

# Making decisions

## The Independent Mental Capacity Advocate (IMCA) Service

Helping people who are unable to make some decisions for themselves



There is a new law that can help - The Mental Capacity Act 2005

# Making decisions

## The Independent Mental Capacity Advocate (IMCA) service

Helping people who are unable to make some decisions for themselves

This booklet provides information on the Independent Mental Capacity Advocate (IMCA) service established by the Mental Capacity Act. It is not a statutory Code of Practice issued under the Mental Capacity Act 2005 and is not a guide to how the law will apply to specific situations.

---

This document has been produced by:



---

It was written by:



## Acknowledgements

The Mental Capacity Implementation Programme (MCIP) published this booklet. MCIP is a joint government programme between the Department of Health, the Department for Constitutional Affairs, the Public Guardianship Office and the Welsh Assembly Government that has been established to implement the organisation, process and procedures to launch the Mental Capacity Act in 2007.

Sue Lee from Speaking Up wrote this booklet. We are grateful to her and the rest of the team at Speaking Up.

## Contents

<b>1</b>	<b>Introduction</b>	<b>6</b>
<b>2</b>	<b>Advocacy</b>	<b>7</b>
	What is advocacy?	7
	Who needs advocacy?	7
	What is an advocate?	8
	Non-instructed advocacy	8
<b>3</b>	<b>The IMCA service</b>	<b>11</b>
	Why have an IMCA service?	11
	What is mental capacity?	12
	Does a person lack capacity?	12
	What does an IMCA do?	13
	Who is the IMCA service for?	13
	When does an IMCA not need to be instructed?	15
	What is meant by ‘having nobody else who is willing and able to be consulted’?	15
	When will the IMCA service be available?	17
	Who has a duty to instruct IMCAs?	17
	Who is the ‘decision-maker’?	17
<b>4</b>	<b>How the service works</b>	<b>18</b>
	Who should be referred to the IMCA service?	18
	What is serious medical treatment?	18
	What is meant by serious consequences?	19
	IMCA and changes to accommodation	20
	What are ‘long term accommodation’ moves?	21
	Involving IMCAs in adult protection cases and care reviews	22
	IMCA and adult protection procedures	22
	IMCA and care reviews	23
	The referral process	25
	Limitations of the service	26
	What if a person requiring an IMCA is receiving funding from outside the area where they are currently living?	27

<b>5</b>	<b>How an IMCA works</b>	<b>28</b>
	Who can be an IMCA?	28
	How do IMCAs work?	28
	The main elements of IMCA work	30
	Finding out the person's wishes and feelings, values and beliefs	30
	Finding and evaluating information	31
	Considering alternative courses of action	32
	Representing and supporting the person who lacks capacity	32
	Getting a second medical opinion	33
	Auditing the decision-making process	33
	Communicating the IMCAs findings	33
	How do IMCAs challenge a decision?	34
<b>6</b>	<b>Complaints</b>	<b>35</b>
	What to do if you are not happy with the IMCA service	35
<b>7</b>	<b>What if I want to know more?</b>	<b>36</b>
<b>5</b>	<b>Some useful contacts</b>	<b>37</b>

## 1. Introduction

IMCA stands for Independent Mental Capacity Advocate.

IMCA is a new type of statutory advocacy introduced by the Mental Capacity Act 2005 (the Act). The Act gives some people who lack capacity a right to receive support from an IMCA.

The service comes into effect in April 2007, in England and in October 2007 in Wales. Local authorities (LAs) have commissioned IMCA services in England and local health boards are commissioning in Wales. Responsible bodies, the NHS and LAs, both have a duty to make sure that IMCAs are available to represent people who lack capacity to make specific decisions, so staff affected will need to know when an IMCA must be involved

IMCA services are provided by organisations that are independent from the NHS and local authorities.

The aim of this booklet is to explain:

- what advocacy is
- the role of an IMCA
- how the IMCA service works in practice
- who will benefit from the IMCA service
- how to make a referral to the IMCA service.

## 2. Advocacy

### What is advocacy?

Advocacy is taking action to help people:

- express their views and wishes
- secure their rights
- have their interests represented
- access information and services
- explore choices and options.

Advocacy promotes equality, social justice and social inclusion. It can empower people to speak up for themselves.

Advocacy can help people become more aware of their own rights, to exercise those rights and be involved in and influence decisions that are being made about their future.

In some situations an advocate may need to represent another person's interests. This is called non-instructed advocacy and is used when a person is unable to communicate their views.

### Who needs advocacy?

Anyone who needs support to:

- make changes and take control of their life
- be valued and included in their community
- be listened to and understood

A person accessing advocacy could, for example, be someone with a learning difficulty or an older person who has dementia.

## What is an advocate?

An advocate is someone who supports a person so that their views are heard and their rights are upheld.

They can help a person to put their views and feelings across when decisions are being made about their life.

They can give support which will enable a person to make choices and they inform people of their rights.

An advocate will support a person to speak up for themselves or, in some situations, will speak on a person's behalf.

Advocates are independent. They are not connected to the carers or to the services which are involved in supporting the person.

An advocate will work one-to-one with a person to develop their confidence wherever possible and will try to ensure that the person feels as empowered as possible to take control of their own life.

## Non-instructed advocacy

The majority of service users who will access the IMCA service are likely to be people with learning disabilities, older people with dementia, people who have an acquired brain injury or people with mental health problems. But IMCAs may also act when people have a temporary lack of capacity because they are unconscious or barely conscious whether due to an accident, being under anaesthetic or as a result of other conditions.

Many will have significant barriers to communication and will be unable to instruct the advocate themselves. In addition, it is likely that many people using the service will be unable to express a view about the proposed decision.

A non instructed advocate will always attempt to get to know the person's preferred method of communication and will spend time finding out if a person is able to express a view and how they communicate. IMCAs will be experienced at working with people who have difficulties with communication.

If the person is unable to communicate their views and wishes relating to the decision to be made, an advocate will use [non-instructed advocacy](#).

“Non-instructed advocacy is taking affirmative action with or on behalf of a person who is unable to give a clear indication of their views or wishes in a specific situation. The non-instructed advocate seeks to uphold the person’s rights; ensure fair and equal treatment and access to services; and make certain that decisions are taken with due consideration for their unique preferences and perspectives” Action for Advocacy 2006

**The key principles of non-instructed advocacy are:**

- The client does not instruct the advocate.
- The advocacy is independent and objective.
- People who experience difficulties in communication have a right to be represented in decisions that affect their lives.
- The advocate protects the principles underpinning ordinary living which assumes that every person has a right to a quality life.

There are a number of approaches that an advocate may use when undertaking non-instructed advocacy. The ‘Watching Brief’ approach was devised by ASIST, an advocacy organisation, and can be used when the person is unable to communicate a view and the advocate therefore cannot find out what the person might want.

It sets out a process whereby the advocate can ask how particular aspects of a person’s life will be enhanced or detracted by the proposed decision. It protects or argues for ordinary life principles and works from the basis that every human being is entitled to have a quality life. It sets out nine quality of life domains that are used as a basis for the advocate to ask questions of whoever is proposing

to make a decision. The advocate does not offer an opinion or express a view on a particular course of action.

The strength of this approach lies in the fact that service providers are required to think about why they are making the specific decision and to justify the actions proposed. In other words asking 'why?' can be very powerful. An advocate actively probes the process by which providers reach a decision.

An advocate will go to meetings on the person's behalf and look at any proposed decisions to make sure that:

- All options have been considered
- Where a person's own preferences and dislikes can be identified, that these are taken into account
- No particular agendas are being pursued
- The person's civil, human and welfare rights are being respected

### Example

Emma, a 40-year-old woman who has high support needs, had lived at home with her father until his sudden death. A decision needed to be made about where Emma would live in the future and a referral was made to the IMCA service. The IMCA met with Emma's social worker and was told that she does not have any spoken language, that she is unable to sign and has very limited methods of communication. The IMCA met Emma and found that it was not possible to get a view from her about her future accommodation. The IMCA then used non-instructed advocacy.

IMCA advocacy is not best interests' advocacy. The advocate does not offer their own opinion or make the decision.

## 3. The IMCA service

### Why have an IMCA service?

In the past, many people who lacked the capacity to make decisions for themselves may not have been listened to. IMCAs safeguard the rights of those with nobody else to speak for them.

#### **The benefits of an IMCA service**

The main benefits for the person who lacks capacity are:

- having an independent person to review significant decisions being made
- having an advocate who is articulate and knowledgeable not solely in relation to the Act but also about a person's rights, health and social care systems and community care law
- receiving support from a person who is skilled at helping people who have difficulties with communication to make their views known
- having an independent person who can support and represent them when certain serious decisions are being made and they have nobody else who can be consulted.

There are benefits also for decision-making bodies as practitioners working in those bodies may find that:

- the collaborative way in which IMCAs work will mean that practitioners are assisted in their decision-making processes by a person with a good knowledge of the Act
- the information brought to the attention of the decision-maker by the IMCA may be extremely useful and can often save valuable time for the practitioner
- complex decisions can be made with more confidence and in many cases more quickly due to the involvement of an IMCA.

(Based on Evaluation of IMCA pilots by Cambridge University.)

## What is mental capacity?

Mental capacity is the ability to make a decision.

The Act covers situations where someone is unable to make a decision because the way their mind or brain works is affected, for instance by illness or disability. The lack of capacity may be temporary because they are unconscious or barely conscious whether due to an accident, being under anaesthetic or as a result of other conditions such as the effects of drugs or alcohol. It includes everyday decisions such as what to wear or when to take a bath and more serious decisions such as where to live.

## Does a person lack mental capacity?

The MCA requires 'decision specific' assessments of capacity.

All staff and all unpaid carers can and should make assessments of capacity for simple decisions - such as can someone decide what to wear or eat. Of course the more serious the decision, the more formal the assessment of capacity should be.

Many staff can make assessments about whether to refer to an IMCA using the following questions.

A person is assessed as lacking the ability to make a decision, and needing an IMCA, if they cannot do one or more of the following:

- Understand information given to them about the decision.
- Retain the information for long enough to make the decision.
- Use or weigh up the information as part of the decision making process.
- Communicate their decision (by any means, e.g. talking, sign language or blinking).

The assessment must be specific to the decision which needs to be made, for example, not a generic test of capacity. Whether and

how such assessments are recorded may vary according to the seriousness of the decision made. An IMCA should be instructed for the specific decisions outlined below.

### What does an IMCA do?

An IMCA safeguards the rights of people who:

- are facing a decision about a long-term move or about serious medical treatment
- lack capacity to make a specified decision at the time it needs to be made
- have nobody else who is willing and able to represent them or be consulted in the process of working out their best interests, other than paid staff.

Regulations under the Mental Capacity Act give local authorities and NHS bodies powers to involve IMCAs in other decisions concerning:

- a care review
- adult protection procedures (even in situations where there may be family or friends to consult).

IMCAs are independent and will generally work for advocacy providers who are not part of a local authority or the NHS.

### Who is the IMCA Service for?

The IMCA service is provided for any person, aged 16 years or older, who has no one able to support and represent them, and who lacks capacity to make a decision about either:

- a long-term care move
- serious medical treatment
- adult protection procedures
- a care review.

Such a person will have a condition that is affecting their ability to make decisions.

Many factors can affect a person's capacity such as:

- acquired brain injury
- learning disability
- mental illness
- dementia
- effects of alcohol or drug misuse.

Capacity can also be affected by other illness, trauma or other factors.

A person's capacity may vary over time or may depend on the type of decision that needs to be made.

IMCAs should be available to people who are in prison, in hostels, and on the streets and who lack capacity to make decisions about serious medical treatment or long-term accommodation.

### Example

Alan, a 32-year-old man who has learning difficulties and autism, lives in a care home which is due to close. Alan will need to move to new accommodation.

Alan's social worker is aware that he does not have any family or friends to consult about the decision. She believes Alan lacks capacity to understand the decision to be made and she contacts the local IMCA service to make a referral.

## When does an IMCA not need to be instructed?

IMCAs do not need to be instructed if:

- a person who now lacks capacity previously named a person that should be consulted about decisions that affect them, and that person is available and willing to help
- the person who lacks capacity has appointed an attorney, either under a Lasting Power of Attorney or an Enduring Power of Attorney, and the attorney continues to manage the person's affairs
- the Court of Protection has appointed a deputy, who continues to act on the person's behalf.

However, where a person has no family or friends to represent them, but does have an attorney or deputy who has been appointed solely to deal with their property and affairs, they should not be denied access to an IMCA. The Government is seeking to amend the Act, at the earliest opportunity, to make it clear that, in such circumstances, an IMCA should always be appointed to represent the person's views when they lack the capacity to make decisions relating to serious medical treatment or long-term accommodation moves.

## What is meant by 'having nobody else who is willing and able to be consulted?'

The IMCA is a safeguard for those people who lack capacity, who have no one else other than paid staff who 'it would be appropriate to consult' (apart from adult protection cases where this criterion does not apply). The safeguard is intended to apply to those people who have no network of support, such as close family or friends, who take an interest in their welfare.

Decision-makers in the NHS and local authorities will need to determine if there are family or friends who are willing and able to be consulted about the proposed decision. If it is not possible, practical and appropriate to consult anyone, an IMCA should be instructed.

The person who lacks capacity may have friends or family but there may be reasons why the decision-maker feels it is not practical or appropriate to consult with them.

**Examples of situations where it may be appropriate to instruct an IMCA:**

- The family member or friend is not willing to be consulted about the best interests decision.
- The family member or friend is too ill or frail.
- There are reasons which make it impractical to consult with the family member or friend, for example, they live too far away.
- A family member or friend may refuse to be consulted.
- There is abuse by the family member or friend.

**Example**

A decision needed to be made regarding future accommodation for a man who has mental health problems who had remained as a voluntary patient in a hospital for a number of years. He was assessed to lack the capacity to make the particular decision and the care manager was uncertain about his eligibility for the IMCA service as his mother was named as next of kin. On further investigation, she discovered that the man's mother was elderly, had mental health problems herself, was currently unwell, and had not had any contact with her son for two years. Consequently, she decided that there was nobody who was able to support and represent the man and made a referral to the IMCA service.

If a person who lacks capacity already has an advocate, they may still be entitled to an IMCA and the IMCA would consult with their advocate.

### When will the IMCA service be available?

The service will be available for 52 weeks of the year, in office hours, excluding Public Holidays and weekends.

### Who has a duty to instruct IMCAs?

Staff in the NHS or a local authority, for example, doctors, care managers or social workers all have a duty, under the Mental Capacity Act, to instruct an IMCA where the eligibility criteria are met. This duty starts, in England, on 1st April 2007 and in Wales on 1st October 2007.

### Who is the 'decision-maker'?

The decision-maker is the person who is proposing to take an action in relation to the care or treatment of an adult who lacks capacity, or who is contemplating making a decision on behalf of that person. Who the decision maker is will depend on the person's circumstances and the type of decision. For example, the decision-maker may be a care manager or a hospital consultant.

Staff working in statutory organisations, in the local authority or NHS, who are involved in making best interests decisions should know when a person has a right to IMCA and when they have a duty to instruct an IMCA.

## 4. How the service works

### Who should be referred to the IMCA Service?

Any person who meets the following criteria must be referred to the IMCA service.

- Is a decision being made about **serious medical treatment** or a **change of accommodation**; or a care review or **adult protection procedures**? (There will be LA policy on care reviews and adult protection)
- Does the person lack capacity to make this particular decision?
- Is the person over 16 years old?
- Is there nobody (other than paid staff providing care or professionals) whom the decision-maker considers willing and able to be consulted about the decision? (This does not apply to adult protection cases.)

### What is serious medical treatment?

NHS bodies must instruct and then take into account information from an IMCA where decisions are proposed about ‘serious medical treatment’ where the person lacks capacity to make the decision and there are no family or friends who are willing and able to support the person.

Serious medical treatment is that which involves:

- giving new treatment
- stopping treatment that has already started
- withholding treatment that could be offered.

And where there is either:

- a fine balance between the benefits and the burdens and risks of a single treatment

- b a choice of treatments which are finely balanced
- c what is proposed would be likely to involve serious consequences.

A person will have a right to an IMCA if such treatment is being contemplated on their behalf and the person has been assessed as lacking capacity to make the decision for themselves at that time.

An IMCA cannot be involved if the proposed treatment is for a mental disorder and that treatment is authorised under Part IV of the Mental Health Act 1983. However, if a person is being treated under the Mental Health Act and the proposed treatment is for a physical illness, for example, cancer, an IMCA can be involved.

### Example

William, who was detained under Section 3 of the Mental Health Act, became physically unwell and diagnostic tests revealed that he had cancer. He was assessed to lack the capacity to make a decision about the various options for treatment and had nobody who could be consulted about the decision. Consequently a referral was made to an IMCA.

### What is meant by serious consequences?

Serious consequences refers to those which could have a serious impact on the person. It could include treatments which:

- cause serious and prolonged pain, distress or side-effects
- have potentially major consequences for the patient (for example, major surgery or stopping life-sustaining treatment)
- have a serious impact on the patient's future life choices (for example interventions for ovarian cancer).

## Example

Peter was admitted to hospital having fallen at the nursing home. He was in the late stages of dementia and although clearly in pain was unable to tell the hospital staff where the pain was. Investigations showed that his hip was broken and a decision needed to be made about treatment, however he lacked capacity to consent to or refuse medical treatment. An IMCA was appointed.

The only situation in which the duty under the Act to instruct an IMCA need not be followed is when an **urgent** decision is needed, for example, to save a person's life. However, if further serious treatment follows an emergency situation, there will be a need to instruct an IMCA.

Treatment which is regulated by Part 4 of the Mental Health Act 1983 (for patients who have been detained under the Mental Health Act 1983) cannot be included in the definition of 'serious medical treatment'.

How do IMCAs work with serious medical treatment decisions?

The IMCA will:

- check if the best interests principle has been followed
- ensure the person's wishes and feelings have been considered
- seek a second medical opinion if necessary.

## IMCA and changes to accommodation

The local authority or the NHS must instruct an IMCA where decisions are proposed about a move to or change in accommodation where the person lacks capacity to make the decision and there are no family or friends who are willing and able to support the person.

The right to an IMCA applies to decisions about long-term accommodation moves to or from a hospital or care home or a move between such accommodation if:

- it is provided or arranged by the NHS
- it is provided under section 21 or 29 of the National Assistance Act
- it is part of the after-care services provided under section 117 of the Mental Health Act 1983 - following a decision made under section 47 of the National Health Service and Community Care Act 1990.

### Example

Bert, a man in his 80s, had a stroke whilst at home which had led to a stay in hospital lasting many weeks and was now ready to be discharged. Bert had always lived an independent life up until his illness but now his condition was such that his social worker had serious concerns about whether it would be in his best interests to return to his former home. After an assessment of his capacity to make the decision and enquiries about any family or friends who may be consulted about the decision, the social worker makes a referral to an IMCA.

### What are 'long-term accommodation' moves?

This applies if an NHS organisation or local authority decides to place a person who lacks capacity:

- in a hospital – or move to another hospital - for a stay likely to last longer than 28 days
- in residential accommodation for a stay likely to last longer than 8 weeks.

It applies to long-stay accommodation in a hospital or care home, or a move between such accommodation. This may be accommodation in a care home, nursing home, ordinary and sheltered housing, housing association or other registered social housing, or in private sector housing provided by a local authority or in hostel accommodation.

If the placement or move is **urgent**, an IMCA need not be instructed, but the decision-maker must involve an IMCA as soon as possible after making an emergency decision if the person is likely to stay in hospital longer than 28 days or longer than 8 weeks in other accommodation.

There is no duty to involve an IMCA if the person is required to stay in the accommodation is under the Mental Health Act 1983.

### Involving IMCAs in adult protection cases and care reviews

When people meet the IMCA criteria, local authorities and the NHS have a **DUTY** to instruct an IMCA for changes in accommodation and serious medical treatment decisions. For care reviews and adult protection procedures, local authorities and the NHS have **POWERS** to appoint an IMCA where they consider that the appointment would be of particular benefit to the person concerned. Local authorities, in England, should have a policy on how IMCAs will be involved in care reviews and adult protection procedures. NHS bodies and local authorities in Wales will be similarly required to have such a policy in place.

### IMCA and adult protection procedures

Local authorities and the NHS have powers to instruct an IMCA to support and represent a person who lacks capacity where:

- it is alleged that the person is or has been abused or neglected by another person
- it is alleged that the person is abusing or has abused another person.

Local authorities and the NHS can only instruct an IMCA if they propose to take, or have already taken, protective measures. This is in accordance with adult protection procedures set up under statutory guidance (Published guidance: for England - No secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse ([www.dh.gov.uk](http://www.dh.gov.uk)); for Wales - In safe hands ([www.ssiacymru.org.uk](http://www.ssiacymru.org.uk)).

In adult protection cases, access to IMCAs is not restricted to people who have no one else to support or represent them. People who lack capacity who do have family and friends are still entitled to have an IMCA to support them in adult protection procedures. The decision-maker must be satisfied that having an IMCA will benefit the person.

### Example

A young woman who has a learning disability lived at home with her family. Her care manager had evidence and consequently serious concerns that her needs were not being met and that she was at serious risk of harm and neglect. The care manager made a referral to the IMCA service and an IMCA was instructed to support and represent the person throughout the adult protection proceedings.

### IMCA and care reviews

A responsible body can instruct an IMCA to support and represent a person who lacks capacity when:

- they have arranged accommodation for that person
- they aim to review the arrangements (as part of a care plan or otherwise)
- there are no family or friends whom it would be appropriate to consult.

Reviews should relate to decisions about accommodation:

- for someone who lacks capacity to make a decision about accommodation
- that will be provided for a continuous period of more than 12 weeks and were arranged by a LA/NHS
- that are not the result of an obligation under the Mental Health Act 1983
- that do not relate to circumstances where sections 37 to 39 of the Act would apply.

### Example

A man who is in his 70s and has dementia was placed in a care home following a long stay in hospital. His care manager had made a best interests decision which his family did not agree with and they had requested that he leave the care home, indicating that they may remove him. Due to serious concerns about the man's safety, an adult protection strategy meeting was held and an IMCA instructed. Prior to attending the care review, the IMCA met with the man who gave a clear indication that he was happy and did not want to leave the care home. The IMCA was able to communicate the man's views and wishes at the care review meeting.

Where the person is to be detained or required to live in accommodation under the Mental Health Act 1983, an IMCA will not be needed since the safeguards available under the Mental Health Act will apply.

## The referral process

Staff working in local authorities or the NHS must be able to identify when a person has a right to an IMCA and know how to instruct an IMCA.

The first step is to know which organisation has been commissioned to provide an IMCA service in the local authority, or local health board, area where the person currently is. This information can be found out from the local authority or from information and advice centres such as the Patient Advice and Liaison Service (PALS) or the Citizens' Advice Bureau (CAB) in the area or from Community Health Councils in Wales. The Department of Health also has an IMCA website with the details of all the IMCA providers.

Local arrangements will be in place with each IMCA service provider regarding the ways in which referrals can be made. Initial referrals may be made by phone or email.

At the time when the referral is made it must be evident that:

- a person lacks the capacity to make the particular decision
- the decision is either serious medical treatment; a change in accommodation, a care review or an adult protection case
- there is nobody who can appropriately support and represent the person (does not apply to adult protection).

### **The IMCA will:**

- establish the referred person's preferred method of communication
- meet with the referred person and use a variety of methods, as appropriate, to ascertain their views
- consult with staff, professionals and anyone else who knows the person well who are involved in delivering care, support, and treatment
- gather any relevant written documents and other information
- attend meetings to represent the person raising issues and questions as appropriate
- present information to decision-maker verbally and via a written report
- remain involved until decision has been made and be aware that the proposed action has been taken
- audit the best interests decision making process
- challenge the decision if necessary.

### **Limitations of the service**

An IMCA cannot be involved if:

- a person has capacity
- the proposed serious medical treatment is authorised under the Mental Health Act 1983 and is therefore for a mental disorder rather than a physical condition
- the proposed long-term change in accommodation is a requirement under the Mental Health Act 1983
- there is no identifiable decision about a long-term change in accommodation or serious medical treatment or decisions relating to a care review or adult protection procedures

- there is any other person (not in a paid capacity) who is willing and able to support and represent appropriately the person who lacks capacity
- decisions are being made in relation to a person's finances unless there are adult protection procedures in which an IMCA is involved.

The IMCA will stop being involved in a case once the decision has been finalised and they are aware that the proposed action has been carried out. They will not be able to provide on-going advocacy support to the person. If it is felt that a person needs advocacy support after the IMCA has withdrawn, it may be necessary to make a referral to a local advocacy organisation.

### What if a person requiring an IMCA is receiving funding from outside the area where they are currently living?

Each IMCA service will cover a local authority, or local health board, area and all eligible people in that area, whether on a permanent or temporary basis must be referred to the local IMCA service. For example, if a person is living in a care home in Cambridgeshire but Essex County Council are providing the funding for that placement and there is a need to refer the person to IMCA, the Cambridgeshire IMCA service will provide the service.

#### Example

A man who has a learning disability and autism receives funding from the county where he originally lived as a child to live in a care home in a different area. The care home is closing and different accommodation needs to be identified. A care manager from the funding authority is involved and knows that the IMCA service provided in the area where the man currently lives, is the right service.

## 5. How an IMCA works

### Who can be an IMCA?

Individual IMCAs must:

- have specific experience (related to working with people who need support with making decisions, advocacy experience and experience of health and social care systems)
- have IMCA training
- have integrity and a good character, and
- be able to act independently.

All IMCAs must complete the IMCA training in order to work as an independent mental capacity advocate and have enhanced checks with the Criminal Records Bureau (CRB) that show no areas of concern.

IMCAs must be independent and cannot act as an IMCA if they are involved in the care or treatment of the person or if they have links to the responsible body instructing them or to anyone else involved in the person's care or treatment, other than as their advocate.

### How do IMCAs work?

The IMCA's role is to support and represent the person who lacks capacity and to audit the way the decision is being made. IMCAs do not make the decision on behalf of the person they are representing; the final decision will always be made by the decision-maker.

The IMCA will:

- be independent of the person making the decision
- provide support for the person who lacks capacity
- represent the person without capacity in any discussions on the proposed decision
- provide information to help work out what is in the person's best interests

- raise questions or challenge decisions which appear not to be in the best interests of the person.

The IMCA service will build on good practice in the independent advocacy sector. But IMCAs have a different role from many other advocates. Unlike some other advocates, they have rights and duties under the Mental Capacity Act to:

- provide statutory advocacy
- support and represent people who lack capacity to make decisions on specific issues
- meet in private the person they are supporting
- access relevant health and social care records
- provide support and representation specifically while the decision is being made
- act quickly so their final report can form part of the decision-making process.

## The main elements of IMCA work

There are four main elements to the IMCA work which can broadly be summarised as:

- 1 Ascertaining the views, feelings, wishes, beliefs and values of the person using whichever communication method is preferred by the client and ensuring that those views are communicated to, and considered by, the decision-maker.
- 2 Non-instructed advocacy. Asking questions on behalf of the person and representing them. Making sure that the person's rights are upheld and that they are kept involved and at the centre of the decision-making process.
- 3 Investigating the circumstances. Gathering and evaluating information from relevant professionals and people who know the person well. Carrying out any necessary research pertaining to the decision.
- 4 Auditing the decision-making process. Checking that the decision-maker is acting in accordance with the Act and that the decision is in the person's best interests. Challenging the decision if necessary.

## Finding out the person's wishes and feelings, values and beliefs

An IMCA will try to find out what the person's wishes, feelings, values and beliefs might be. They will find out what method of communication the person prefers to use and will be experienced at communicating with people who have difficulties with communication. The person may use sign language, such as Makaton or BSL or need information to be presented using pictures or photographs. An IMCA will also talk to staff or anyone who

knows the person well and will examine copies of relevant health and social care records or written statements made by the person when they still had the capacity to do so.

Where possible, decision-makers should make decisions based on a full understanding of a person's past and present wishes. An IMCA should provide the decision-maker with as much of this information as possible - and anything else they think is relevant.

### Example

A young woman who has learning difficulties lived in short break accommodation after leaving the family home and now permanent accommodation needed to be found. She was able to communicate very clearly to the IMCA what kind of accommodation she would prefer, expressing a wish to have a quiet environment and a garden. The IMCA was able to support the person to put forward her views to the people who would be making the decision.

## Finding and evaluating information

IMCAs have a right to:

- meet the person who lacks capacity in private
- examine and take copies of, any records which the person holding the record thinks is relevant to making the best interests decision.

The IMCA may also talk to other people who know the person who lacks capacity well or are involved in their care or treatment who may have information relevant to the decision. In investigating the person's circumstances, the IMCA will be able to gather together information to give to the decision-maker.

In most cases, a decision by the decision maker on the person's best interests will be made through discussion involving all the relevant people who are providing care or treatment, as well as involving the IMCA.

### Considering alternative courses of action

The IMCA will need to check whether the decision-maker has considered all possible options and that the proposed option is, according to the Mental Capacity Act, the least restrictive of the person's future choices or would allow him or her the most freedom. The IMCA may suggest alternatives where there is evidence that these are more consistent with the wishes and feelings of the person.

### Representing and supporting the person who lacks capacity

The IMCA should find out if the person has been given the appropriate support to enable the person to be as involved as possible in the decision-making process.

They will attend meetings to represent the person and will use non-directed advocacy approaches to ask questions about the proposed decision. The IMCA will make sure that the views, feelings, values, wishes of the person and any other relevant information such as religious and cultural factors are made known to the decision-maker.

#### Example

An IMCA is appointed for a serious medical treatment decision. Whilst carrying out their investigations, the IMCA discovers that the person is a practising Jehovah's Witness and realises that this is a significant factor to be brought to the attention of the person proposing the treatment.

Sometimes an IMCA might not be able to get a good picture of what the person might want. They should still try to make sure the

decision-maker considers all relevant information by:

- raising relevant issues and questions
- providing additional, relevant information to help the final decision.

### Getting a second medical opinion

The IMCA has a right to seek a second medical opinion on behalf of a person who lacks capacity when a decision is being made about serious medical treatment. This puts the person who lacks capacity in the same position as a person who has capacity who has a right to request a second medical opinion.

### Auditing the decision-making process

Throughout the decision-making process the IMCA will be ensuring that:

- the principles of the Act are being followed
- the person is being supported to participate in the decision-making process as fully as possible
- the person is at the centre of the process
- the best interests check list as set out in section 4 of the Act is being followed
- the decision-maker is giving clear, objective reasons for making a particular decision about what is in the person's best interests
- anyone making a decision in the best interests of a person who lacks capacity is not making that decision based on assumptions which cannot be justified.

### Communicating the IMCAs findings

An important part of the IMCA's role is to communicate their findings and often there will need be a continual dialogue between the IMCA and the decision-maker.

The IMCA will submit a report to the decision-maker which gives details of their investigations, providing as much relevant information as possible. The report may include questions about the proposed action or may include suggested alternatives if there is evidence that these might be better suited to the person's wishes and feelings.

The decision-maker must take into account the information from the IMCA when working out what decision is in the best interests of the person who lacks capacity.

There may sometimes be situations where an IMCA thinks that the decision-maker has not paid enough attention to their report and to relevant information and has concerns about the decision made. They may then need to challenge the decision.

### How do IMCAs challenge a decision?

The IMCA may initially use informal methods and may ask for a meeting with the decision-maker to explain any concerns and request a review of the decision. Where there are serious concerns about the decision made, an IMCA may decide to use formal methods to challenge the decision.

Examples of formal methods are:

- use the relevant complaints procedure
- refer to the Independent Complaints Advocacy Service (ICAS)
- consult the Patient Advice and Liaison Service (PALS) in England or Community Health Councils in Wales
- refer case to the Court of Protection
- approach the Official Solicitor.

In particularly serious or urgent cases, the IMCA may approach the Official Solicitor or seek permission to refer a case to the Court of Protection for a decision. If an IMCA wants to challenge the way in which a particularly serious decision has been made they can with legal advice, consider applying for a judicial review.

## 6. Complaints

### What to do if you are not happy with the IMCA service

In the first instance the person who is unhappy about the service should approach the IMCA providing the service or their manager. If matters are not resolved, the IMCA provider's complaint policy should be used. If after this there are still concerns, the person may want to approach the local authority,( or local health board in Wales), that is responsible for commissioning the particular service.

## 7. What if I want to know more?

Title	Available from
Further information on the IMCA service	<a href="http://www.dh.gov.uk/imca">www.dh.gov.uk/imca</a> email: <a href="mailto:imca@dh.gsi.gov.uk">imca@dh.gsi.gov.uk</a>
Information on the Mental Capacity Act 2005	<a href="http://www.dca.gov.uk/legal-policy/mental-capacity/index.htm">www.dca.gov.uk/legal-policy/mental-capacity/index.htm</a> T 0845 330 2900 E <a href="mailto:makingdecisions@dca.gsi.gov.uk">makingdecisions@dca.gsi.gov.uk</a>
Other information booklets like this one	You can view these electronically by going to: <a href="http://www.dca.gov.uk/legal-policy/mental-capacity/publications.htm">www.dca.gov.uk/legal-policy/mental-capacity/publications.htm</a>  To order hard copies you can email: <a href="mailto:reorder@inprintlitho.com">reorder@inprintlitho.com</a>
The Mental Capacity Act 2005	You can view this for free by going to: <a href="http://www.dca.gov.uk/legal-policy/mental-capacity/index.htm">www.dca.gov.uk/legal-policy/mental-capacity/index.htm</a>  You can order a hard copy from TSO by calling 0870 600 5522 or emailing <a href="mailto:customerservices@tso.co.uk">customerservices@tso.co.uk</a> .
The Code of Practice for the Mental Capacity Act	You can download this for free by going to:  <a href="http://www.dca.gov.uk/legal-policy/mental-capacity/index.htm">www.dca.gov.uk/legal-policy/mental-capacity/index.htm</a>  You can order a hard copy from TSO by calling 0870 600 5522 or emailing <a href="mailto:customerservices@tso.co.uk">customerservices@tso.co.uk</a>

## 8. Some useful contacts

The following government departments are working together to implement the Mental Capacity Act in 2007

Department	What it is/does	Contact
<b>Department for Constitutional Affairs (DCA)</b>	Responsibilities include running the courts, and improving the justice system, human rights, information rights law, policy on running elections and modernising the constitution	5th Floor Steel House, 11 Tothill St, London, SW1H 9LH <a href="http://www.dca.gov.uk/">www.dca.gov.uk/</a> E <a href="mailto:makingdecisions@dca.gsi.gov.uk">makingdecisions@dca.gsi.gov.uk</a>
<b>Department of Health (DH)</b>	Responsibilities include setting health and social care policy in England. The Department's work sets standards and drives modernisation across all areas of the NHS, social care and public health	Wellington House, 133-155 Waterloo Road, London, SE1 3UG <a href="http://www.dh.gov.uk">www.dh.gov.uk</a> T 020 7210 4850
<b>Public Guardianship Office (PGO)</b>	The administrative arm of the Court of Protection and part of the Department for Constitutional Affairs. It provides financial protection services for clients who are not able to manage their financial affairs because they lack capacity	Archway Tower, 2 Junction Road, London, N19 5SZ <a href="http://www.guardianship.gov.uk">www.guardianship.gov.uk</a> T 0845 330 2900 E <a href="mailto:custserv@guardianship.gsi.gov.uk">custserv@guardianship.gsi.gov.uk</a>
<b>Welsh Assembly Government</b>	Develops policy and approves legislation that reflects the needs of the people of Wales	Cathays Park, Cardiff, CF10 3NQ <a href="http://www.wales.gov.uk">www.wales.gov.uk</a> T 029 2082 5111

The following organisations provide information about advocacy and/or provide advocacy services

Organisation	What it is/does	Contact
<b>Action for Advocacy</b>	A resource and support agency for the advocacy sector, information, training and advice	PO Box 31856, Lorrimore Square, London, SE17 3XR <a href="http://www.actionforadvocacy.org">www.actionforadvocacy.org</a>
<b>British institute of Learning Difficulties</b>	Works with the government and other organisations to improve the lives of people in the UK with a learning disability. They train staff, family carers and people with a learning disability. Also funds Speak Out, a project that provides advocacy for adults with learning disabilities	Campion House, Green Street, Kidderminster, Worcestershire, DY19 1JL T 01562 723 010 <a href="http://www.bild.org.uk">www.bild.org.uk</a>
<b>Speaking Up</b>	Provides advocacy services for people who experience learning difficulties, mental ill health and other disabilities. They also run training courses and events with other organisations who want to understand, consult and involve disabled people	1a Fortescue Road, Cambridge, CB4 2JS T 01223 566258 F 01223 516638 E <a href="mailto:info@speakingup.org">info@speakingup.org</a> <a href="http://www.speakingup.org">www.speakingup.org</a>

## Notes

Other booklets in this series include:

- 1 Making decisions about your health, welfare or finance. Who decides when you can't?
- 2 Making decisions. A guide for family, friends and other unpaid carers
- 3 Making decisions. A guide for people who work in health and social care
- 4 Making decisions. A guide for advice workers
- 5 Making decisions. An Easy Read guide

These booklets are available in other formats on request.

To order:

**T** 023 80 878038 or 023 80 878036

**F** 023 80 528324

**E** [reorder@inprintlitho.com](mailto:reorder@inprintlitho.com)

The booklets are also available online at:

[www.dca.gov.uk/legal-policy/mental-capacity/publications.htm](http://www.dca.gov.uk/legal-policy/mental-capacity/publications.htm)

The Mental Capacity Implementation Programme published this booklet. It was written by Sue Lee at Speaking Up.

© Crown copyright 2007