



HM Government

National Mental Capacity Forum

Chair's Annual Report 2017

May 2018



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The five statutory principles of the Mental Capacity Act 2005



Hand logo courtesy of Shropshire Council

One – presume capacity

A person must be assumed to have capacity unless it is established that they lack capacity

Two – provide support

A person is not to be treated as unable to make a decision unless all practicable steps to help him/ her to do so have been taken without success

Three – unwise decisions

A person is not to be treated as unable to make a decision merely because he/ she makes an unwise decision

Four – best interests

An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his/her best interests

Five – less restrictive option

Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action

Chair's introduction

This is my second annual report as Chair of the National Mental Capacity Forum.

The last year has seen the 10th anniversary of the Mental Capacity Act 2005 (MCA) being implemented in October 2007. This anniversary was marked by many teams across England and Wales who work with the MCA on a daily basis.

The second year of the National Mental Capacity Forum has seen continuing progress in embedding the principles of the MCA, raising awareness of its wide application and in developing tools to promote the Act and its workings.

Notable work in the financial and banking sector has been the widespread development of guidelines and accompanying training for front line staff on providing services to people who are vulnerable. This has included increased awareness of fraud and scams into which people are easily lured. This was also supported by a Government amendment to the Financial Guidance and Claims Bill to make a core duty of the new regulator to ensure that guidance has regard to the needs of people 'in vulnerable circumstances'. This will cover both those with fixed and those with fluctuating impairments in capacity for decision-making; for some of them the impairment may have been precipitated by extreme trauma.

Important work also continues by health and social care practitioners, voluntary organisations, solicitors for the elderly, the utilities, first responders emergency services and others who interact with those who may lack capacity to make particular decisions and their friends and families that support them. Trading standards officers undertake extremely important work, recruiting many to be 'scambassadors' to widen awareness of potentially fraudulent approaches to people who for whatever reason may be vulnerable.

One major source of vulnerability is frailty and failing mental capacity, combined with loneliness. Yet the loneliness of many older people has received scant attention until recently. Many lonely elderly people are vulnerable to exploitation. They may continue to subscribe to fundraising initiatives and to lotteries that they will have no chance of winning, partly because they value the envelope dropping through the letterbox, which signals to them somehow that they are not completely forgotten in society. Their lack of familiarity with internet fraud methods makes them vulnerable as the world around us all switches more and more to on-line transactions. In some areas, moves to set up compassionate communities and neighbourly schemes have begun to address some of these problems, by establishing hospice volunteer visitors, matched by interests, to people who are housebound and frail.

Whilst a person's decision to spend money on such postal 'prize lotteries' could be seen as 'unwise' the degree of emotional pressure that the mailings generate in those who often have some degree of impaired decision-making capacity means this iceberg cannot be ignored.

In my last annual report I published my four priorities for the Forum for the coming year, which were:

- Hearing the voice of the person
- Improving understanding
- Supporting carers
- Reducing/preventing exploitation

Each of the chapters in this report describes the achievements and ongoing work against one of the priorities.

While many individuals and organisations have worked tirelessly over the last year, I wish in particular to thank several people for their contributions. The members of the Implementation Groups have continued to work with their own professional contacts to develop projects to improve implementation of the MCA.

Rachel Griffiths has continued to provide an invaluable 'voice of the user' perspective to the Forum's work. She had previously played an important role in the Care Quality Commission to develop standards and train inspection staff to evaluate the MCAs application. She also is now working with Health Education England to review and improve all their e-learning material on the MCA.

Lorraine Currie, as well as providing leadership in Shropshire Council and developing initiatives as a Consultant for the Association of Directors of Social Services, has, with Rachel Griffiths, been an invaluable source of support and advice.

The Forum has continued to work with an extremely limited budget and with staff support from the Ministry of Justice and Department of Health and Social Care. Fortnightly review meetings have ensured cross departmental working, supplemented by in-depth meetings with Welsh Government. One major piece of work in Wales, with Health and Social Care Research Wales, was a consultative meeting to produce clear guidance on clinical trials involving people with capacity impairments, in a format understandable to professionals, individuals and their families alike.

The Forum's mission continues to be to improve the lives of people with impaired mental capacity – whether that impairment is temporary or permanent, mild or severe. It is important that such people are supported and empowered to make their own decisions about their lives wherever possible. Where they cannot do so, decisions made on their behalf must be in their best interests, not in the interests of others or of health care systems. That can pose challenges to budgets but we, as a society, must not fail people who are vulnerable.

The Forum's Leadership Group (membership at the end of the document) has met three times over the year. The Leadership Group has been particularly focused on fostering local innovation and action in the different disciplines that members have access to. Despite the lack of a budget to fund infrastructure projects, the Forum has been an active catalyst to facilitate initiatives.

It has continued to be a strategic cross-sector sounding board. I have been impressed at how members, and the organisations and sectors they work in, have maintained the dedicated momentum for change and improvement despite having neither protected time nor a budget to work from. The Leadership Group and Forum members have undertaken these roles in addition to their demanding day to day roles.

The Forum, with its own webpages hosted within SCIE's Mental Capacity Act Directory, has continued to grow. It now has over 500 members with some bloggers who have written with touching honesty and clarity about their own experiences. Because of the potential cross-over between Forum initiatives and SCIE's separate resources, the Forum web presence has been rearranged to facilitate access and make joining the Forum an easier single step process as it is important that the Forum is accessible. I hope that this simpler and quicker application process will help to make it a more helpful resource to professionals working with those who may lack capacity, as well as being an accessible source of information to people who have some degree of impaired capacity and to their families and close friends who support them.

Over 100 of these members attended the successful second annual Mental Capacity Action Day on 27th February 2017. This was generously hosted The Royal College of Physicians, following on from the lead of the Royal College of Anaesthetists who hosted our ground-

breaking first Action Day on 15th March 2016. Both events owed much of their success to the personal commitment of the College Presidents and their Executive teams.

I am delighted that the British Medical Association has followed this generous lead with its offer of hosting the next annual MCA Action Day on March 5th 2018. The BMA Ethics Department has also started work on producing improved guidance for health care about Best Interests Decisions, the processes required and the way that meetings are conducted to ensure that a person's interests are as comprehensively represented as possible.

My most sincere thanks also go to those members of the public who care passionately about the welfare of those with impaired capacity and who have offered constructive criticism to me and to the Forum's Leadership Group throughout the year.

In my third year as Chair of the Forum, the complexities of the current Deprivation of Liberty Safeguards and the Law Commission proposals for Liberty Protection Standards will need a great deal of my focus. It is clear that any new system must be more effective at improving the outcomes for individuals than the current bureaucratic processes have been, with their delays and at times variable interpretation of the regulations. Additionally the Mental Health Act (MHA) review will need to look carefully at the interface between the MHA and the MCA. A series of consultative meetings we have held with care of the elderly physicians and psychiatrists has revealed complexities in clinical practice when capacity is impaired and differences around the country.

It is exciting and rewarding to see the momentum that has developed around awareness of the MCA, its core principles and the ways in which it can empower people in deciding how they want to live. And this work has revealed how much more there is to do.

The report includes a few illustrative examples of initiatives relevant to the implementation of the MCA. This is a small selection, supplied by the Leadership Group, of the enormous amount of activity that is happening nationally. Submissions for the Action Day reveal hundreds of different projects, all of which aim to improve the implementation of the MCA in practice.



Ilora Finlay

Professor Baroness Finlay of Llandaff

Chair of the National Mental Capacity Forum

Action against priorities - Improving understanding

Introduction

The Mental Capacity Act 2005 (MCA) is everyone's business. Practitioners in all sectors need clear information to build their understanding of the MCA through clear and simple messaging that helps them take responsibility in care and decreases inappropriately risk-averse attitudes. Such messaging must cover:

- The five principles of the Act and what they mean in practice,
- How to assess, where necessary, whether someone lacks capacity for a decision (being clear that capacity, and hence the assessment, must be recognised as decision and time specific),
- Recognition that capacity can and often does fluctuate, and
- The various learning styles of those we seek to influence.

Understanding of the core principles across all sectors

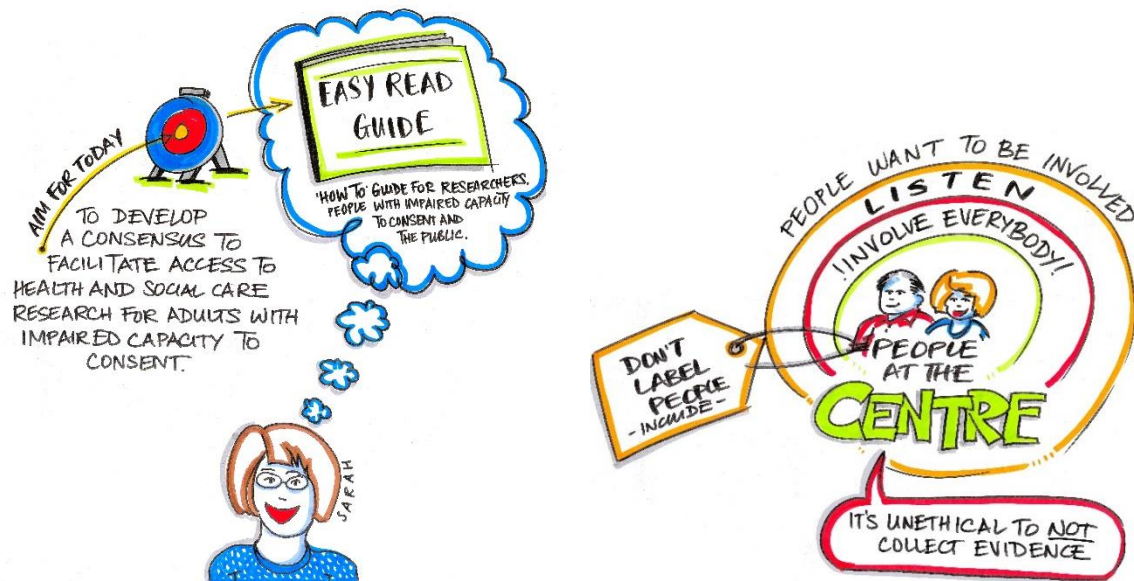
Awareness of the five principles of the MCA has been increasing, as the take up of the simple 'hand' aide memoire developed by collaboration between Shropshire County Council and Taking Part Advocacy featured in the first MCA Action Day in 2016. Since then it has gained traction across many services, serving to highlight the principles, and it is rewarding to see recognition of the principles in a variety of conferences and across different sectors, which certainly was not evident two years ago.

The Mental Capacity Action Day in February 2017 developed this theme, with an emphasis on the perspective of service users.

Mental capacity research: Making good research happen for the benefit of all

In conjunction with The Welsh Health and Social Care Research Institute and hosted by Welsh Government, an event on Mental Capacity in Research brought together researchers from across England and Wales, with the aim of stimulating research in the field of impaired capacity to foster improved care.

This day was unique in having people with impaired capacity who had been recipients of the effects of the MCA as co-chairs in each of the workshop events. The keynote address was given by William Mieville-Hawkins who had sustained a very serious brain injury in a road accident from which he was not expected to recover. The audience was spell-bound as he and his mother shared their experiences of profound coma, being recruited into a study while still in a coma as there was no clear 'best pathway' and the benefits of this as he awakened.



Several people commented that being involved in research studies made them feel more valued as individuals, that their experience was recognised and they were glad to contribute of the general good of others. The day was recorded by an artist who also assisted in the production of 'Research and Impaired Mental Capacity in Adults: Guidance for Researchers'¹, aimed at promoting inclusive research to the benefit of all.

Joining the Forum

During 2017 the application process to become an associate member of the on-line National Mental Capacity Forum² was made simpler and quicker. The Forum currently has 539 members. Its web pages are hosted in the SCIE (Social Care Institute for Excellence) website, which has led to some confusion of roles as several members have found it hard to find the National Mental Capacity Forum pages. The NMCF members' area hosts some powerful blogs from those with lived experience of the MCA in their own lives. The Leadership Group have agreed that the aim is to attract more people and to maintain the original vision of the site as somewhere for practitioners to share information.

The Forum seeks to act as a catalyst for innovation and dissemination of effective projects and does not endorse specific publications. The Forum is not in a position to quality assure contributions. Two independent videos are being prepared, on assessing decision-making capacity in everyday practice and on specific aspects of supporting people in their decision-making, as an additional resource for training.

On SCIE's own website the mental capacity pages remain popular for accessing materials, with 1.5 million page views in the last year. Of these, the brief guide to DoLS was the most popular. The MCA Directory is a collection of materials sent in by professionals and academics throughout the country, is separate from SCIE and funded by Government, despite being accessed via the SCIE website; this had around 47,000 hits last year.

¹https://www.healthandcareresearch.gov.wales/uploads/News/research_and_impaired_mental_capacity_in_adults-guidance_for_researchers.pdf

² <https://nmcforum.ning.com/>

The financial sectors

The past year has seen many projects, aimed at improving the implementation of the MCA across the financial sectors, come to fruition. Staff training and staff support systems have been developed, with impressive collaboration between different commercial providers through their common professional societies. This has led to initiatives to ensure widespread staff training and specific training to protect customers from fraud, as outlined in the next chapter.

Understanding and responding to the needs of customers is key to doing the right thing. This is especially important when people experience challenges or when life feels uncertain and extra help and support is needed.

Staff training gives confidence, especially when faced with less familiar or more complex situations, and means that front line staff can carry on providing the trusted and local support many people prefer for longer. The Building Society sector has established support services for people with impaired mental capacity. They continue to champion the needs of people with mental capacity limitations across the industry as well as work with consumer organisations to understand key issues better. Work with charities has further identified steps to be taken to improve understanding through simplifying how numerical information is presented, and simplifying common financial terms to make them easier to understand.

This approach for supporting members has been both informed by and validated through primary research, which has helped the leading building societies identify what they are doing well as well as provide insight and understanding to identify new areas to explore.

GOOD PRACTICE EXAMPLE

Nationwide Building Society management teams have trained all frontline colleagues to help them recognise when decision-making might feel difficult so that the right help can be offered in the right way, and members are able to continue to be independent and stay in control. Nationwide Building Society have also delivered training to help their colleagues to spot signs that might indicate that someone is at risk of exploitation or financial abuse.

To support frontline staff, they have extended the role of their specialist support service to be a single point of contact for additional information and guidance.

Support is now available to more members including people with learning disabilities, people living with mental health problems, people seeking help to manage gambling addiction, and people with dementia. Over 6000 members have benefited so far from the tailored support specialist case managers offer. The service is also working closely with carers to help build coping strategies for supporting others as well as managing the financial impact brought about by increased caring responsibilities.

Disseminating informative materials

There have been many initiatives throughout the year aimed at providing a range of information suitable for different audiences. Below are some examples of initiatives developed over the year to aid understanding of the MCA:

The Association of Directors of Adult Social Services (ADASS) produced a note for councils to offer guidance about when the intervention of the Court of Protection may

be needed in relation to welfare decisions where a person lacks mental capacity for the decision³,

The National Mental Capacity Act Competency Framework⁴, the National Centre for Post Qualifying Social Work and Professional Practice (NCPQSW) and Centre for Leadership, Impact and Management Bournemouth (CLiMB),

ADASS produced two straightforward guides to Deprivation of Liberty Safeguards and Orders to help families and carers understand the processes their family members may be experiencing⁵,

The Next of Kin leaflet, produced by NCPQSW at Bournemouth University to explain decision-making authorities, has had extensive take-up. An addendum is planned about valid Advance Decisions to Refuse Treatment targeted at the NHS⁶,

39 Essex Chambers have updated their publications, A Brief Guide to Carrying Out Capacity Assessments⁷ and A Brief Guide to Carrying Out Best Interests Assessments⁸ which both provide guidance for social workers and those working in front-line clinical settings,

The Bournemouth University Group launched The National Mental Capacity Act Competency Framework⁹.

The role of the utilities sector in identifying people who are in vulnerable circumstances

The utilities sector is working on different approaches to increase awareness of mental capacity in order to better support vulnerable individuals. 36,000 people are on the utilities sector's vulnerability list.

The Gas Distribution Network has worked on carbon monoxide (CO) detection by installing alarms wherever possible. As a result of this, there were no deaths from CO-poisoning due to gas appliances last year for the first time ever.

Internet and telecoms providers overall will be a focus for work next year to find ways to halt costly payments on contracts when a person suddenly loses capacity, such as following sudden illness or brain injury, or when dementia progresses. These can prove expensive to the person's family at a time of distress. Currently such contracts are often only suspended after the Court of Protection has appointed a Deputy, which can be weeks or months after sudden brain injury occurs.

Our world is increasingly driven by technology and data. Regulators want utility companies to use this data and insight to understand their customers, to ensure they receive a tailored, seamless and stress-free customer experience. This is more important than ever because vulnerability is an issue facing customers across all sectors and it is here to stay. As

³ <https://www.adass.org.uk/applications-to-the-court-of-protection-a-guide-for-council-staff>

⁴ <http://www.ncpqsw.com/publications/national-mental-capacity-act-competency-framework/>

⁵ <https://www.adass.org.uk/quick-guide-to-deprivation-of-liberty-safeguards-dols>

⁶ <http://www.ncpqsw.com/financial-scamming-publications/nok/>

⁷ <http://www.39essex.com/content/wp-content/uploads/2018/02/Mental-Capacity-Guidance-Note-Capacity-Assessment.pdf>

⁸ <http://www.39essex.com/content/wp-content/uploads/2017/11/Mental-Capacity-Guidance-Note-Best-Interests.pdf>

⁹ <http://www.ncpqsw.com/publications/national-mental-capacity-act-competency-framework/>

customers move in and out of vulnerable situations, identifying those who might need extra support is a challenge.

GOOD PRACTICE EXAMPLE

Ofwat, the economic regulator for the water and waste water sector in England and Wales, and Ofgem, the UK energy regulator, through the UK Regulators Network (UKRN), have published a report which sets out how the two sectors can work together to make better use of customer data to support those who may be vulnerable. This covers sharing non-financial data, such as access difficulties and a wide range of disabilities, to improve the service to customers.



Customers should always understand why their data is being collected and, if applicable, with whom it is being shared. In line with the ethos of the MCA to empower people to make decisions, and to support them if their capacity to make decisions is impaired, customers need companies to be transparent about the data they hold and how it can be accessed. Customers may need support to make informed decisions about how their data is used and shared.

Water and energy companies offer free, non-financial support (such as accessible bills, help with water meter readings, or targeted support in case of an emergency) to their customers through their respective special assistance registers and priority services registers (PSRs). These services in water and energy are very similar – customers who need support from their water company often need support from their energy company too, and vice versa.

If water and energy companies share the non-financial data they hold about their customers who would benefit from extra support, they will be able to provide better support and a seamless, stress-free experience. This should limit the need for customers to have the same potentially upsetting conversation, divulging sensitive personal information on repeated occasions, particularly where the issues faced by customers are less widely understood, for example, where customers have mental health challenges.

Through the Energy Association Networks (ENA) Safeguarding Customers Working Group (SCWG) the energy industry (gas and electricity) have developed improvements to Safeguarding Services, including their Priority Services Registers. This alerts companies to those in vulnerable situations before any interaction, allowing customers to be offered additional person-centred support, such as using agreed alternative contacts.

Companies in the sector have been working at different rates to ensure their staff are mindful of the MCA and the five principles which underpin it. Some water companies have also implemented training for their staff covering dementia awareness (Dementia Friends training from the Alzheimer's Society) and mental health. This now needs to be built on; companies need to introduce a cultural change within their organisations to ensure all their staff are empathetic and trained to help those who need it most. Building links with multi agency referral schemes can mean that the utilities can make the most of every interaction and refer in customers who may benefit from support such as befriending or scam support services.

GOOD PRACTICE EXAMPLE

New safeguarding services have been developed including the free supply and fitting of Locking Cooker Valves (illustrated) and a new Accessible In Home Display (AIHD) developed with the Royal National Institute of Blind People (RNIB).



Locking cooker valve

The challenges for the police

The police are often called when a person with impaired capacity is causing concern in the community. This is a difficult situation for officers who need specific training for the task of managing such situations, particularly when a mental health liaison officer is not available.

Police in Wales

Dyfed Powys Police have been promoting an overview of the MCA in each of their mental health Awareness Training days.

The teaching is based on the five statutory principles of the MCA. It involves exploring the questions that arise from these, including real examples of when the MCA can and cannot be used.

Gwent Police have also undertaken intensive officer training on mental health, the MCA and its role in policing.

I.D. CURE mnemonic for front-line police officers in Wales assessing capacity

People may be deemed to lack capacity if they cannot do one or more of the following four things:

1. **C**ommunicate their decision
2. **U**nderstand information given to them about the decision to be made
3. **R**etain that information long enough to be able to make the decision
4. **E**valuate, use or weigh up that information as part of the decision-making process

AND

the person is suffering from either an **I**mpairment or **D**isturbance of the mind or brain (which may be permanent or temporary)

The 5 MCA principles governing police response in Wales

1. Officers must assume that a person has capacity unless it is established that they lack capacity
2. Officers should not treat a person as unable to make a decision unless they have taken all practicable steps to help the person to do so without success
3. Officers should not treat a person as unable to make a decision merely because they make an unwise decision
4. Officers should act or make decisions under this Act for or on behalf of a person who lacks capacity in that person's best interests
5. Before acting or making the decision, officers must have regard to whether they can achieve the purpose for which it is needed as effectively in a way that is less restrictive of the person's rights and freedom of action

A particular difficulty arises in the practical allocation of suicidal intent. Where a person who is threatening suicide appears to know exactly what they are doing and why, others may be reluctant to conclude they lack capacity – basing this judgement on principle 3 of the MCA (i.e. a person is not to be treated as unable to make a decision merely because he makes an unwise decision).

It is not the decision to take their own life that necessarily shows lack of mental capacity, however, but rather their inability to consider or fully think through alternative options such as counselling, medical assistance or help from statutory or voluntary agencies (evaluating that information as part of the process of making the decision – section 3(c) MCA).

A police officer may undertake proportionate acts to safeguard someone's best interests (section 4(9) of the MCA) in accordance with the principles of the Act (section 1 MCA). Officers will then be protected by a defence against any legal liabilities ordinarily arising from that act, under section 5 of the MCA, as long as they acted in the best interests of someone whom they reasonably believed lacked capacity. If this involves restraining a person, it must be done in accordance with section 6 of the MCA, in that the actions must be both necessary to prevent harm to the person and a proportionate response to the likelihood and seriousness of that harm.

Removing and detaining (in whatever setting) a person who lacks the mental capacity to take the decision in question for themselves will usually amount to a deprivation of liberty (section 4B of the MCA) and may only occur where it is necessary to provide a life-sustaining treatment or to do a 'vital act' necessary to prevent a serious deterioration in their health.

Supporting people wherever they are

There is an untapped opportunity for work with ex-prisoners to raise awareness and increase support to those with impaired mental capacity in prisons. This should be explored in conjunction with schemes such as prisoner-carers, where one to one support could be provided for within the prison population, particularly for elderly prisoners whose sentences hold no imminent prospect of release.

Broadening reach

Health Education England

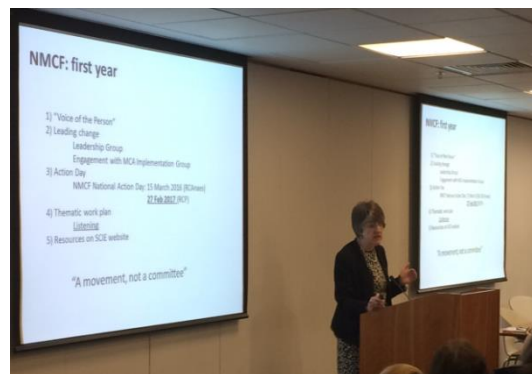
Currently, Health Education England's e-learning materials on the MCA are being revised and updated. This project, led by Rachel Griffiths, will ensure there is proper emphasis on the voice of the person in all learning content and that material reinforces best practice.

NHS England

There have been a large number of conferences, meetings and training sessions with attendees committed to spreading understanding of the MCA.

EXAMPLE

NHS England sponsored a National Mental Capacity Conference for 160 multi-agency professionals from across England and Wales in January 2017, repeated in February 2018, under the theme of "Supported decision making".



Baroness Finlay at the 2017 conference

Intensive care staff training

The Royal College of Anaesthetists (RCoA) have continued their commitment to the MCA, with a programme of workshops for intensivists in communication and in capacity assessment. I have participated in two such major RCoA meetings (one in England and one in Wales).

The General Medical Council

New on-line learning materials have been developed as a resource that can be used in appraisal and revalidation processes.

Medical Schools

The Medical Schools Council included a briefing on the MCA for all Heads of Medical Schools at their autumn meeting, and another meeting of medical school leads on MCA teaching was held to facilitate sharing of ways that the MCA is maintained as a major theme in undergraduate teaching and assessment.

Supporting decision-making

A number of local authorities are beginning to develop and take forward work looking at schemes for supported decision-making. This was the subject of a workshop at the National MCA Action day in 2017 provided by Lorraine Currie. The workshop encouraged participants to look at models of decision-making and necessary support provided to people before capacity is assessed.

GOOD PRACTICE EXAMPLE

Shropshire Council have started to develop a supported decision-making model where Lorraine Currie provides a Supported Decision-Making course and has introduced a pilot with a small number of social workers to trial an early draft of a supported decision-making tool with a plan to refine and develop it further during 2018. She is linking with Central Bedfordshire Council who are doing similar work with practitioners and with providers to start from a supported decision-making perspective. In the light of the Law Commission recommendations about the wider MCA, this area will benefit from a collaborative approach over the coming year.

There are a number of individuals who work through their own companies to support the wider aims of the MCA.

GOOD PRACTICE EXAMPLE

TSF Consultants work across health, legal and financial sectors and aims to improve mental capacity assessments, including enhanced understanding of the practicalities involved. TSF have also developed specific tools to accurately identify the threshold of understanding – which forms the bedrock of any assessment – and then provide appropriate support to make the decision in question.

Research on Vulnerability and Lending, published in June 2017, has led to attempts to develop a computer algorithm able to recognise vulnerable and incapacitated adults at the point of application for financial products. User testing will begin in 2018.

Action against priorities - Hearing the voice of the person

Introduction

Active listening is key to understanding what a person needs and wants. This involves listening to the person and properly consulting those who know and love that person in order to ensure that we know what their wishes, feelings, beliefs and values are. Those directly affected by capacity impairments and their families need to feel valued, be treated with kindness and be involved in the decision-making process. This allows the person to be empowered as much as possible.

'No voice unheard, no right ignored'

I met former Health Minister, Norman Lamb MP, to discuss my concerns that the impact of the 'No voice unheard, no right ignored' consultation risked fading. The resource difficulties for mental health services provision have become ever more evident over the past year.

This has highlighted that well written policies are not easily translated in to practice in a changing political and economic climate.

Supporting people to stay in their own homes

An increasingly important issue this past year, and for the future in 2018, has been 'accommodation moves'. Social and health care staff must ensure that decisions about people moving out of their own home are only taken when that is genuinely the only or most appropriate solution and in their best interests – established after comprehensive assessment and consultation.

This is particularly salient in the context of hospital discharges and for people who are 'self-funders', where NHS pressures can sometimes result in professionals losing sight of a person's right to live in their own home even where there is an element of risk. Others might consider it unwise for them to return to their own home and setting up support at home can cause a delay in their discharge, resulting in pressures to move more quickly into a care home setting.

People who are admitted to hospital from their own home have every right and reasonable expectation of being discharged 'back home'. Local authorities have an important role in such circumstances in advocating for individuals' rights and in challenging other professionals who may be 'risk averse'.



Andy Butler supporting a client to remain living at home

In order to ensure this support of individuals, The National Framework for NHS Continuing Healthcare guidance is being reviewed to ensure it is informed by and compliant with the MCA. Proposals from the Law Commission for new Liberty Protection Safeguards will also

require scrutiny to ensure they empower people to be in their own homes if that is what they wish and avoid inappropriate pressures to move to a care home.

Best interests decisions

Following a meeting with the British Medical Association (BMA) Ethics Department to apprise them of the need for guidance to doctors, such targeted guidance is currently being drafted. It is particularly important given the marked power imbalance that often exists in favour of clinicians rather than the family, when difficult decisions have to be taken on behalf of a person who lacks capacity. Despite the process laid out in the MCA for taking a best interests decision on behalf of the person, the way meetings are sometimes conducted can leave the family overwhelmed and intimidated, feeling inadequate weight has been given to their expression of the views and values of the person they love.

There are particular difficulties around best interest decisions as there is a culture of considering these as a one-off event rather than part of an ongoing process of clinical review and anticipatory care planning. Sometimes there seems to also be failure to recognise that such decisions must weigh in the balance whether the benefits of an intervention outweigh its risks and burdens and that such weighing up must not be motivated by a wish to bring about the person's death, even though the inevitability of death is accepted and care during dying is planned.

Clinically Assisted Nutrition and Hydration

One contentious area has been the cessation of Clinically Assisted Nutrition and Hydration. The Mental Capacity Act Code of Practice¹⁰ (paragraphs 6.18 and 8.18) states that Court approval must be sought for such actions, but the High Court has decided that the Code of Practice does not impose a legal obligation on clinicians to seek Court approval. Following this the Court of Protection's Practice Direction 9E was withdrawn, as of 1st December 2017, meaning there is no longer a requirement to go to court, provided that family members and medical practitioners all agree that Clinically Assisted Nutrition and Hydration should be withdrawn in a person with a persistent vegetative state or minimally conscious state. The Royal College of Physicians, the General Medical Council and the BMA have produced interim guidance on this difficult issue. I contributed to the consultation process as chair of the National Mental Capacity Forum.

As the numbers of patients in minimally conscious states across England and Wales is not known, the Royal College of Physicians Council have strongly endorsed the National Mental Capacity Forum's suggestion that systematic longitudinal data collection is urgently required through a national register and dataset. This would allow auditing of how the guidelines are being followed and avoid the problems that were encountered with the Liverpool Care Pathway. Such a database of Prolonged Disorders of Consciousness Deaths could be confidential, with details anonymised, but used for an annual report, to allow scrutiny of how decisions were taken and to inform future practice.

¹⁰ <https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>

Making a will, including testamentary capacity

From July to November 2017 the Law Commission consulted on “Making a Will”.

The Law Society¹¹ has supported the Law Commission's proposal to adopt the definition in the MCA for testamentary capacity. The Law Society stated the view that this legal test will address the current issues identified by the Commission where different tests are applied depending on whether a testator is executing a will, or if one is being made once a testator loses capacity to make a will themselves.

The Law Society also strongly agreed with the Law Commission that a Code of Practice would be helpful in providing guidance to the court, legal and other professionals as to how capacity should be assessed. A clear Code of Practice, written in plain English would inform lay persons who may be supporting loved ones to make a will or who may question how their capacity may be assessed.

The Law Commission has recommended that the making of a statutory will should remain within the jurisdiction of the Court of Protection. They suggest that the fact a person had not made a will before losing capacity should not preclude the making of a statutory will on their behalf. Many people make a will in later life and it cannot be assumed that a person makes an active choice not to make a will, rather than they simply have not taken active steps to do so.

Individual solicitors continue to promote the MCA and its principles in their everyday working life. This includes pro bono work such as working with local hospices, care homes and community groups to provide free training events. Many solicitors are active members of Dying Matters, which encourages conversations around planning for mental incapacity and death.

Travel assistance

Travelling by rail or by air is an everyday experience for many but, for those with impaired capacity, railway stations and airports can be particularly confusing and frightening. Cardiff Wales Airport and several major hub airports in England have instigated guidance services to help travellers navigate the complexities of their travel, with specific guidance and training programmes for their terminal staff. They also ensure an appropriately trained member of staff always on duty. Security staff are now being trained to support those with autism through airport security screening checks.

People with disabilities that are not visible may find negotiating physical space difficult. For example people with movement disorders may need assistance on and off transport but those with a different disability need other types of personalised assistance.

¹¹ The Law Society represents all solicitors in England & Wales and considers mental capacity through their specialist committees, namely The Mental Health & Disability Committee, The Wills & Equity Committee and The Private Client Section Advisory Group.



Illustrations from a project “I am a passenger” by art student Grace Currie, highlighting the challenges of travelling with a disability that is not visible.



This sign in the Ministry of Justice is an example of good practice, highlighting that “not every disability is visible”.

Embedding ‘the voice of the person’

Rachel Griffiths has led Forum Leadership activities related to hearing the voice of the person, through speaking at conferences on the ‘voice of the person’ - in Leeds, Bristol, London, Hereford and Birmingham and running workshops to foster open discussion. These include workshops on how better to ‘hear the voice of the person’ for Best Interests Assessors and Deprivation of Liberty Safeguard Medical Assessors in Leeds, and writing and running six full-day workshops, for Research in Practice for Adults (RiPfA), in London, Birmingham and other locations, on improving social work practice making decisions within the empowering ethos of the MCA, in particular, the importance of giving weight to someone’s wishes and feelings, by hearing the voice of the person.

These have been supplemented by numerous pro-bono consultations (Rachel Griffiths Consultancy Ltd) for individuals living with the MCA about what is required of professional decision-making, with advice as to how to quote from the Act, relevant case law and its associated code of practice to empower these individuals.

Rachel also represents the National Mental Capacity Forum’s importance of the ‘voice of the person’ in Department of Health and Social Care work on exploration and planning. She has also contributed to a publication, due in 2018, on the complexities of modern social work practice, highlighting the importance of hearing the voice of the person and incorporating that into practice.

The voice of the person in IT systems

Technology can be used to enable the voice of the person in a number of ways to ensure that the citizen's views are included first and foremost in social care records, not seen as an add-on.

GOOD PRACTICE EXAMPLE

Stef Lunn, working with OLM Systems, has been developing a software product that allows local authorities' social workers and other social care staff to harness the power of modern technology in the following ways:

- Practitioners are prompted to have conversations with people about their choices and risks, and record these in a way which embodies the spirit and the letter of the MCA.
- The system supports people to undertake and record their assessment and any best interests decision, with written and video guidance for the less experienced practitioner
- The development of Smart forms which can use sophisticated logic to prompt practitioners to ask relevant questions at appropriate times.
- By harnessing simple technology, the person's voice is really heard (the inclusion of video and voice recording as part of the service user record) rather than watered down or paraphrased in care act, mental capacity, best interests, DoLS recording and even Advanced Decisions to Refuse Treatment/prior expressed wishes. The inclusion of rich media can enable people to capture their plans and preferences in a different format where such authenticity is helpful.

Supporting carers and broadening reach

Traditionally health and social care records are held in closed systems. People can only gain access to those records if they apply, which can prove a lengthy process. In order to empower individuals and facilitate person centred support, people and their carers need secure direct access to their social care records as held by care homes, local authorities or any other care provider. Whilst some parts of these records may need to remain inaccessible to the user, there needs to be a good reason why people and their advocates cannot have ready access to their own data.

Supporting vulnerable people

Support to vulnerable people requires joint working between different agencies, many of which have not traditionally worked together in a preventive capacity.

This needs a change in thinking and attitudes for each agency to foster a sense of responsibility to those citizens whose capacity impairments make them particularly vulnerable to different types of targeted crime.

GOOD PRACTICE EXAMPLE

Warwickshire Police have identified a disturbing trend in vehicle fraud where finance is taken out in the name of a vulnerable person – undue influence is used to facilitate this - and then the car is stolen from that person leaving them liable for the payments on a vehicle they do not benefit from. Local solicitors' firms are developing software to help the car finance companies to identify potentially fraudulent applications of this nature.

Societal attitudes

Improved implementation of the MCA should lead to better support of those with capacity impairments, but this needs to be objectively demonstrated.

RESEARCH EXAMPLE – THE NEED TO REFLECT

Lucy Series, Cardiff University, is supported by Wellcome Trust to research into changing ideas about the 'empowerment' of people with mental disabilities connected with the Mental Capacity Act 2005 over the past three decades. Her research aims to enhance understanding of contemporary debates about mental capacity laws and disability rights, particularly whether the MCA's empowering reputation has been hindered by problems of implementation, or whether the MCA's core mechanisms violate international disability rights laws. This historical research is based on written materials as well as interviews with key players in the development, implementation and critiques (past and present) of the MCA over the past three decades. The aim of the research is to enhance understanding of debates about the empowering status of the MCA and similar laws internationally.

Action against priorities - Supporting carers

Introduction

The families and carers of people with impaired capacity need to feel better supported in their role, confident that practitioners will engage and appropriately involve them when decisions need to be taken. Carer fatigue is a widespread problem, and carers often report feeling they have to fight against bureaucratic barriers to get the right care in place. Some families have felt they are labelled as 'difficult' and I have been told of cases where a carer's power under a Lasting Power of Attorney has not been recognised, or they are not being consulted and heard in the Best Interests Decision-making process, which they should be under the Act.

When a person loses mental capacity to some degree, it is the family who often carry the major part of responsibility for care. In our fragmented society, increasingly these are children caring for a parent with an illness or disabling condition.

For any carer, the professional support system needs to work like clockwork to minimise their stress, but all too often it is unreliable, fragmented and varies in quality. Much has been done to ensure individual staff are well trained, but the management systems in which they work do not always allow them to provide the individualised care they would like to provide.

COMMENTS FROM A SPOUSE

"The carers were very responsive to her needs and skilled in communicating with her. The only problems were changing attendants and unreliable timing. Carers work as a team of ten and there is no notification of who will attend. This means that she gets confused and cannot establish a firm relationship, routine and care pattern, which are important to her management. I have to keep on instructing different carers in what is needed, how to manage her and her foibles, and orientating them in relation to finding clothes, operating showers etc.

The morning visit was listed as 7 am – 9 am, with no indication on a day to day basis of who is coming or when. If the carer doesn't arrive until nearly 9 am, she is getting restless and trying to care for herself, often with disastrous results."

The bereaved

Acute grief can impair decision-making capacity such that the bereaved person has little recall of events in the days following bereavement and can take decisions over financial outlay on a funeral that are completely unaffordable. Poor understanding of the limits of the funeral grant and bereavement support can aggravate this – I have heard of families attempting to crowd-fund a funeral after the event because they could not afford the costs they had incurred while in shock.

I raised this at the Annual Conference of Funeral Directors and Crematoria, where some discussion focused on the difficulties of determining whether a bereaved family member (often the parent of a child) was making a competent unwise decision or they were so distressed that their decision-making capacity was seriously impaired.

The problems for the bereaved, including those acutely distressed and those with learning difficulties, was also raised in my Keynote address to the Coroners Society of England and Wales. Coroners and their officers showed great insight and awareness of the difficulties, trying to ensure the inquest hearing is understandable to the bereaved and providing a CD recording of the proceedings. This allows family members to go over the hearing again and explain findings to those who have difficulty understanding and retaining the information at the time.

The Coroners Courts Support Service is a voluntary service that provides support practically and emotionally to the family and other witnesses attending the Coroners' Courts. They liaise with those appearing before the coroner's court to ensure their understanding of its role and the procedures, in order to facilitate its smooth and effective administration. As they encounter great distress amongst those attending, particularly where there are difficulties with comprehension or serious after-effects of trauma, the service will signpost families and witnesses to other agencies, for ongoing help with coming to terms with their bereavement.

Court mediation

A group of solicitors, barristers, medics and judges, who are passionate about improving the implementation of the MCA, have initiated a project to develop a mediation service for applicants to the Court of Protection to try to avoid costly court processes and to resolve issues that are in dispute, without needing to resort to lengthy and expensive Court of Protection proceedings. As an observer on this group I have been struck by their dynamic and proactive approach, open to criticism and keen to achieve better outcomes with attention to detail of how such processes should work. As their project progresses, its evaluation will be the test of applicability and cost efficacy over time.

When an attorney loses capacity

I have taken action on the growing issue whereby an attorney loses capacity and the donor who created the Lasting Power of Attorney has lost capacity to appoint another attorney. An application to the Court of Protection for deputyship must be made, but this can lead to delays in making decisions, particularly at a time when family and friends of the person (the donor) may be struggling to cope with sudden illness in the attorney. I have discussed this with Alan Eccles, Public Guardian, and Senior Judge Hilder at the Court of Protection. Over the coming months we will try to find a non-legislative solution that avoids unnecessary delays and allows caring relatives to know that they have put in place plans that are appropriate for the person they love.

The Office of the Public Guardian is also going to highlight the need to think ahead when completing the Lasting Power of Attorney forms such as appointing joint/several attorneys, or naming a replacement attorney or attorneys, which is already provided for. This should help to avoid this hiatus if the registered attorney is incapacitated.

Transition to adulthood

Life expectancy has increased for those with learning difficulties. When people reach the age of 18, parents suddenly find themselves excluded as decision-makers unless they are appointed by the Court of Protection as Deputies. Although some young people want

increasing independence, those with more profound impairments in capacity can find they become subjects of decisions at odds with their parents' perception of their wishes.

The difficulties at transition need a greater focus across all sectors of health and social care than they have received to date. The Court of Protection processes can feel frightening for parents who are already struggling with their own increasing age and the needs of their severely disabled child.

It is essential that practitioners recognise that the relatives who are primary care givers are a rich source of information about the person's wishes and feelings, and what is important to them. The MCA mandates that people 'interested in the welfare' of the person must be properly consulted. Without this consultation, there is little chance that the best interests of the individual will be correctly identified.

Alzheimer's and other dementias

During the last year dementia has had a high profile. A wide range of publications, from the Alzheimer's Society and others, aim to support people with dementia and their families on different aspects of decision-making have produced with a focus on making these publications more accessible to different communities.

GOOD PRACTICE EXAMPLE

The Lasting Power of Attorney digital assistance service, run by the Alzheimer's society, provides support to people wishing to make Lasting Powers of Attorney following a diagnosis.

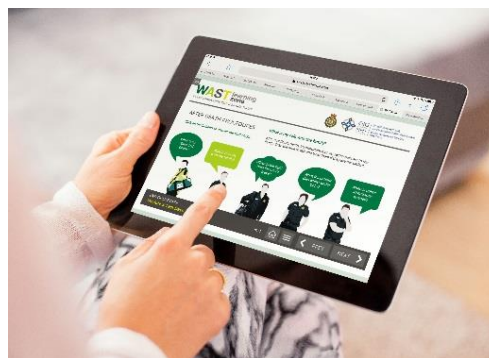
As part of the Dementia Friendly Communities programme, a range of sectors including dentistry have developed guidance for working with people with dementia, with a focus on capacity and supported decision-making.

The Alzheimer's Society has also continued to Chair the Mental Capacity and the Third Sector group, which meets quarterly and brings together third sector organisations representing a wide range of areas including people affected by particular conditions, older people and carers, as well as advocacy providers. A priority area has been engaging with the Law Commission's proposals to reform the Deprivation of Liberty Safeguards system.

Advance care planning

Advance Care Planning (ACP) has increasingly become incorporated in to clinical and social care sectors. This helps formal and informal carers know what a person wants or does not want in their care, allowing open discussion at any point as their situation changes.

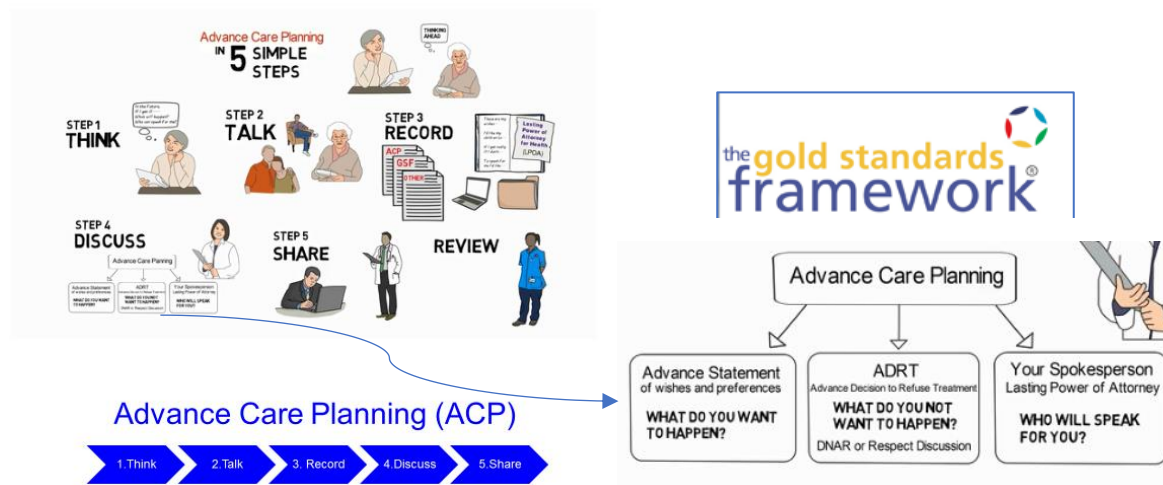
The Welsh Ambulance Service Trust has developed an e-tool to support front line staff in providing care and enabling them to feel confident in using the ACP to make appropriate care decisions that respect the person's expressed wishes. Such planning builds on staff understanding the legal framework of an Advance Decision to Refuse Treatment, Best Interests decision-making and an Advance Statement of Wishes.



Welsh ambulance e-learning to improve care decision support

Other initiatives include the pan-Wales drive to embed ACP into routine end of life care. This project, started by Byw Nawr with support from the Welsh Government, has been incorporated into the core clinical record of specialist palliative care services. It has achieved 49.7% of all patients known to specialist palliative care services having a clear ACP during the last 90 days of life. In the socially deprived area of Cwm Taf, where almost 40% of those with palliative care needs at any level are known to the specialist palliative care services, 69.5% of these patients now have an ACP discussed with their wishes recorded and updated, whereas it was 38.8% two years ago.

The Gold Standards Framework have produced guidance on ACP which includes easily understood video supportive materials, as in the illustration below:



In addition, many NHS services have produced their own guidance on ACP.

Care Quality Commission

Since the introduction of the Deprivation of Liberty Safeguards (DoLS) in 2009, the Care Quality Commission (CQC) has produced an annual report on the operation of DoLS. For the second year running this was integrated into CQC's annual State of Care report which, alongside giving high profile to the findings, contributes to sector understanding of the issues and the setting of priorities.

Day to day regulation in CQC continues to support providers to implement the entire MCA and helps to ensure that the DoLS scheme is correctly operated. This is through their inspection programme, setting requirements and enforcement. CQC has also made available web-based

updated resources around the MCA and DoLS scheme¹². CQC contains an active MCA steering group, which is reviewing its strategic focus on the training and support of inspection staff.

During this past year, internal “MCA surgeries” were introduced to help inspectors develop their confidence in inspecting and reporting on MCA practice. These have expanded to bring together inspectors from the Primary Medical Services Directorate with those inspecting Adult Social Care, to allow dilemmas and real scenarios they have encountered to be discussed in a scheduled telephone conversation with MCA operational leads. Staff members are able to dial in and listen to the discussions; feedback has shown staff value the opportunity to develop their own understanding and knowledge.

A renewed focus on data analysis is facilitating greater understanding of MCA and DoLS compliance and is informing discussions with the Department of Health and Social Care about the regulatory implications of the proposed Liberty Protection Safeguards.

Supporting carers and users

The NHS England Commissioning for Quality and Innovation (CQUIN) targets for 2016/17 were aimed at improving the pre-assessment pathway of those with learning difficulties by ensuring that patients were given hospital passports and easy-read discharge information about their admissions.

GOOD PRACTICE EXAMPLE

The Learning Disabilities teams at University College London Hospital (UCLH) worked with carer representatives, as members of the Learning Disabilities Steering Group to improve patient experience and decrease early mortality in this group. In addition, outreach by the Safeguarding Best Interest Assessors supports Local Authorities to assess local patients quickly and reduce delays.

In partnership with Camden Safeguarding Board, UCLH is developing a system to also incorporate tools to identify and record patients’ capacity, best interests decisions, Advance Decisions and Lasting Power of Attorney for Health and Advance Care Planning.

¹² <http://www.cqc.org.uk/help-advice/mental-health-capacity/about-mental-capacity-act>

Action against priorities - Reducing / preventing exploitation

Deprivation of Liberty Safeguards (DoLS)

In the first year of the National Mental Capacity Forum's work, the spread of the fundamental principles of the MCA were a priority. At that time the scale of the workload involved in DoLS, the backlog of assessments and the overall costs incurred following the Cheshire West judgment were becoming evident.

Lorraine Currie, as Chair of the National DoLS Leads Group has a national overview of the challenges from the perspective of local Authorities and the DoLS Leads. This group has had a focus on sharing best practice in assessing for DoLS, as well as maintaining a focus on quality by sharing best practice, service improvements and information from regional audits. The challenge for the DoLS leads remains how to achieve a balance between processing large numbers of requests and maintaining quality standards in the process and outcomes of these assessments.

GOOD PRACTICE EXAMPLE

The National DoLS Leads Group carried out an exercise to "walk through" the Law Commission proposals for the Liberty Protection Safeguards. Using three case studies providing differing scenarios they looked at each step of the new proposals and what the implications would be for the social care workforce. This exercise really helped with envisaging how the proposals would work in practice and the kind of practice changes which will be needed.

The Law Commission had undertaken an extensive review of the Mental Capacity Act and the Deprivation of Liberty Safeguards (DoLS). Their final report and draft Bill on 'Mental Capacity and Deprivation of Liberty'¹³ were published in March 2017. The Government's interim response was published in October 2017 followed by its final response in March 2018, indicating a broad acceptance of the principles proposed.

DoLS aim to protect people who lack mental capacity, but who need to be deprived of liberty so they can be given care and treatment in a hospital or care home. DoLS have been criticised since they were introduced for being overly complex and excessively bureaucratic, with delays and excessive costs associated with the way they operate.

Following the Law Commission report and proposals, I instigated two meetings between the Law Commission leads, Tim Spencer-Lane and Alex Ruck-Keene, and those working in front line care. The aim was to work through with real examples how any new system might work in practice. The first meeting revealed some stark differences between different parts of Health and Social Care, particularly Mental Health Units and acute sector liaison psychiatry, and the difficulties of timing around consent to treatment when capacity is fluctuating. The second of these meetings, with care of the elderly physicians and psychiatrists, revealed the difficulties at the interface of the Mental Health Act and the MCA and the workloads that assessments impose on services that are feel themselves to be near breaking point already.

¹³ <https://www.lawcom.gov.uk/project/mental-capacity-and-deprivation-of-liberty/>

On 9th February 2018 of the Parliamentary Joint Committee on Human Rights announced its inquiry into 'The Right to Freedom and Safety: Reform of the Deprivation of Liberty Safeguards inquiry' is calling for evidence on:

- Whether the Law Commission's proposals for Liberty Protection Safeguards strike the correct balance between adequate protection for human rights with the need for a scheme which is less bureaucratic and onerous than the Deprivation of Liberty Safeguards
- Whether the Government should proceed to implement the proposals for Liberty Protection Safeguards as a matter of urgency
- Whether a definition of deprivation of liberty for care and treatment should be debated by Parliament and set out in statute

The National Mental Capacity Forum is disseminating this call for evidence.

Preventing financial exploitation

Vulnerable people are often exploited by financial and other scams.

Work with banks, building societies and other sectors is well under way, and will continue to raise awareness of these risks. This will better enable organisations to recognise pointers to possible exploitation and ensure that front line staff respond rapidly. There is also a need to improve protection of vulnerable people from being exploited through targeted mailing, telephone calls and other intrusive and unsolicited communications.

The Trading Standards work to expose scams and protect vulnerable people is very important. To help raise the profile of this important work, it features on the Forum website, and I have highlighted its work in many presentations, and have become a 'Scambassador'.

Legislation: Financial Guidance and Claims Bill

In late 2017 I tabled amendments to the Financial Guidance and Claims Bill – to publicise the need to protect from exploitation those in 'vulnerable circumstances'. People under great stress may experience times of impaired capacity for a particular decision or decisions. At such times they can make a decision which at another time they would not make; and which do not fall into the category of an 'unwise decision' made with full mental capacity for that decision.

These changes were accepted by Government.

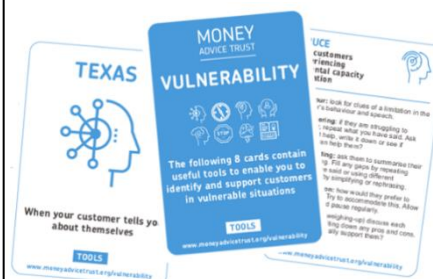
Financial sector initiatives

The Equity Release Council annual meeting in July 2017 included a plenary session which discussed the lack of safeguarding in telephone banking and internet banking facilities for people who lacked mental capacity. There has been no validation to date that voice recognition software can reliably detect coercion or other undue influences on a person in telephone banking systems. There was discussion about risks of fraud in equity release related to retirement plans, with some participants relating powerful person stories of family

coercion and criminality. In the financial sector these risks are clearly recognised and there is ongoing work to address this challenge.

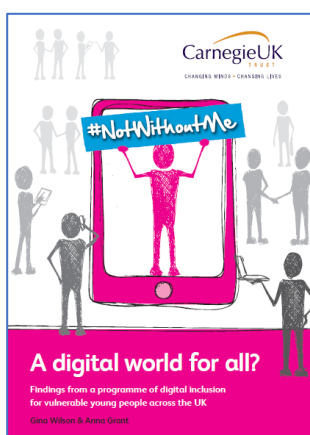
GOOD PRACTICE EXAMPLE

The Finance and Leasing Association, with Bristol University, have produced easy-to-refer-to guidance for staff when dealing with customers who may be in vulnerable circumstances. This is also supported by courses they run which are aimed to equip participants with skills to understand the principles of the MCA, who may act on behalf of a vulnerable person, and be able to assess and deal with the factors relevant to vulnerability. To date, more than 11,000 staff in 160 creditor organisations have now been trained on vulnerability.



Vulnerability guides produced by the Finance and Leasing Association.

Young people at risk



Carnegie UK is an organisation that supports young vulnerable people who are not digitally able. Carnegie dispelled the idea of all young people being 'digital natives', and detailed the steps being taken to try and address this problem.

Being digitally-able is a must in today's society, and the organisation challenges the use of banning access as a form of punishment for misuse. Carnegie UK advocates ways to help such young people use technology safely, without which young people with learning difficulties and psychological disorders all too easily become the victims of entrapment by criminals operating via the internet.

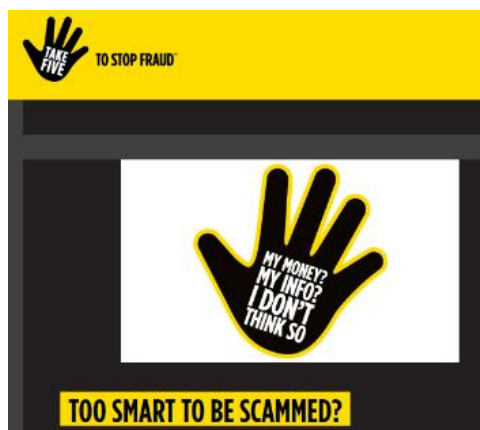
The Leadership Group has also discussed on-line grooming and scamming and how to deal with it. The solution requires working alongside people. These issues of course can affect anyone, not just those with impairments in capacity.

Preventing scams

Awareness of the multiplicity of financial scams has increased across all sectors in the past year. The National Trading Standards Scams Team has launched Friends Against Scams¹⁴ with the aim of recruiting one million people this year across all walks of society to support people to detect possible scams and avoid being victims. This means identifying those who are potentially vulnerable.

¹⁴ <https://www.friendsagainstscams.org.uk/>

As criminals are usually one step ahead of the game, this Friends Against Scams programme is linked to and supported by the banking sector.



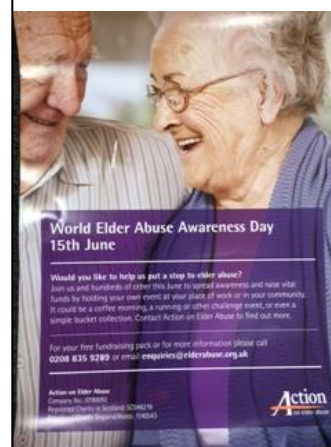
Other initiatives include 'Take Five'¹⁵, advising people to always stop and think before disclosing personal details.

An All Party Parliamentary Group on Financial Crime and Scamming has been set up. It aims "to allow parliamentarians to understand the nature of financial crime and scamming, its impact on society and on vulnerable and susceptible citizens; and to address issues on how we appropriately respond to these challenges".

Research into financial scamming¹⁶ has confirmed that it is often the elderly in the early stages of dementia with reduced levels of cognitive function who are most at risk of financial scamming. There is clear and very concerning evidence that this group is being actively targeted by criminals.

GOOD PRACTICE EXAMPLE

On World Elder Abuse Awareness Day (15th June 2017) UCLH, jointly with Camden Trading Standards, organised an event to highlight financial abuse and scamming. Discussion involved scores of patients, carers, families and staff to raise awareness in Camden, where financial abuse is one of the commonest forms of abuse. Attendees were encouraged to 'spread the word' about the risk of being scammed. Victims shared their stories and experience; several admitted that they were embarrassed to confess to their families that they were scammed as they did not perceive themselves as vulnerable. Support was given through advice from the Trading Standards Lead, the provision of safety "block" filters for the telephone and through leaflets to be disseminated widely.



¹⁵ <https://takefive-stopfraud.org.uk/>

¹⁶ <http://www.ncpqsw.com/financial-scamming/>

Building Societies Association

The main priority in 2017 of the Building Societies Association (BSA) has been to take up the Financial Conduct Authority's challenge of making it easier for customers to bring in third party support when they want some extra help in running their finances but are not yet at the stage of needing a formal Power of Attorney arrangement. BSA have published a "3rd Party Support - Best Practice" guide for BSA members. The next stage is underway, through partnership working with other sectors, to publicise such services to encourage customers and / or family to talk to their building society about early planning for any anticipated support arrangements.

Industry effort has focussed on help for consumers targeted by fraudsters via the public / private partnership Joint Fraud Taskforce. The Banking Protocol – a scheme to encourage early intervention in branches with individuals targeted for financial crime – has prevented £9m of fraud and led to 110 arrests. The BSA Taskforce is also working on initiatives to tackle on-line fraud.

The BSA continues to raise awareness of the enabling spirit of the Mental Capacity Act via senior management education, including a very successful National Mental Capacity Forum session at the 2017 annual conference, with another planned for 2018.

Bank closures

For those with capacity impairments who have difficulty using chip and pin, the closure of high street bank' branches poses potential major difficulties. The move to transfer face to face financial transactions to Post Offices will need local adjustments to ensure appropriate privacy and support. Many people with a degree of impaired capacity currently cope in the familiar setting of their local bank branch, but may have difficulty managing money in a different setting. One anxiety expressed by some people with learning difficulties is that chip and pin is difficult to cope with and that they can feel pressurised when in a queue with people who are in a hurry to buy stamps or post parcels.

The major banks have apparently looked at shared premises now that their local footfall is low, due to increased use of internet banking. They have discounted this and therefore have negotiated with the Post Office for service delivery. The impact of this change must be monitored to detect increased vulnerability and fraud.

Integrating record systems

The roll out of Electronic Health Record Systems, to provide a single, integrated digital health record should provide an opportunity to reduce and minimise some of the risks identified in

GOOD PRACTICE EXAMPLE

Case example - Through better safeguarding

Devon County Council, working with a commercial organisation, is developing software to support multi-agency safeguarding hubs. A single repository will bring together information from a range of agencies to tackle situations that are becoming increasingly familiar in Safeguarding Adult Reviews. This is where people can easily 'slip under the radar' because they appear to have a low level of need, but are referred to many agencies. The system flags up these well-known causes for concern.

Safeguarding Adults Reviews and Domestic Homicide Reviews where communication and information sharing for vulnerable patients are often cited as a key contributor to failures to act.

Recognising exploitation



Modern Slavery Act
2015

GOOD PRACTICE EXAMPLE

The London Safeguarding Adults Board recently commissioned the International Organization for Migration and Stop the Traffik to develop, pilot and evaluate comprehensive multi-disciplinary modern-day slavery awareness training to meet the needs of frontline and ancillary professionals working in key agencies such as health and social care, the police and the voluntary sector. This training equips staff to identify modern slavery and human trafficking, and to recognise people smuggling, to prevent and reduce the exploitation of vulnerable people in the community.

White Ribbon Day in November 2017 supported the UN campaign to eliminate violence against vulnerable women.

Deprivation of Liberty Safeguards

The current system of Deprivation of Liberty Safeguards (DoLS) has been reviewed by the Law Commission, whose recommendations to Government regarding Liberty Protection Safeguards are awaiting response.

As part of a wider consultation on these, small consultative sessions have been held in England and Wales with front line professionals to work through, using real examples, how such a new system might operate in practice. Those involved included consultants in care of the elderly, in old-age psychiatry, Directors of Nursing in Wales and representatives from a range of key professional stakeholders.

Repeated themes emerged from these sessions as follows:

- A general lack of understanding, particularly amongst many healthcare staff, of the DoLS process and why it is needed.
- There is frustration at the bureaucracy that takes front line staff away from interacting with patients, the lack of resources to manage applications for DoLS in a timely manner as evidenced by the outstanding waiting lists.
- Confusion exist around the interface between DoLS and the Mental Health Act.
- In some places, patients with a diagnosis of dementia are (wrongly) automatically excluded from detention under the Mental Health Act. There is tension between Mental Health and DoLS assessors as to who has responsibility for protecting the rights of such patients.
- Delays in the processes leave many patients without any type of DoLS in place because the time for an urgent DoLS (one week + a second week renewal) has expired and formal assessment is delayed for weeks or months.
- If patients die during this interim period they are still being referred to a coroner even when the death is expected, as they do not fit the revised definition of 'state custody' when subject to a DoLS.
- Only about 4-8%¹⁷ of those assessed under DoLS are thought to have improved care as a result of the process. For over 90% the staff could not identify benefits.
- The most beneficial part of assessment results from improved care planning and management plans to make care more person focused. A majority of those consulted felt that currently care plans are becoming a tick box exercise with little personalised focus, but improvements to care planning are the key to better outcomes, not the DoLS process per se.
- Many staff do not know what the benefit is for the individual but have to go through a bureaucratic process to comply with regulations.

¹⁷ Personal communication to Baroness Finlay during several consultative discussions with staff (both from social care and from healthcare) who are involved in the frontline of DoLS processes.

- Delays in signing off DoLS are due to too few staff trained as authorised signatories and the difficulties of taking staff away from care provision to deal with the paper work required with assessments.

Recommendations for the short term include:

- Improvement in basic care planning and care management could better inform the DoLS process. An emphasis on good care planning for the person would place that person at the centre of care and help organisations consider what matters to him or her. This should include a focus specifically on decision-making and capacity impairments, how this can be managed during the care episode, and whether there is the need for a DoLS application. There is an urgent need for processes to be streamlined.
- The announcement is most welcome of the Joint Committee on Human Rights inquiry into the Right to freedom and safety: Reform of the Deprivation of Liberty Safeguards. Their findings will inform the next phase of reform of this part of the Mental Capacity Act.

Priorities for the next year

The following year will be taken up with several areas that have proved contentious to date:

1. The Deprivation of Liberty Safeguards proposed by the Law Commission, the Joint Committee on Human Rights inquiry and the Government's responses, as well as the next steps over implementation of improved regulations.
2. The current Mental Capacity Act Code of Practice is a strong candidate for interim revision, as some parts are now out of date; this is particularly true of the DoLS additional code.
3. The difficulties around transition from children to adult services as a person reaches 18 may need clear guidance to create a more seamless transition to independence and greater protection of those who will probably never reach independence.
4. The cessation of life sustaining nutrition and hydration must be monitored to ensure appropriate protection of the patient, to audit the 'best interests' decision-making processes, and examine the long-term outcomes of such processes. This requires the establishment of a confidential register of such deaths.
5. Those who provide advocacy services of any type hold an enormous amount of responsibility for the safeguarding and wellbeing of vulnerable people. It is important that those providing advocacy services are nationally registered and regulated. There is a need for an independent uniform complaints and disciplinary procedure in the event of concerns being raised.
6. For decision-making support to be effective, those providing support must listen attentively and non-judgementally to the person with impaired capacity, and identify ways to maximise the person's decisions making ability. This requires people across all walks of life to recognise their responsibility to others they encounter in any sector.

National Mental Capacity Forum Leadership Group - Terms of Reference

Context

The Mental Capacity Act 2005 (MCA) is fundamental legislation that both protects and empowers individuals that may lack mental capacity. It affects as many as two million people in England.

Evidence shows that awareness, understanding and implementation of the MCA are less than satisfactory. As a result, many individuals may not be benefiting from the rights afforded to them by the law.

The MCA encapsulates an approach and culture that puts the best interests of the individual first and foremost, taking account of their unique needs and preferences, wishes and beliefs. Improving implementation will have wide benefits for those with dementia, a learning disability or other mental health disorder. It will allow those with capacity to plan for a future time when they may not.

To make real progress on MCA implementation, joint action between a range of different partners is required at a local level, close to the individual concerned.

Purpose

The ultimate purpose of the National Mental Capacity Forum (NMCF) is advocate at a national level for the MCA and to identify and support local actions to improve awareness, understanding and implementation of the MCA to realise improved outcomes and benefits for individuals who may (or may in the future) lack mental capacity.

It will do this by:

- Being action-focused, developing priorities
- Bringing together a wide range of parties with a role in implementing the MCA
- Reaching out and engaging organisations where MCA implementation is poor
- Emphasising the need for collaborative working, reflecting the need for integration of services around the individual
- Providing insight to the MCA Implementation Group to inform Government policy.

Leadership Group of the National Mental Capacity Forum

The NMCF is led by the Chair, Baroness Illora Finlay.

The Chair is supported by the Leadership Group which comprises a range of individuals with experience and expertise in implementation of the MCA.

The role of members of the Leadership Group is:

- To advise the Chair on MCA work already underway
- To advise the Chair of specific areas for improvement in the MCA landscape
- To reach out into their respective sectors/ organisations to leverage support for the MCA
- To offer expertise to local MCA projects, to help them achieve successful outcomes

Management

The Ministry of Justice and the Department of Health and Social Care provide secretariat support for the National Mental Capacity Forum including: organising meetings, co-ordinating papers, holding central lists of actions and progress against these, co-ordinating the production of a quarterly newsletter.

However, actions identified will be pursued by members from within their own resources. There is no preferential access to government funding.

Membership of the Leadership Group is for one year in the first instance.

National Mental Capacity Forum (England and Wales) Leadership Group - Membership

Members of the Leadership Group are all people who are active in a personal capacity in promoting the implementation of the MCA across a range of disciplines. They do not represent their employers, but I am most grateful to these employers for allowing them to take additional time to work with me and to support the National Mental Capacity Forum work programme.

Baroness Ilora Finlay NMCF Chair,
Rachel Griffiths, NMCF Voice of the Person Lead

Other current members:

Since 2015:

Keith Brown, National Centre for Post Qualifying Social Work, Bournemouth University
Sam Cox (with Rachel Hutchings deputy), Policy Department, Alzheimer's UK
Mandy Griffin and Debbie Ho, Nationwide Building Society
James O'Sullivan, Policy Adviser, Building Societies Association
Betsey-Lau Robinson, Head of Safeguarding & MCA, University College London Hospital NHS Foundation Trust
Gary Rycroft, Solicitor, Lancaster

Since 2017:

Andy Butler, Principal Social Worker, Surrey County Council.
Lorraine Currie, Shropshire Council and Association of Directors of Adult Social Services
Tim Farmer, TFS Consultants
Kay Galvin, South Wales Fire and Safeguarding
Jo Giles, Cadent (formerly National Grid)
Clementine Maddock, Psychiatrist and MCA lead, Royal College of Psychiatrists
David Rees, Police liaison officer, Welsh Government

Previous members:

Michael Brown OBE, National Police Chiefs Council, College of Policing (2015-16)
Jonathon Holmes, Sense (2017)
Sam Kyeremateng, Medical Director, St Luke's Hospice, Sheffield (2015-17)
Stephanie Lunn, MCA Birmingham Project (NHS) and OLM Group (2015-17)
Rob Mitchell, Principle Social Worker, Calderdale Council (2016-17)
Lucy Series, Wellcome Research Fellow, Cardiff University (2015-16)



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