



Leeds Independent
Mental Capacity
Advocacy Service
(LIMCAs)

Annual Report
2008-09

ARTICULATE
ADVOCACY **cic**

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■ PLEASE NOTE: The names and other identifying factors in case examples have been changed to protect individuals’ confidentiality; the dilemmas have not.

Crunching the numbers

PROCESSING data quickly and efficiently is essential to an effective and highly-responsive IMCA service.

In two years, Articulate Advocacy has made great progress in developing data management systems which allow individual cases to be tracked day-by-day, ensuring that enquiries are answered, referrals taken on and IMCAs assigned as quickly as possible.

Data processes designed by Articulate Advocacy also allow reports to be completed speedily and then forwarded to those involved.

The automated systems have also been created so that figures can be fed into the Department of Health’s national database as necessary without compromising confidentiality or breaching data protection legislation.

Articulate Advocacy has built on software that was already in operation, so making best use of existing resources and building on staff familiarity with those systems.

Such data systems are due to be extended in 2009-10 to improve further information handling.

Speaking up for those without voices

A director's introduction:

BY THE very nature of their circumstances, people who need Independent Mental Capacity Advocates deserve services of the highest ethical standards, but who watches to make sure that everyone is doing their best by these most vulnerable of individuals?

Over the past two years Articulate Advocacy has developed an IMCA service which is widely respected amongst health and social care professionals, while simultaneously remaining strongly assertive in upholding the rights of every individual.

Local authorities, the National Health Service, the government agencies who commission IMCA services are all acting on behalf of society more generally or the Leeds community more widely.

Broader dimensions

However, IMCAs face particular dilemmas - because not only are they working to provide a voice for each person who does not have the capacity to make decisions themselves, but because there is also a broader, social and political dimension to trying to ensure that the care available for such individuals is of the best possible standard.

The first two years of providing an Independent Mental Capacity Advocacy service for Leeds have been exciting and a challenge; setting up new organisations and providing extra facilities always are.

Although Articulate Advocacy will be continuing to provide that service for another three years, the period of innovation is by no means over.

Preparing for the introduction of safeguards surrounding the deprivation of liberty placed demands on everyone during the last year.

This year will no doubt reveal the true effects of this latest protection for highly vulnerable people.

Ralph Porter
Chair

An IMCA's tale

"I'd been seeing one elderly lady who was living in a care home for quite sometime when on one visit, when I had a pen and a pad in my hand, she suddenly reached for them.

"Only then did we discover that she could communicate clearly - in writing - and she did clearly have the capacity to make decisions for herself.

"She reminded us that no one should take conventional means of communication, such as speaking or making gestures, for granted."

On the board

ARTICULATE ADVOCACY now has three directors - Ralph Porter, Gwyneth Christie and Paul Seccombe.

Ralph is a long-serving chair of Leeds Advocacy, a charity set up in 1989 to provide services for people with learning disabilities in the city. Gwyneth Christie has served as a trustee for many years and Paul Seccombe has worked for the organisation since its early days. He has been its chief executive since 2006.

Facts and figures: 2008-09

Referral causes and reasons

CAUSES OF INCAPACITY ¹	2008-09	2007-08
Learning disabilities	31%	17%
Dementia	29%	50%
Cognitive impairment	13%	15%
Mental health problems	11%	16%
Acquired brain damage ²	6%	
Other causes	3%	2%

PILOT PROJECT PROJECTIONS

Learning disabilities		36%
Dementia		32%
Other causes		32%

REASONS FOR REFERRALS

	2008-09	2007-08
Changes of accommodation	52%	68%
Serious medical treatment	15%	13%
Care reviews	13%	10%
Safeguarding (adult protection)	10%	3%
Other concerns	20%	6%

1. Totals may not equal 100% as some individuals may meet two or more criteria or lose capacity more than once. 2. This category includes alcohol-related and road injuries.

Uptake trends

TWO years is not long in which to collect data. However, some trends and other events have become apparent in this time.

For example, in July 2008, there was a marked increase in the number of people with mental health problems requiring IMCAs because they were facing changes in accommodation. The requests for IMCAs came mostly from those working in Leeds Adult Social Care and the Primary Care Trust's Joint Care Management Team (PCT JCMT).

This second year of operation has revealed that the demands for IMCA services from particular client groups are now nearer the pilot project projections from 2006, with the greatest need

coming from people with learning disabilities, slightly ahead of the needs of those with dementia. The proportion of people with dementia referred to the IMCA service also decreased noticeably in 2008-09.

Data analysis now shows the involvement of IMCAs in helping people with acquired brain damage - including those affected by alcohol use - as being recorded separately.

A separate analysis of IMCA response times in February 2009 revealed that referral forms being issued in response to emergency requests for IMCAs were taking four days to be returned. After that, all the eligible referrals were assigned IMCAs within two working days.



WHILE most of LIMCAs' work during 2008-09 has involved vulnerable individuals who were already known to health and social care services, IMCAs really come into their own when younger people find themselves without capacity, without family or friends.

Most months, IMCAs are assigned to work with individuals needing serious medical treatment who have neither the capacity themselves nor the family or friends who could make decisions in those individuals' best interests.

The youngest person requiring IMCA support during the year was just 16 years old

Demographics

THE vast majority of individuals receiving support from IMCAs remains white and British. The relatively smaller number of referrals received from across Leeds' ethnic communities appears to reflect the respective sizes and family structures evident in such population groups.

Articulate Advocacy employs sessional advocates from these communities specifically to ensure that the IMCA service is as culturally appropriate and sensitive as it can be.

Personnel

A SMALL group of dedicated, specially-trained Independent Mental Capacity Advocates has continued to work for Articulate Advocacy in Leeds.

Staff turnover has been low; the few IMCAs who have left did so mostly because they were moving away from the area for other reasons.

Since the services were introduced, training for IMCAs has been organised directly by the Department of Health. This is now being formalised, with the introduction in England of recognised City & Guilds qualifications, an approach which not only adds to such individuals' skills but provides a further guarantee for the people of Leeds that IMCA work meets the vital professional standards expected in the 21st century. The assessment and validation process has taken some time, but every IMCA working for Articulate Advocacy should have completed this by October 2009.

Some IMCAs are also undertaking additional training so they will be qualified to undertake Deprivation of Liberty work (see pages 6-7). This training should also be complete ahead of the January 2010 deadline.

Liaison and development

Articulate Advocacy is also working closely and informally with the Advocacy-Network Leeds and Action for Advocacy on tailoring aspects of national advocacy qualifications to meet specific local needs and circumstances.

A key manager now regularly attends meetings of the Safeguarding Adults Board in Leeds and liaises closely with the Advocacy-Network Leeds organisation to monitor and ensure high standards of advocacy.

Liberty – and professional dilemmas

ALTHOUGH the original contract between Articulate Advocacy and Leeds city authorities to provide the Independent Mental Capacity Advocacy service was due to end at the end of March, advocates who could have been transferred to an alternate provider had to be prepared during the year for a major law change that came into effect on April 1st, 2009.

The change to legislation regarding the **Deprivation of Liberty** is one of the most significant developments for those caring for vulnerable individuals for many years.

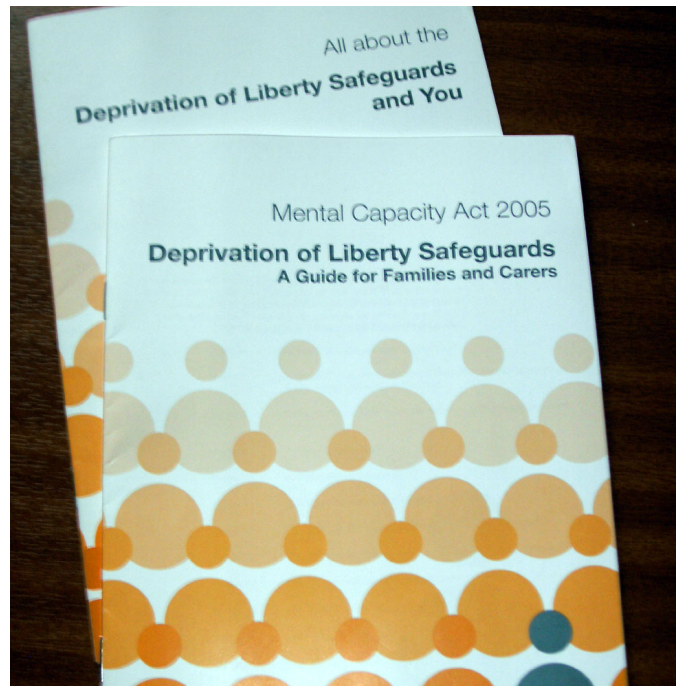
The updating of the law came about because the European Court of Human Rights made a ruling regarding a man with autism and learning disabilities and who could make decision for him about staying in hospital. The Court ruled that because hospital staff had to make the final decision about whether he should stay there or be cared for at home, he had been deprived of his liberty.

Now, safeguards have been enshrined in law for England and Wales to make sure this cannot happen again. The move is the latest stage in the evolution - some may call it a revolution - in the way society relates to those whose mental ability is impaired. The use of acronyms has not changed, however; these measures have already become known, even officially, as “MCA DOLS”.

This is the latest in a steady stream of changes which began with the introduction of IMCAs themselves two years ago.

With special extra training to make sure they are fully aware of the safeguards and how they can be brought into use, IMCAs act as a vital part of the continual “check and balance” aspect of such procedures to protect vulnerable people.

Traditionally, to lose one’s liberty under mental



health laws, a person had to be “sectioned”, a process that involved a doctor and social worker. The Deprivation of Liberty safeguards replace a long-standing way of working for many professionals.

In the run-up to the change, many local authority purchasing and commissioning bodies as well as providers of social and health care services drew up guidelines and advice for their staff.

One county council said: “People likely to be affected by these proposals are mainly those with learning disabilities, or elderly people with dementia, but also a minority of other people who lack capacity to consent to where they received care or treatment.”

This view mirrors the findings of Independent Mental Capacity Advocates in Leeds. When IMCAs started work in the city, they discovered they were primarily dealing with two distinct groups of people: those who were known by health and social care providers, because they had histories of illness or disability, and those who were

running into contact with “the system” for the first time.

Now some people whose medical histories have included dealings with mental health services are having their situations reviewed. For those with some existing conditions, the process will be little more than a formality. For others, it is more complex.

IMCAs employed by Articulate Advocacy have been briefed to expect difficulties at first. “The philosophical dilemmas will be immense,” said one.

Those dilemmas are most intense in the age-old conflict between the public good, personal safety and individual liberty. Politicians may have debated whether the safety of many is more important than the freedom of one, but now the question faces frontline care staff.

Medical and social care professionals, many of whom have spent long years training and developing their professional expertise, will face more direct challenges. IMCAs are now legally empowered to ask consultants or senior social workers to justify their decisions. If they don’t like what they hear, and they don’t think that the professionals’ judgement has been in the best interest of the individual, they have ultimate recourse to the Court of Protection.

As one senior social worker has told IMCAs working for Articulate Advocacy, “it is not a badge of honour to have to call upon the deprivation of liberty safeguards for anyone”.

For Articulate Advocacy, the involvement of IMCAs as qualified, but still lay, independent individuals in such processes is a measure of how seriously the protection of highly-vulnerable people is now taken and how measures are in place to try to ensure their best interests really are met.

The Bournemouth legacy

BOURNEWOOD, a psychiatric hospital in Surrey, has become synonymous with the debate about the deprivation and restriction of liberty.

In 1997, a 49-year-old man with autism called Mr L, was detained at the hospital after becoming distressed at a day centre. As he had admitted himself voluntarily, he was kept there for his own “best interests” under the unclear provisions of common law, despite claims from his carers that he was well enough to live at home.

The consequent legal battle went through the High Court to the European Court of Human Rights in 2004. Judges there said the common law concept of “necessity” was too arbitrary and lacked the safeguards accorded to those “sectioned” under the 1983 Mental Health Act.

Nine years after Mr L went into hospital, the “Bournemouth gap” remained as wide as ever, with campaigners rejecting Department of Health proposals in May 2006.

While this represented a lingering dilemma for health and social care professionals, the later addition of public outcry for more action provided a greater incentive for change.

The political temperature had been raised as long ago as 1992 - as a reaction to a killing at a London Underground station. The stabbing of Jonathan Zito by a man with paranoid schizophrenia provoked calls for people with mental illnesses and histories of violence to be compulsorily detained and treated.

However, Mr Zito’s widow Jayne was determined that politicians should respond and she led a long campaign for a law change. In 1998, she said: “To minimise the risk to themselves and others, there has to be legal powers in place and if needs be, they have to be removed from the community. It raises issues of civil liberty but we can’t allow these patients to pose a threat to themselves and the general public.”

In 2006, then Health Minister Rosie Winterton announced measures that would be added to the Mental Capacity Act 2005 and amend the 1983 Mental Health Act. These proposals said that everyone involved would have to act in the best interests of a person in care, that the detention criteria would be strengthened, that everyone would have the right to someone independent to represent their interests and that challenging detention decisions would become easier.

Safeguarding - protecting adults

SAFEGUARDING became a major topic of public and political debate in 2008 - when the death of “Baby P” hit the headlines.

Outrage seems louder and more passionate when children are involved - but the same dangers, primarily abuse and neglect, can face vulnerable adults.

For some individuals such as Asif (see page 11), a young person’s sexual needs, complex family dynamics and having siblings who were also vulnerable meant that the involvement of an IMCA was essential in trying to identify and meet his best needs when the time came for a move to new accommodation.

IMCAs are needed in such circumstances because family members may not be the best people to do this, even though they may consider themselves to have life-long knowledge of a vulnerable person’s interests and wishes. And, as the *No Secrets* guidance from the Department of Health demands, and however socially challenging it may be, safety has to take priority over confidentiality.

When this happens, care professionals face added potential difficulties in dealing with resentment from family members who may feel indignant about being excluded. They may feel slighted simply because of they are being denied the opportunity to take part in making a decision that they consider very important or they may feel aggrieved because they feel they are being maligned.

By working with other health and social care professionals in such circumstances, IMCAs can bring greater independence and objectivity to such decision-making processes.

IMCAs, like the health and social care professionals with whom they work, are specially trained in issues surrounding abuse, neglect and safeguarding. Articulate Advocacy works within the *Safeguarding Adults* national standards for adult protection, developed by the Association of Directors of Social Services (ADSS) and involving the Association of Chief Police Officers (ACPO), the Commission for Social Care Inspection (CSCI), Public Guardianship Office (PGO) and the Department of Health.

What is safeguarding?

SAFEGUARDING - in terms of mental capacity and IMCAs - primarily focuses on making sure that vulnerable adults are not abused or neglected or abuse others.

People without capacity may face greater risks than others of dying, serious physical injury or illness, serious deterioration in their physical or mental health, or serious emotional distress.

Sometimes, although they may be nearest, a person’s family or friends may not show that they have an individual’s best interests at heart, so an IMCA can be involved instead.

Alternatively, a person who does not have capacity may be abusing or threatening others. In these circumstances too, families and friends could have wishes which are not in the best interests of the individual concerned so, again, an IMCA may be called in.

When this happens, IMCAs have formal meetings with decision makers and carers to check whether someone meets the legal criteria of having capacity or not.

As people’s conditions vary, they may have capacity one week, but not the next.

OF THE safeguarding cases requiring Articulate Advocacy IMCAs in 2008-09, the majority involved people with learning disabilities. However, IMCAs were also provided for people with mental health problems, cognitive impairment and acquired brain damage.

The eldest person involved was aged 93, while the youngest was just 21. Fascinatingly, none was born between late 1933 and autumn 1952. Otherwise, the age range appears reasonably evenly distributed from 1952 onwards. Fewer safeguarding cases involved people older than 75, but this appears to be in line with predicted life expectancy figures.

Quite why fewer people born during the depression of the 1930s, the Second World War and the post-war “baby boom” have required such services may merit further academic investigation.

Bottling it all up

FOR Helen, contact with the IMCA service began when staff at her local off-licence noticed just how much wine she was buying. They knew the high-flying well-paid executive had a 13-year-old daughter who could be vulnerable because of her mother’s drinking.

Indeed, as an IMCA discovered when they got involved, questions had to be answered about whether Helen had the capacity both to look after herself and her daughter.

For Ernest and Elsie, alcohol had also become a problem. Being made redundant in his late 50s and facing a forced early retirement he hadn’t wanted affected Ernest. He started drinking more and more. So too did Elsie, his wife of more than 20 years.

Over time, the amount they were drinking affected both their physical and mental health. After

How safeguarding works

ANYONE can raise fears for another person’s safety. Neighbours, friends and family can all contact authorities such as health and social services or even the police if they think someone is in danger.

When that happens, councils now have **safeguarding systems** in place. After a duty officer takes the first call, a dedicated social worker is assigned to each particular case. Teams that could include other care professionals, health workers, doctors, voluntary organisations and the police, come together to assess the information and, if necessary, to take action to protect the person in potential danger.

The first priority is that person’s wellbeing. Once this is established, possible action over neglect or other offences may be considered.



assessments, neither husband nor wife was found to have the capacity to look after themselves or each other. Their personal medical conditions varied, but neither could help make decisions about where or how the other would live, so an IMCA became involved.

Now, ways have been found which let all these individuals recover – in circumstances which are best for them and for those around them.

What decision makers had to say . . .

- It was very helpful to have a full and objective report to draw on.
- (The IMCA's) involvement allowed the client's needs to be met rather than the organisational needs.
- The IMCA was very committed and crucial to our decision and the feedback from the family was that they were very happy too.
- It was useful having someone to look at the situation from the service user's point of view only.
- It's an excellent service – which makes decision-making much easier.
- I don't think the service user was interested in any reports; he made his own informed decisions once he regained capacity.
- (The service) was very useful as the service user was in hospital in Leeds and I was in North Yorkshire; so I relied upon the IMCA to obtain the client's wishes and views.
- The IMCA became too involved.
- Within hospitals, the IMCA role should be publicised more, so that NHS staff respect what they advise.
- The IMCA should be available immediately when needed, not one or two days later.
- (IMCA) involvement was useful in this case to move it forward; the report was necessary to show that the procedure was adhered to.
- The service was excellent.

Anticipated developments

NOW that Articulate Advocacy has been awarded the contract to provide the IMCA service for Leeds for another three years, we can continue to ensure that we strive to provide the highest-quality service for very vulnerable individuals.

All decision-makers are sent feedback forms and their comments are reviewed regularly. These are taken into account in individual assessment and supervision sessions with IMCAs and in monitoring the effectiveness of processes and procedures.

Following such feedback, extra attention was paid in 2008-09 to responses times - both between receiving initial enquiries and the return of referrals forms and then between this and the allocation of IMCAs and contact with service users. This year, efforts will be made to accelerate the return of referral forms from the health care sector and such data will continue to be monitored regularly and closely.

We are also aiming to develop a web-based referral system for health and social care professionals - which may also reduce referral times even further.

Paul Seccombe
Chief Executive

Acknowledgements

The board and managers of Leeds Advocacy and Articulate Advocacy cic - would like to record thanks to the Leeds Adult Social Care commissioning body and the MCA Stakeholder Group for their help and advice and to the many health and social care professionals with whom the organisation and individual IMCAs have worked during this second year of an evolving and positive working relationship.

Report conceived and written by Adam Christie, Modus Operandi Communications (0113 294 1212), photographs © Chris Aspinall 2009.

Young and vulnerable

Asif is a young man with learning disabilities who lives with two siblings who also have learning disabilities. They receive home care but an IMCA became involved when Asif needed to move.

Asif wants to continue living with his siblings and says he has a girlfriend, but his carers have been unable to find out who she is. After psychological assessments, Asif was then considered not to have the capacity to consent to sexual contact, so safeguards were put in place.

Concerns involving a parent and another sibling had been raised in the past, so making them

ineligible for involvement in making decisions about Asif's best interests.

Safeguarding meetings usually consider all the factors, but the nature of the additional difficulties confronting Asif meant that the IMCA faced a further dilemma – being able to discuss his specific circumstances and best interests confidentially with others involved in his care.

The IMCA's work then included checking Asif's capacity assessment, considering all the family dynamics, his sexual needs and other referrals involving parents and his siblings.

Mental Capacity and advocacy - explained

WHAT happens to any of us when we are too ill to make decisions for ourselves? What happens if we don't have any family or friends who could help health and social care professionals decide what is best for us?

As people live longer, families break up, and we move around, or as we try to find work or develop our careers, more of us find ourselves on our own at times of emergency or trauma.

The Mental Capacity Act 2005 set out to provide safeguards for people in such circumstances - by clarifying what we mean by "mental capacity" (when and how we are able to take decisions and communicate our wishes to others) and then make sure that there is someone else - an independent "advocate" - on hand to find out more about our lives, how and where we live and not only establish our interests, but work with health and social care workers to ensure that we get looked after as well as possible. This was the second year of these legal obligations.

Such Independent Mental Capacity Advocates - IMCAs - are trained individuals, usually employed by charities or similar agencies working outside the National Health Service and social services. They work within carefully set guidelines and have to provide comprehensive reports about what they do. They work alongside doctors, nurses, social workers and those running nursing and care homes to make sure that any decisions about, for example, medical treatment and where we live are thoroughly thought through.

IMCAs are called in at set times during the decision-making process if someone without a family or friends has dementia, learning disabilities or cognitive impairment.

The Leeds Independent Mental Capacity Advocacy service (LIMCAs) has been run since January 2008 by a community interest company called Articulate Advocacy under contract from the NHS and Leeds City Council.

Articulate Advocacy CIC
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Telephone: 0113 244 0606 Fax: 0113 244 0178
E-mail: office@articulateadvocacy.com
Unit A4, 26 Roundhay Road, Leeds LS7 1AB
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