

# Leeds Independent Mental Capacity Advocacy Service

(LIMCAs)

## Annual Report 2007-08

**A**RTICULATE  
ADVOCACY **cic**

# Mental Capacity and advocacy

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 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 was 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.

These 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, those running nursing and care homes, to make sure that any decisions about, say, medical treatment and where we live are thoroughly thought through.

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

The Leeds Independent Mental Capacity Advocacy service (LIMCAs) is run by a community interest company called Articulate Advocacy under contract from the NHS and Leeds City Council. This is their first annual report.

## Food for thought

Clive Walsh was in his 20s when he had a motorcycle accident that left him brain damaged and in a wheelchair. Two decades on, Clive - whose parents had both died - choked.

Despite being disabled, Clive knew what he wanted until the choking accident. Being without oxygen for 20 minutes caused further brain damage and Clive went into a persistent vegetative state.

Doctors thought Clive didn't have long to live, so they decided to turn off his life support system - but Clive breathed on.

That's when an IMCA, an Independent Mental Capacity Advocate, became involved. The advocate found out from Clive's long-term carers that they

felt Clive was aware of some of what was happening around him.

The advocate took part in discussions about how Clive could be fed. The doctors didn't want to put a tube into Clive's stomach, because of the infection risks.

The IMCA later reported that the operation did go ahead - on the condition that Clive would only be given antibiotics if an infection appeared. He would also be checked after two days to see if it was in his best interest for the treatment to go on.

And, thinking that Clive would live on, the advocate was ready to become involved in helping with decisions about where he would live.

# Getting started in Leeds

Leeds Advocacy put in a bid for the new Leeds Independent Mental Capacity Advocacy service - LIMCAs - commissioned to start work on 1<sup>st</sup> April 2007 in accordance with the legislative timetable for the Mental Capacity Act 2005.

Although, it had been planned to submit a bid that would require the employment of full-time staff with the requisite amount of management and administrative support; when the tender specification was announced, it required the service to be commissioned on a per-hour formula. After some recalculations, the final proposal was based on a team of 15 IMCAs, with two managers and administrative support to cover the anticipated demand.



Thus, on 1<sup>st</sup> April, the three IMCAs and one manager who had been trained began work from Leeds Advocacy's main office. The first referral forms were issued, based on the requirements of the Department of Health national IMCA service database.

## Service contract

In late December 2006, a bid was submitted and - after negotiation - was accepted in January 2007. The service contract was for one year with the option of a further 12-month extension. Leeds Advocacy was appointed as the principal contractor with sub-contractors if necessary.

Preliminary timings were tight because enough IMCA hours had to be available to meet the predicted demands from 1<sup>st</sup> April 2007. Finding training places was difficult.

Consequently, because of delays in training sufficient IMCAs as a result of the national demand, the Leeds' commissioning body accepted that the service would initially be provided by a few IMCAs who could meet the demand until others received training.

By June 2007, all 15 IMCAs had been trained and many service routines developed. Much thought went into the design of the template for the IMCA reports; consequently, they have met most situations and the needs of recipient decision-makers.

In January 2008, the commissioning body notified Leeds Advocacy that they intended to extend the contract for the further 12 months.

Subsequently, the management structure was reviewed and a social enterprise company - Articulate Advocacy cic - established to manage the LIMCA service in the future. Operations were transferred in the weeks immediately after that.

## Uptake and demographics

By 31<sup>st</sup> March, 175 inquiries had been received, of which about 130 had become formal referrals, involving about 100 individuals, in line with expectations that some service users would incur multiple decision-making interventions.

The 2006 pilot project run by the University of Cambridge<sup>1</sup> forecast that approximately 36 per cent of service users would be people with learning disabilities while 32 per cent would be people with dementia. The remaining 32 per cent would be people with mental health issues, brain injuries, autism, cognitive impairment<sup>2</sup> and so on.



Over the 2007-08 year in Leeds, the majority of referrals by far (based on primary diagnostic identifiers) - at approximately 50 per cent - related to people with dementia; 17 per cent had learning disabilities, 16 per cent had mental health problems, 15 per cent had cognitive impairment, 2 per cent had autism.

In Leeds, most of those referrals - approximately 68 per cent - related to decisions concerning change of accommodation, 13 per cent to serious medical treatment, while 10 per cent related to care reviews, 3 per cent concerned adult protection and the remaining 6 per cent representing other topics.

## Data summary

### PILOT PROJECT PROJECTIONS

People with learning disabilities	36%
People with dementia	32%
Other causes	32%

### CAUSES OF INCAPACITY

#### (Leeds 2007-08)

People with dementia	50%
People with learning disabilities	17%
People with mental health problems	16%
People with cognitive impairment	15%
People with autism	2%

### REFERAL REASONS

#### (Leeds 2007-08)

Accommodation	68%
Serious medical treatment	13%
Care reviews	10%
Adult protection	3%
Other concerns	6%

## Personnel

Independent Mental Capacity Advocates in Leeds represent many different and diverse backgrounds, but all were experienced advocates before taking on this role.

They genuinely feel that the work is of great importance in protecting and assisting some of society's most vulnerable individuals.

Despite some initial turnover, in-house staffing has now settled and it is anticipated that fruitful exchanges of experiences, information and ideas will take place at regular team meetings.

## Referral trends

Uncertainty remains regarding the “appropriate to consult” status of friends or relatives of service users, both in connection with the Code of Practice and in protection issues locally - because a formal policy does not become available until a major review of Leeds’ local procedures and practices is complete in summer 2008.

As care reviews should be initiated six weeks after a service user has moved accommodation, the referral data would indicate that this does not appear to be happening automatically.

Also, the few referrals received from parts of Leeds’ black and minority ethnic communities appear disproportionate in relation to demographics. The MCA Stakeholder Board is investigating the local position. (The 2006 pilot project analysed by the University of Cambridge<sup>3</sup> identified only two Asian referrals, one a Bangladeshi and the other an Indian, among 157 initial clients, of whom 118 were white British.)

Examination of the first year’s data has also revealed that no referrals were received from primary care physicians, the police service, the probation or prison services. Improving the profile of the LIMCAs service throughout the criminal - and civil - justice system is considered a priority for the 2008-09 contract year.

Fewer referrals from managers of independently managed or owned care and nursing homes were received than the demographic data regarding residents would have suggested. Where referrals regarding such residents have been received, they resulted from social care or medical interventions. Consideration should be given to improving the promotion of the LIMCAs service to such managers and proprietors, possibly with the provision of appropriate training regarding

the current legislative requirements and the involvement of IMCAs.

By the half-year, in September 2007, service demand had not however met the forecasts because fewer social care staff and medical staff had received the necessary Mental Capacity Act 2005 training. This was consistent with national trends at the time.

That a significant proportion of hospital referrals were received from social care staff may indicate that medical staff, at all levels, may benefit from being more confident in making direct IMCA referrals themselves.

LIMCAs promotion and publicity has primarily remained the responsibility of the commissioning body. However, Leeds Advocacy and Articulate Advocacy managers have undertaken talks and other presentations to publicise the service, its formation and early experiences, primarily to peers and health and social care professionals.

### Footnotes

<sup>1</sup> The Evaluation of the Pilot Independent Mental Capacity Advocate (IMCA) Service, Redley et al, University of Cambridge Learning Disabilities Research Group, December 2006.

<sup>2</sup> Op cit, Figure 3.

<sup>3</sup> Op cit, Table 3.

***12 per cent of IMCA interventions have involved people aged 35 or younger***

## A matter of understanding

Alzheimer's Disease hit Wendy early. By the time she was just 52, she was frequently becoming confused. Wendy had been a carer and, after the disease developed, she continued to share a house in a Leeds suburb with Tamara, whom she used to look after.

One day, while she was at day care, Wendy had a seizure. She was hurried to hospital where she became even more bewildered.

Doctors wanted to put a tube down Wendy's throat, so an IMCA was brought in to help make sure that she understood what they wanted and to see if she could give consent.

The IMCA got Wendy to draw a picture of herself and used that to show her what would happen. Wendy was worried that this would be painful, but the IMCA was able to explain that she would have an anaesthetic. Wendy was able to show that she understood and said yes to the operation.

After discussing Wendy's worsening dementia with the hospital staff and a specialist nurse, the advocate stayed in touch to be able to help when the time came for Wendy to move from hospital to a care home, rather than going back to the house she shared with Tamara.

## Anticipated developments

Legislative changes regarding the deprivation of liberty due to come into effect in the spring of 2009 also require that IMCAs should receive additional training to expand their skills so they can be involved in these decisions. Such training will be undertaken by the Leeds IMCAs during the course of this second contract year.

Individual advocates as well as Articulate Advocacy expected to be involved in the - informal - promotion of this extension to the service.

*“The youngest person helped by an IMCA this year was just 21.”*

## Acknowledgements

The board and managers of Leeds Advocacy - and Articulate Advocacy cic - would like to record thanks to the Leeds Adult Service Commissioning Team, the MCA Stakeholder Group for their help and advice through the year and the many health and social care professionals with whom the organisation and individual IMCAs have worked with during the first year of an evolving and positive working relationship.

Report conceived and written by Adam Christie, Modus Operandi Communications (0113 294 1212), photographs ©Adam Christie 2008.

## Comfort and the familiar

Romany Barbara Strichardt was 65 when she broke her femur. Barbara had been living alone and had no family or friends when she went into hospital. There, the doctors also found that she had inoperable cancer.

While she was in hospital, the nurses started to worry about her mental health. After a while, her thoughts became so bizarre and psychotic that she was moved to a mental health hospital.

Although Barbara's mental health settled down, she was still ill and it was apparent to everyone that she wouldn't be able to go home and look after

herself. Three options were available: she could go to a hospice, a care home or stay where she was.

An IMCA helped Barbara make it clear that she wanted to stay at the hospital as she was familiar with the staff and the layout.

Even though the doctors there were concerned that they might not be able to provide the best possible care if Barbara's cancer got worse and made breathing difficult, the nurses thought she should stay where she was.

So, with the IMCA's involvement, Barbara didn't have to move again. She died on the ward where she was comfortable.

### Further reading and information

The Department of Health for England has produced a set of booklets providing introductory information about the Mental Capacity Act and IMCAs.

1. For people who may be unable to make some decisions for themselves/ who wish to plan ahead for the future
2. For family, friends and unpaid carers
3. For people who work in health and social care
4. For advice workers
5. Easy Read - due for publication after July 2008
6. The Independent Mental Capacity Advocate (IMCA) service

These are all available online at:  
[www.dca.gov.uk/legal-policy/mental-capacity/publications.htm#booklets](http://www.dca.gov.uk/legal-policy/mental-capacity/publications.htm#booklets)

Alternatively, type "IMCA" into the search function on the Department of Constitutional Affairs website - [www.dca.gov.uk](http://www.dca.gov.uk) - and many more resources will be identified.

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