opinion; request a formal or informal 'best interests meeting'; or seek mediation.

You can ask for an advocate to speak on your behalf if you do not feel comfortable doing this by yourself; or you may ask for your son to have an advocate involved.

If the decision-maker is employed by a local authority (Council) or by the NHS, then you can make a formal complaint. All organisations should have a Complaints Policy in place so ask for a copy of this.

If you remain unhappy with the final outcome, you can go to the Court of Protection and ask for them to challenge the decision. You can find out more by ringing 0845 330 2900.



3: Issues for advocates

What decisions will I be involved in?

Advocates can be involved in helping an individual to communicate their views and feelings and promoting the rights of individuals. Advocates can also play an important role in mediation or being involved in complaints procedures when a person is unhappy about decisions that have been made on their behalf.

How do I know if a person can make a decision for himself or herself?

The Act tells us that we must always assume that an individual can make decisions for themselves, unless proven otherwise. The 5 Principles guide all of our practice:

- Always assume that an individual can make their own decisions unless proven otherwise
- All practicable steps must be taken to support the person to make their own decision
- People have the right to make unwise decisions – so long as they understand the implications of each decision
- When acting as decision-maker we must always act in the person's best interests – the Act provides us with a Best Interests Checklist to support us to do this
- When acting as decision-maker we must weigh up the pros and cons of a decision and take the least restrictive option

The process of assessing the person's capacity to make a decision is a two-stage assessment. The first part is:

- does the person have an impairment or disturbance of the brain?
This includes people with learning disabilities, mental health problems, and stroke and brain injuries.

If the answer to this is yes, then we go to the second part of the process:

- Do they understand the decision needing to be made and the information about this?
- Can they retain the information for long enough to make the decision?
- Does the individual understand the implications of their decision?
- Can they communicate this decision to you?

If the answer to all of these is yes, the person has the capacity to make the decision themselves. However if the answer is no to any part of this process then it may mean that a decision needs to be made in the person's best interests.

What if the family challenge the decision made by the individual?

The main issue here is about the individual's capacity to make the decision. You will be covered by the Act if:

- you have used the 5 Principles to guide you
- you have used the two-stage assessment to assess the person's capacity
- you have documented the process, including what the decision is and how the decision is made

The family can still challenge the decision but so long as you have worked within the framework of the Act you will be protected from any potential actions from the family. (See answer to **What if I disagree with a decision that is made about my son?**).



4: Issues for Independent Mental Capacity Advocates (IMCAs)

What decisions will I be involved in?

IMCAs are involved in specific decisions for specific individuals. Local authorities and NHS agencies have a statutory duty to involve IMCAs in specific decisions about people who are especially vulnerable. IMCAs only work with people who lack capacity to make decisions themselves and who also have no family members or friends who can be consulted with about the decision needing to be made.

The decisions that IMCAs are involved in are about the following:

- serious medical treatment, for example if someone should have an operation
- where decisions need to be made about someone moving into a home or hospital

The other decisions where an IMCA may become involved is in the care review process for a person who lacks capacity and has no family members or friends to be involved.

The only time that an IMCA may become involved where there are family members, is where there are potential safeguarding issues for people who lack capacity, either as a potential victim of abuse or as a potential perpetrator of abuse.

What will my role be?

The IMCA's role is to 'represent and support the individual who lacks capacity'. This involves working with the person who lacks capacity, involving them as far as is possible within the decision, and where possible, find out what their wishes and feelings are about this, considering issues such as their chosen methods of communication, culture, religion and social networks. The IMCA will collate all other relevant information, for example from other professionals, and access any current or historical written information which helps with the decision-making process. The IMCA will not make the decision but will present their findings to the decision-maker to enable them to make their decision.

5: Issues for support workers

Do I have to use the 5 Principles every time I support an individual to make a decision?

It is important the principles are applied as some people can have 'fluctuating capacity', so they might be able to make some decisions at one time but not at other times. The Act tells us that front line staff do not have to be 'experts', but they just need to have a 'reasonable belief' that a person lacks capacity to make decisions or give permission themselves; staff must have taken every possible step to try to support the person to make the decision or give permission; they must apply the two-stage assessment and they must also act in the person's best interests.

It will be important that the support plan for each individual addresses issues of choice and decision-making, and sets out how workers provide the right support when choices and decisions are to be made.

What about when I work with people who cannot make their own decisions. How am I protected?

'Section 5 Acts' ensure that anyone providing care and treatment for people who lack capacity will be protected from liability. So long as you take steps to follow the Act, you will be protected.

There are restrictions around this regarding restraint and paying for goods and services, so it is important that you find out more information around these to ensure that you are protected from liability.



6: Issues for decision-makers

What is meant by 'best interests'?

The Act does not define the term 'best interests' as it recognises that it is so personal and unique to each individual. However, it does provide us with a Best Interests Checklist to support decision-makers in their role and ensure that they are working in line with the Act.

What decisions can I make?

Decision-makers will make decisions as part of their role or responsibility, ie frontline staff may make decisions about what that person is having for tea; GPs about medical treatment.

However, there are a range of 'excluded' decisions that are not covered by the Act because they are so personal to the individual and cannot be made on behalf of another person. These include:

- voting
- whether someone should or should not marry or enter into a civil partnership
- whether someone should have a divorce or civil partnership dissolved

How can I make sure that I make decisions 'lawfully'?

As decision-maker you have an obligation to follow the Best Interests Checklist to make sure that you are covered by the Act. Briefly, this includes:

- involve the person who lacks capacity in the decision
- consult with others who are important to the person who lacks capacity
- consider the wishes and feelings of the person
- consider the options available and take the least restrictive alternative

More detail about this is included within this guide.



7: Issues for service managers

What guidance and assessment tools are available?

There are a range of resources available with the main source of guidance being the Mental Capacity Act 2005 Code of Practice. This can be accessed via the Ministry of Justice or Department of Health websites to download, or can be bought from The Stationery Office. It is crucial that all staff have access to this as it has legal implications for everyone involved in a paid or voluntary role.

Whilst there is a range of 'formal' assessment tools, for example where a formal assessment is needed for legal purposes, on a day-to-day basis there is no requirement to have formal assessment processes in place or recorded documentation. However, many organisations are introducing these to ensure that they have evidence if challenged; it is down to the individual service or organisation to devise their own assessment tools and documentation that work for them. Many organisations' assessment tools are readily accessible on the internet, so it can be useful to have a look at what others have in place to help you develop your own.

How do I ensure that my service/staff are working in line with the Act?

Staff need to be aware of the Code of Practice. Training specific to their role is also important to emphasise the key issues of the Act, for example the 5 Principles, the assessment process, and what is meant by 'best interests'. Even more important is making sure that staff are implementing these in their everyday practice, using quality mechanisms such as supervision, handovers and team meetings.

In addition, it is important to have appropriate processes and documentation in place to evidence the decision-making process and outcomes for individuals.

What documentation needs to be in place?

Much of the documentation will already be in place, such as person-centred plans and risk assessments. The way in which an individual makes everyday decisions must be clearly recorded in their support plan.

On a day-to-day basis there are no requirements to have recorded documentation about the decision-making process. The documentation that you may need to introduce will be around documenting the assessment process for decisions that are other than everyday decisions, and will include what process has been gone through to assess the individual's capacity to make the decisions. Examples of what should be included are:

- What steps have been taken to support the individual to make the decision himself or herself?
- How has the information about the decision been communicated to the person concerned?
- Do they understand this? How do you know?
- Can they retain the information for long enough to make the decision? What evidence supports this?
- Does the individual understand the implications of their decision? What evidence supports this?
- Can they communicate this decision to you? What is their decision?

If the assessment identifies that the individual cannot make the decision then a 'best interests' decision will need to be made for each decision, and therefore documentation will also be needed to evidence the outcomes from this. The format of the Best Interests Checklist in the Code of Practice provides a good framework.

Brief guide to the Mental Capacity Act 2005

Implications for people with learning disabilities

By Elaine Hardie and Liz Brooks

The Mental Capacity Act 2005 affects the approximately two million people in England and Wales who are unable to make some or all decisions that affects their lives.

This guide is for:

- professionals who work with people who have a learning disability
- parents and carers
- friends
- advocates and self-advocacy groups
- anyone wanting to know more about the Mental Capacity Act and how it applies to people with a learning disability

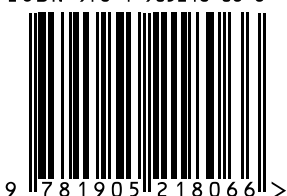
The guide aims to:

- explain the key points of the Act
- explain what some of the choices and decisions might be
- help you to support someone with a learning disability to plan ahead and talk about their future

The guide provides case studies to demonstrate key points of the Act and practical examples to explain how the Act might be applied in a real-life situation.

The book is accompanied by a poster that highlights the 5 Principles of the Act.

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