HM Government

National Mental Capacity Forum

Chair's Annual Report 2019

11 July 2019

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Third Report of the National Mental Capacity Forum

July 2019

Contents

Chair's introduction

Welcome to my third report on the National Mental Capacity Forum work that has been undertaken with wide support and enthusiasm from many. Working together, sometimes in far flung disparate groups, we share a passionate desire to improve the lives of those for whom decision making poses difficulties. For some their difficulties have been present since birth, for others they have acquired brain injury from sudden external force or accident, while many have internal damage to their thinking or expressive functions through disease processes.

The past year has been particularly busy on the legislation front. The problems of the backlog of assessments of those who, for whatever reason, have been deprived of their liberty was of increasing concern. A legislative window allowed the Mental Capacity (Amendment) Act 2019 to be brought forward, starting its passage in the House of Lords and recently completing all parliamentary stages to receive Royal Assent in May 2019.

It flowed from the Law Commission report on Mental Capacity and Deprivation of Liberty[1]. The Law Commission had spent three years investigating the processes in place and reported fully with recommendations that had been widely debated. The Law Commission report was led by Tim Spencer-Lane, and the Department of Health and Social Care were fortunate to be able to secure his secondment to advise on the proposed legislation. The legislation that came before Parliament was narrower than that in the Law Commission report. Many stakeholders were involved in providing information to Parliamentarians, which resulted in extensive amendment of the Bill presented.

Simultaneously, Professor Sir Simon Wessely's report on the Mental Health Act 1983[2] was underway with a series of workstreams. One of the important areas of consideration was the interface between the Mental Health Act and the Mental Capacity Act 2005, over which there were extensive discussions. Although at first sight a fusion of both Acts might seem attractive, the complexities suggested this would not be feasible at this stage. In part this is because the Mental Capacity Act aims to empower individuals as much as possible to make their own decisions, puts an onus on those providing care or assistance in any capacity to respect the person's wishes and feelings, to do everything possible to support the individual and also provides a framework in the event that a decision must be taken on behalf of someone who lacks capacity for that decision at that time.

Sectors not directly involved in health and social care have continued to drive forward improvements in protecting vulnerable customers, although the closure of many high street banks' branches has required significant changes in routes of financial support for some. The alarming increases in fraud and scams has highlighted the difficulties faced by those trying to empower people with impaired capacity at any level to live as independently as possible while fulfilling their duty of care.

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[1] https://www.lawcom.gov.uk/project/mental-capacity-and-deprivation-of-liberty/
[2] https://www.gov.uk/government/groups/independent-review-of-the-mental-health-act

During the past year the need for guidance on best interests decision making has become evident. The decision of the Supreme Court that the cessation of artificial nutrition and hydration did not necessarily require court sanction in clinically confirmed cases of so-called ‘persistent vegetative state’ and in circumstances where there was no dispute with the family made such guidance urgent. Work on this was led by the British Medical Association, in conjunction with the Royal College of Physicians and the General Medical Council.

From this work, the British Medical Association agreed to produce stand-alone guidance on best interests decision making, which should be published soon. Importantly, all decision makers must consider and respect, as much as possible, a person’s known wishes and feelings and any act, whether of commission or omission, should be necessary and proportionate. Sometimes a decision must be made very rapidly in a person’s best interests but usually there is time to explore with those who know the person well, what the person’s values, wishes and feelings were, and whether any advance statement of wishes or advance refusal of treatment has been recorded anywhere. Thus, best interests decision making should be considered as a process, not a single event. Whenever a meeting is held about a decision it is important to do as much as possible to mitigate the power differential that inevitably exists between those responsible for providing care and those who family and friends care about the person’s welfare.

Progress against last year’s priorities has been better in some areas than in others. Overall those working in areas concerning people with impaired capacity have done a great deal to improve the independence and quality of life of those who for whatever reason have a degree of impaired mental capacity. But recent exposure of care facilities that were thought to be providing good care, but subsequently were found not to be as they had seemed, remains a major challenge. The culture of an institution or service can be very difficult to assess from the outside, which is why the Mental Capacity (Amendment) Act contains a section to allow anyone concerned with the person’s welfare to demand an independent review of the arrangements in place that deprive a person of their liberty. It is often the lowest paid in an institution or the relatives of a resident who become aware that all is not as it should be. They must be further empowered to whistleblowing. But in addition, everyone working in any part of the care sector must explore ways that poor culture can be detected early, because bad attitudes and cruel behaviours seem to infect pervasively across organisations that have been found severely wanting. Research is needed into ways to improve the attitudes of all involved in providing care, including the status of care staff, and into ways of managing staff to develop a sense of pride in good care, with the strength to develop a zero-tolerance of bad attitudes and behaviours in others they work with on a day to day basis.

Ilora Finlay.

Ilora Finlay

Professor Baroness Finlay of Llandaff
Chair of the National Mental Capacity Forum

The National Mental Capacity Forum

The purpose of the Forum is to advocate at a national level for the Mental Capacity Act 2005 (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.

Leadership Group

The Leadership Group of the Forum is made up of representatives from across England and Wales, who have an interest in mental capacity. Details of its membership are listed under **Appendix 1**. The Leadership Group, which meets quarterly, provides expertise and reach into the wide range of sectors where the MCA often applies.

Associate members

The Forum is action-focused, and has a growing number of associate members who work to improve the implementation of the MCA in their areas of practice. Members share a common aim to empower individuals and those providing services to them, and to place the person's rights and wishes at the centre of decision-making. Members come from health, social care, finance and legal sectors, as well as academics and third-sector organisations, and, perhaps most importantly, people with direct experience of the MCA. **Appendix 2** highlights the workstreams undertaken by associate members during 2018-2019.

The Five Principles of the Mental Capacity Act 2005

Hand logo courtesy of Shropshire Council

There are five principles on which the Mental Capacity Act 2005 (MCA) is built:

1. **Presume capacity -** A person must be assumed to have capacity unless it is established that he/she lacks capacity
2. **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
3. **Unwise decisions -** A person is not to be treated as unable to make a decision merely because he/she makes an unwise decision
4. **Best interests -** An act done or decision made for or on behalf of a person who lacks capacity must be done or made in his/her best interests
5. **Less restrictive option -** Before the act is done, or the decision is made, regard must be had to whether the purpose can be as effectively achieved in a way that is less restrictive of the person’s rights and freedom

Progress in changing attitudes and practices around each of these has gone at different speeds, which at times has resulted in overprotective attitudes amongst staff and family, as well as the converse at times. Sometimes a presumption of capacity has meant that both staff across health and social care and families of those with some impairment of capacity fail to protect the person from obvious harms that the person (P) is unable to fully assess, meaning they cannot take a balanced assessment of risks and consider the implications of their behaviours and actions for themselves and for others.

In practice, staff have become good at **principle one** (and often cite it as a reason not to assess capacity) and at **principle three** (and often cite it as a reason not to assess capacity). But all too often, even if staff have not adequately assessed capacity, there is an increasing tendency to proceed to make best interests decisions – a process linked to **principle four** that is laid out on the face of the MCA itself as well as in the Code of Practice.

Over the past year-and- a-half ample time has been taken up in the revisions relating to the duty to P when restrictions must be put in place, through the Mental Capacity (Amendment) Act 2019, which fall under **principle five**. This legislation, which is an additional part of the MCA and replaces Deprivation of Liberty Safeguards (DoLS), with Liberty Protection Safeguards (LPS), will require new processes at a local level across all sectors. It has acted as a spur to the complete revision of the Code of Practice on the MCA. This re-writing is long overdue as the Code reads as outdated and the examples given in now seem stilted and often of little direct relevance to problems encountered in practice. The dangers will be, as at present, that the less restrictive option may prove to be inherently less safe or completely unaffordable in terms of time and finance, even when imaginative thinking of ways to meets P's needs are fully explored.

But **principle two** is lagging in its implementation. It has been called the Orphan Principle[3] of the MCA. There are some excellent examples of support in decision-making that really do empower P and take steps to ensure that P's understanding is maximised, and that information is presented in a way that P is most likely to understand, free of coercive pressures. All too often, other people make assumptions about 'what P would want', and then the principle is not adhered to; in other words, those responsible for care 'support' P to make the decision that these staff want P to make, rather than supporting P to make his or her own decision.

Unfortunately, too much focus has been placed on capacity assessment with greater emphasis on testing rather than on giving support and information. This imbalance must be addressed urgently. The new LPS should provide an important vehicle for such a programme of awareness-raising to improve respect for this important second principle of the MCA.

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[3] https://www.scie.org.uk/mca/directory/forum/video

Progress against priority actions from last year

The priority actions set in last year's annual report[4] were ambitious and some were contentious. They were as follows:

1. The Liberty Protection Safeguards recommended by the Law Commission, and supported by 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.

To take each in order:

1. The Mental Capacity (Amendment) Act 2019 has now received Royal Assent and the Code of Practice is being written with wide consultation with the sectors affected by the new legislation. Supported decision making and clearer, less bureaucratic processes should allow safeguards to be put in place as soon as possible and individuals should experience better care planning, greater empowerment and more personalised assessment in approving restrictions and conditions placed on their care.

2. The Code of Practice for the MCA is now being rewritten, again with wide consultation and different workstreams revising the Code overall, which will

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[4] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/708149/nmcf-annual-report-2017.pdf

incorporate the guidance for the Liberty Protection Safeguards following the new legislation.

3. The inclusion of 16 and 17-year olds in the Mental Capacity (Amendment) Act 2019 will specifically address issues during transition to adult services, as education will have to work in conjunction with health and social care in planning provision for these young people. This will particularly affect those with autism, learning difficulties (whatever the cause) and traumatic brain injury of any sort. It will also affect those young people with mental health issues who at times lose capacity for decision making at a range of levels, due to their underlying condition.

4. Although guidance has now been written on the withdrawal of nutrition and hydration in cases of persistent vegetative state and of other conditions, there has not been any register established of the number of cases where such decisions have been taken. This is a lost opportunity as such a register would allow the audit of decision-making processes and would be a safeguard against inappropriate utilitarian approaches to care becoming powerful influences in decision making.

5. The aspiration that advocacy services are registered and monitored has not been implemented. However, again the Code of Practice for the MCA, in being rewritten, will better clarify responsibilities associated with different roles.

6. Decision making support has come increasingly into focus. The National Mental Capacity Forum Leadership Group has worked tirelessly throughout the past year to change attitudes and approaches. This work has been enhanced by the increasing volume of Books Beyond Words[5] and similar tools that are available and being widely adopted. Additionally, wider teaching of Makaton signing, even at a simple level, is equipping children to communicate better with their peers who have communication difficulties and should improve cohesiveness as they grow up together.

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[5] https://booksbeyondwords.co.uk/about

Education and training

Implementation of any legislation requires extensive training of the staff who will be responsible for implementing that legislation which, in the context of Liberty Protection Safeguards, effectively means the whole of the health and social care workforce.

During the past year all the training on the MCA provided through Health Education England has been subject to major review. The curriculum has been overhauled, new material is being developed and an increasingly interactive training approach is being rolled out, creating new online video clips to support online learning. Health Education England's e-learning for health has focused on medical education in two main outputs: (i) the MCA components of a new programme for Doctors in Training, emphasising the statutory principles and the voice of the person; (ii) a major new programme of 11 MCA sessions for doctors and other health professionals.

Social work training, through Research in Practice for Adults[6], has focused on legal literacy and the importance of the voice of the person. Similarly, the Social Care Institute for Excellence (SCIE)[7] and Quality Compliance Systems (QCS)[8] have expanded their toolkits for the care sector as services are aware that Care Quality Commission inspections are increasingly focused on the implementation of the MCA.

Social care professional regulation now falls under Social Care England, whose remit is to regulate social workers in England to enable positive change and improve people's lives. The professional standards that social workers need to meet will be reflected in the standards required of education and training providers. As curricula are revised, it will be important for training to specifically include the disorders seen in those with acquired brain injury from any cause, not only traumatic head injury, to understand the difficulties in assessing mental capacity in those with focal brain lesions. For example, a functional assessment of capacity may be misleading in those with frontal lobe injury of the brain, but with intact motor skills and speech function, as the ability to weigh up and assess the implications of decisions and action for self and others can be far more impaired that simple testing will reveal. Conversely, those with neurodevelopmental disorders affecting expressive ability may appear to lack mental capacity if there is insufficient communication support for people to express their wishes and feelings.

Across England and Wales many mental capacity projects have focused on education and training

These have focused on the crucial importance of the voice of the person in a range of contexts. Much advocacy has occurred at numerous conferences and seminars that are now taking place around England and Wales, directed at specific groups such as learning disability psychiatrists, General Practitioners, social work professionals, housing providers, statutory

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[6] https://www.ripfa.org.uk/
[7] https://www.scie.org.uk/atoz/?f_az_subject_thesaurus_terms_s=mental+capacity&st=atoz
[8] https://www.qcs.co.uk/

and third sector care providers and advocacy organisations, many of which are in the third sector.

Other examples include:

- Local staff MCA forums in Local Authority Boroughs (e.g. Newham) for staff at every grade to discuss and share experiences, such as the Law Commission proposals for Liberty Protection Safeguards, MCA and tenancies, care managers responsibilities under the MCA, best practice in best interest decision making, MCA and consent, MCA and risk management, and working with Independent Mental Capacity Advocates (IMCAs);

- Clinical Commissioning Groups (e.g. Wandsworth and Merton) mandated training in the MCA for all staff, volunteers and non-clinicians, with awareness of training targeting all GP practices;

- NHS England's National Safeguarding Adults National Network provides a national voice to adult safeguarding leads representing Clinical Commissioning Groups (CCGs) across England and acts as a clinical reference group to the National Safeguarding Steering Group (NSSG). In many areas, responsibility for the MCA implementation and for adult safeguarding lie in the same department or with the same lead individual, despite the concerns expressed by the voice of the person feedback (see page 13 in the First Report of the National Mental Capacity Forum[9]) that safeguarding approaches can be over-restrictive;

- In General Practice, the Royal College of General Practitioners (RCGP) group on safeguarding worked through the past year to augment their guidance on safeguarding of adults.[10] In several areas, exciting initiatives such as the General Practice LeDeR group in Yorkshire, have been running GP training to ensure families have the information they need, using real cases and working with a whole team approach involving staff at every level;

- Across health and social care, educational projects on the MCA have become incorporated in most foundation level training for all clinical staff. In some employing NHS Trusts, this is followed by the provision of three yearly updates, using case work and bespoke discussion around individual cases;

- Three London Boroughs (Kensington and Chelsea, Hammersmith and Fulham, and Westminster) have developed a 'champions' model which involves training up motivated members of front-line staff to be a local MCA Champion and providing on-going support. Champions are drawn from a wide range of teams and professionals. This project is due to be evaluated over the coming year for effectiveness in improving MCA compliance;

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[9] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/595617/nmcf-chair_s-report-2016.pdf

[10] https://www.rcgp.org.uk/clinical-and-research/safeguarding/adult-safeguarding-toolkit.aspx

- Speech and Language Therapists have developed focused training materials using trained actors, to create videos and case scenarios for teaching. Deep dive audits into the way the MCA is used in serious medical treatment decisions have also been used to target training, particularly when communication difficulties impede assessment. The Royal College of Speech and Language therapists[11], with their specialist skills in augmentative and alternative communication, have indicated their desire to play a greater role in assessments, planning and monitoring after training as Approved Mental Capacity Professionals for the new LPS as the Mental Capacity (Amendment) Act is implemented.

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[11] https://www.rcslt.org/

Before I die…

A focus on the needs of those nearing the end of life, who can be fearful they may lose capacity, has resulted in much national and local level activity around the importance of care plans, a recognition of Advance Decision to Refuse Treatment (ADRTs), and the need for early honest discussion of disease, diagnoses and of the difficulties of living with uncertainty.

Examples include:

- The Academy of Medical Sciences 'The Departure Lounge' project is being developed to focus on open conversations and early planning;

- TalkCPR focuses on asking the question 'who will speak for you when you can no longer speak for yourself', with particular reference to cardiopulmonary resuscitation decisions;

- Hospice UK's Dying Matters Week focuses on early conversations about life limiting and life-threatening illness;

- Alzheimer's UK has highlighted the needs to those with early dementia in planning for further loss of capacity;

- Lambeth Advance Care Planning consortium's tent at the Lambeth Country Show aimed to normalise conversations about death and dying, thus empowering the community to talk about advance care planning, Lasting Powers of Attorney, ADRTs and Advance Statements of Wishes.

First responders

Ambulance services and the police are often the first on the scene when an acute crisis occurs. For these first responders, awareness of the MCA is particularly important as assessments need to be rapid and accurate. The front-line paramedics also need to understand the interface between the Mental Health Act and the MCA. For example, the North-East Ambulance Service (NEAS) has focused on the MCA. NEAS undertook an audit of their completed MCA assessment forms, revealing that even when there was no doubt about mental capacity, the assessment forms were being used as a quasi-disclaimer when people refused transport. NEAS are now working with their local police mental health lead to improve training. However, their main difficulty is that severe service pressures to reduce 'down time' mean that it is difficult for crews to be released to attend more than basic training, even though in the long-term it is expected to improve their decision-making and increase their professional satisfaction.

Daily living - as independently as possible

Finance

The financial sector has increased training to staff across banks and building societies to support identifying and helping those customers who have some difficulties with managing their accounts yet are living relatively independently in the community.

The closure of high street banks presents a difficulty for such people. When the cashier knew the customer, and was able to understand their particular needs, arrangements could be put in place to meet individual requirements. Now the role has been handed over to the Post Offices a broader training programme for their staff is needed, covering all aspects of interacting with customers with different types of impairments of mental capacity.

Several banks have plans to introduce community bank staff who can visit their clients at home although there has not yet been a comprehensive evaluation of such services, nor of the risk of criminal exploitation by falsification of identity, resulting in criminals entering people's homes.

The closure of high street banks has forced customers to use online banking. For many, particularly elderly customers, this is their first time they are using online services and they are more susceptible to being scammed, particularly if they have fluctuating or reduced capacity. Scams are increasingly sophisticated and difficult to spot at first sight, as are phishing emails. Although guidance on internet and cyber-crime is being developed by the National Trading Standards e-crime team and Cifas, working with The National Centre for Post Qualifying Social Work and Professional Practice, there is the constant danger that criminals are always one-step ahead and see those with impaired capacity as sitting targets to defraud.

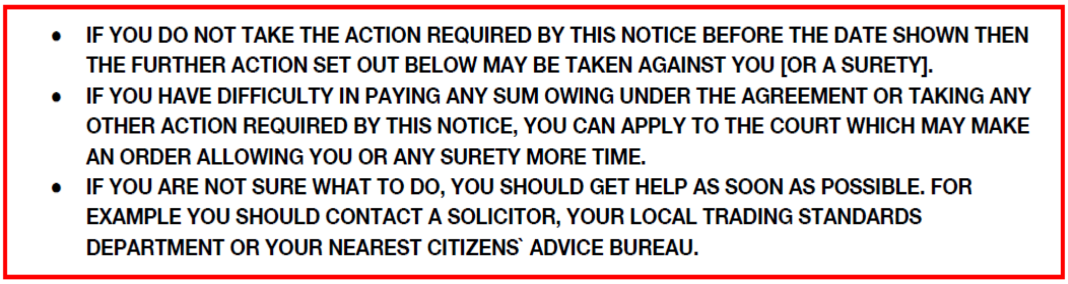
The Building Societies Association has developed national standards of support for victims of financial abuse. They have also determined standards to encourage those with difficulties to run their finances without completely handing over control or compromising privacy or security. A voluntary building societies vulnerability review has been initiated to audit participants' vulnerability policy and practice by the Lending Standards Board.

In the past six months, the finance sector has looked at flexible personalised banking arrangements that are easy to access and can be put in place for those who wish to retain control over many aspects of their finance, but recognise they need help with transactions such as rent, council tax and paying bills. Those with difficulty controlling their spending, particularly those at risk of gambling or exploitation can have a spending limit set, co-managed with an approved signatory.

The concept of a financial Lasting Power of Attorney (LPA) has been taken up widely but there remain many, particularly the elderly, who are reluctant to appoint an attorney as they fear the attorney could take control of their finances. Over the coming year the Office of the Public Guardian (OPG) should ensure that their publicity makes clear how an LPA is triggered and should work closely with the banking sector to ensure continuity for clients.

With a lack of support, money issues and mental illness such as anxiety, depression and bipolar can create a vicious cycle, where problems can escalate out of control. At its worst, this can lead to mounting debt, family breakdown and homelessness. The Money and Mental Health campaign has highlighted the intimidating, and for many incomprehensible, letters that those with debt are sent, particularly the required text as stipulated by the Consumer Credit

Act 1974 (and subsequent regulations) [illustrated below]. There is an urgent need for Government to update the rules on ‘prescribed content’ for debt letters, both in terms of the language and font used and the sources of advice and support that those in debt are signposted to. The threats of court action should be removed and be reserved only for persistent debtors after all other avenues have been exhausted.



- IF YOU DO NOT TAKE THE ACTION REQUIRED BY THIS NOTICE BEFORE THE DATE SHOWN THEN THE FURTHER ACTION SET OUT BELOW MAY BE TAKEN AGAINST YOU [OR A SURETY].
- IF YOU HAVE DIFFICULTY IN PAYING ANY SUM OWING UNDER THE AGREEMENT OR TAKING ANY OTHER ACTION REQUIRED BY THIS NOTICE, YOU CAN APPLY TO THE COURT WHICH MAY MAKE AN ORDER ALLOWING YOU OR ANY SURETY MORE TIME.
- IF YOU ARE NOT SURE WHAT TO DO, YOU SHOULD GET HELP AS SOON AS POSSIBLE. FOR EXAMPLE YOU SHOULD CONTACT A SOLICITOR, YOUR LOCAL TRADING STANDARDS DEPARTMENT OR YOUR NEAREST CITIZENS` ADVICE BUREAU.

Financial fraud and scamming

The National Centre for Post Qualifying Social Work and professional practice has continued to lead the research into financial scamming and fraud on behalf of the National Trading Standards team and the Chartered Trading Standards Institute. Working with partners across the sector, they produced the All-Party Parliamentary Group on Financial Crime and Scamming report that was launched at the House of Commons in June 2018. They also produced and launched learning resources for community nurses and health care workers to help them identify and support victims of scams who are often lonely elderly citizens with cognitive decline, and similar learning resources for Age UK on financial scams.

The incidence of internet cyber-crime is likely to increase as criminal activity becomes increasingly sophisticated and difficult to track.

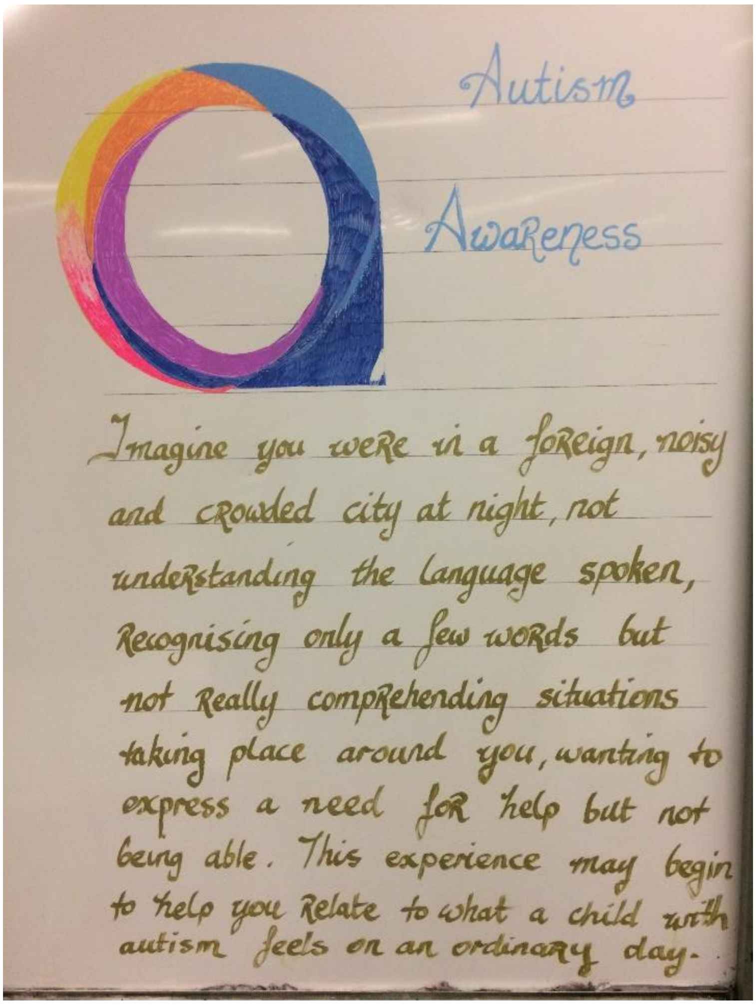
Travelling

Transport is daunting for many, even those without cognitive difficulties.

The poster-board opposite featured at London Paddington Station during Autism Awareness week 2019. It was produced by a member of staff who had prior experience of working with those with learning difficulties, explaining how difficult it is for those with autism to navigate the world around them.

YouTube is now peppered with videos explaining different aspects of autism, although one difficulty is that such videos, although very informative, have not been quality assured.

Similarly, airports have responded to campaigners about the difficulty for those with learning difficulties, autism or early dementia to navigate their way through the system and have developed schemes to escort passengers and provide non-stigmatising identification to alert security staff of a person who may find it particularly frightening to be pressured or challenged.



Autism Awareness

Imagine you were in a foreign, noisy and crowded city at night, not understanding the language spoken, recognising only a few words but not really comprehending situations taking place around you, wanting to express a need for help but not being able. This experience may begin to help you relate to what a child with autism feels on an ordinary day.

The utilities sector

Sharing of at-risk registers is only one part of allowing people to live independently. Simple control systems for heating and safe cooking facilities are essential for those living independently.

Telecoms

BT have recognised that vulnerable customers need to be able to explain in simple terms what their difficulties and concerns are. Their Vulnerability Centre and Dementia Support teams have skilled advisors who are specially trained to support customers. They have been trained on vulnerability products and processes, have enhanced call handling skills and an ongoing understanding of specific impairments. This allows customers to be offered a bespoke faults, billing, and enquiries service with their account appropriately managed.

Employment

Finding paid work can be particularly difficult for those with learning difficulties and other conditions. An example of support into paid work is Shropshire Council's Enable[12] supported employment service, delivered for Wolverhampton City Council's social care customers. This provides employment support for people over 16 years of age with long-term disabilities, including autism or learning difficulties, who are seeking paid employment. The support ranges from help with CVs, job applications, mock interviews, interview support, and job coaching in the workplace. Support can then also continue through learning the role, meeting colleagues, understanding expectations and discussing progress. Although input may be intensive at first, the job coach gradually withdraws over time. An important arm of the project has been to provide support to those who need employment support to prevent them becoming a social care client in the future. The service liaises with the Department for Work and Pensions, the Centre for Mental Health and the British Association for Supported Employment (BASE)[13] on specific client issues.

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[12] http://www.enableservices.co.uk/about/

[13] https://www.base-uk.org/about-british-association-supported-employment

People at the heart of services – co-production

Many organisations are now evaluating services by using paid ‘experts by experience’ to drive up standards.

A powerful example is Dimensions[14] whose experts by experience are involved at every level in running services, in training and in quality assurance.

Their active support model ‘Activate’ has led to a 60% decline in challenging behaviours and a 25% increase in people taking part in meaningful activities.

In 2016 they also launched *#ImWithSam*[15] *to* tackle autism and disability hate crime, aiming for increased reporting of hate crime and better support for victims when they do report - they report that sadly 73% of people with autism and learning difficulties experience hate crime. The project has educated over 1000 police officers to understand the barriers victims face when reporting such crime, including on line abuse. The campaign has also trained other professionals, and works with victims, families and supporters to make people aware of their rights and to hear their views. The campaign is seeking better protection and assurance that people with learning disability and autism are treated equally to other victims, making representation to the Law Commission’s review of hate crime laws.

Relationships

Article 8 of the European Convention on Human Rights declares that people have a right to respect for their "private and family life, home and correspondence", which cannot be interfered with unless" in accordance with law" and "necessary in a democratic society". Obstruction or prevention of a sexual relationship, including by failing to assist someone to acquire capacity to consent to sex, may breach Article 8. However, sexual activity must always be consensual; non-consensual sex is rape.

As more young people are living longer with learning and other difficulties that previously would have been life-shortening, they are developing into adulthood with the normal desires for relationships, intimacy and often desire for sexual expression in a relationship. Recently there have been examples of inappropriate interpretation of such emotions due to either overly permissive or overly protective attitudes. These approaches have been derived from concerns over consent to sexual activity, particularly intercourse, and inappropriate assessments of a person’s understanding of sexual activity. Where there has been no sex education, assessment tools that are formulaic and depend on the person’s ability to name body parts or describe aspects of arousal are inappropriate. At the other end of the spectrum, the person’s rights will be seriously breached if teaching about sexual activity allows sexual exploitation.

Social work training must include training on sexuality and on ways to develop understanding of the needs of young people, while protecting from exploitation and from unplanned pregnancy. This training also needs to cover the difficulties that parents may face in acknowledging sexual development in their child and the difficulties for external agents to

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[14] https://www.dimensions-uk.org/

[15] https://www.dimensions-uk.org/get-involved/campaigns/say-no-autism-learning-disability-hate-crime-imwithsam/

assess consensual activity, particularly where the person lacks capacity to decide about aspects of a new relationship or any potential risk from partners.

The Court of Protection

The Court of Protection (CoP) is appointing increasing numbers of deputies to protect those who lack capacity and therefore cannot chose a person to hold Lasting Power of Attorney on their behalf. CoP is also increasingly involved in issues concerning safeguarding, and disputed or uncertain decisions regarding the lives of people who may lack mental capacity. CoP's increasing caseload is of concern as it will need investment to allow it to modernise its processes and ensure that those whose lives are deeply affected by its rulings are confident that they have had a fair and balanced hearing.

Changes in some services outside the Court have improved the outcomes for clients going through court processes. On this year's Mental Capacity Action Day, Shropshire Council showed how they have improved their outcome evaluations relating to court proceedings by co-production with clients, resulting in satisfaction ratings rising from 58% in 2015-16 to 93% in 2017-18.

Mediation to put the person at the heart of Court of Protection processes

Around two years ago, a group of legal and medical professionals set on a course of action to facilitate better incorporation of mediation within the CoP. The group, which is primarily made up of professionals from London and the South West of England, seek to ensure that mediation is considered as a way of resolving disputes, in every case that is issued in the CoP.

To do this, they have obtained judicial support for a pilot scheme. The pilot scheme will not make mediation compulsory but will provide a clear practical framework for parties wishing to engage in mediation and will be supported by a dedicated website and resources. The pilot will receive academic evaluation, and the results will be presented to the judiciary.

The group hopes to establish an evidence base that mediation supports and facilitates the involvement of the person who may lack capacity in proceedings, as well as reducing the costs of litigation to parties. It aims to provide a clear pathway for ongoing communication between parties after the resolution of the dispute in hand. The project will be rolled out nationwide later this year.

Supported living standards and inspections

The National Autistic Society have instigated their Autism Accreditation[16] scheme which provides additional autism-specific quality control to that from the Care Quality Commission (CQC) inspections and reports. Their website provides a full list of quality assured providers of services to autistic people across the UK. It allows organisations to show they offer excellent support to autistic children and adults, incentivises improvements and can provide reassurance to those responsible for the wellbeing of people with autism.

Many charities are doing a great deal to support those with capacity impairments, including through learning disabilities, brain injuries, autism, physical disabilities, sensory needs, epilepsy, diabetes and challenging behaviour. We hope that in the coming year the CQC will specifically focus on the needs of those with acquired brain injury, whether through acute trauma and head injury, stroke, infection or exposure to toxic substances.

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[16] https://www.autism.org.uk/professionals/accreditation.aspx

The Mental Capacity Action Day

Yet again, the annual Action Day brought together those working actively to improve the implementation of the MCA and to empower those who are directly or indirectly affected by the Act. The day (on March 15th, 2019) was generously hosted by the Royal College of Nursing who opened the day with a clear commitment to the core principles of the MCA across all areas of nursing and a desire to improve the experience of all who need care of any sort.

An update on the Mental Capacity (Amendment) Act was presented at the Action Day. The amendments to the Act were explained, which clarified the large amount of work undertaken to date and the ways in which the Act had been improved during its passage through Parliament. These changes included clarifying that the responsible body is required to provide a copy of the authorisation record to the person affected or their representative person, and the ability of any member of staff to whistle-blow on inadequate implementation of the care arrangements as planned. The presentation made clear that the number of assessments will be reduced and should focus on those with greatest need and ensure arrangements are tailored to the individual's wishes and feelings, while having to show they are necessary and proportionate to the situation.

The voice of the person

As always, the voices of those with lived experience of the MCA were central to the day. Listening to the Include Choir was a real highlight with renditions of 'Let's go fly a kite' and the choir's own anthem 'Battle Hymn to the MCA', which involved audience participation through singing and Makaton signing.

The message from 'Jim', who had experienced several episodes of lacking capacity, was clear: "When I am unable to make decisions for myself, I need professionals involved who have the skill to assess me and, if necessary, make decisions for me to keep me safe."

The Forum received many more submissions, from all sectors, than could be highlighted during the Action Day; some abstracts were selected for presentation on the day and included the following developments:

- Research on assessing capacity for individuals with learning difficulties and autism who are at risk
- Educating the primary care workforce about the MCA
- Using the power of communications (telecoms) to make a better world
- Lived Experience of fluctuating capacity
- The role of the Care Quality Commission in the review of the Mental Health Act and its interface with the MCA

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Also featured were sessions covering:

- Experience of being an 'expert by experience' for the Care Quality Commission – a personal journey
- Running a dementia café
- Ageing well without children
- How brain injury affects decision making

- how to make a safe PACT (Preferences and Advance decision for Crisis or Compulsory Treatment) - advance decision making in mental health
- Supported decision-making in dementia
- Innovating small business (chocolate making) to empower young people with autism
- Banking changes to meet clients’ needs
- Financial services for those with fluctuating capacity
- Utilities sector support for individuals to make their own decisions
- Money and mental health
- Sexual and other intimate relationship needs
- Providing good care for older LGBT people who lack mental capacity
- Contested capacity assessments and best practice in best interests’ decision-making – research and update
- Best interests’ decision-making under the new NICE guidelines
- Shropshire’s ‘My Enquiry and Safety Plan’

The Public Guardian

The then Public Guardian, Alan Eccles CBE, presented a keynote at the Action Day, highlighting the changes during his time in post and his vision for the future. He described some of the challenges facing the Office of the Public Guardian (OPG) in encouraging and enabling pro-active future planning, and championing an individual’s right to autonomy, but safeguarding ‘adults at risk’ from abuse. The OPG has now published deputyship standards, improved deputy reporting, promoted a proactive approach to future planning and respond rapidly with appropriate action if a concern is raised. He also set out their vision for the future, in the diagram below.

Office of the
Public Guardian

OPG’s future direction

Empowering
Supporting decision making. People protected and empowered

Personal
In our services, our understanding of our users and in our approach

Accessible
Digital services and high-quality interaction with users

Engaging
Highly engaged, motivated staff who see how their role protects the vulnerable

Respected
Product and service legitimacy, thought leaders, trusted, regarded and known for what we do

2025

Supported decision-making

Support for decision-making requires those providing support to recognise and take time to support the person to make their own decision, avoiding coercive pressures to a decision that is for the convenience of others.

Books beyond words

Support tools, such as Books Beyond Words[17] have been developed to provide additional aids in a wide range of situations, including in bereavement, during required medical treatment and when abuse is witnessed or experienced.

Examples are:

When Someone Dies:

When Dad Died:

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[17] https://booksbeyondwords.co.uk/

Finding a safe place from abuse:

Supported decision making in practice – the invisible scaffolding to independent living

This second principle of the MCA is a strong counterbalance to the whole process of capacity assessment and care provision. It strongly places the onus on professionals to do all they can to reflect on their own behaviours, on the resources they are deploying to be focused on the individual and to listen and give credence to all the messages and signals from the person about all aspects of living.

Work in Shropshire has shown that the steps required to support a person before embarking on assessing capacity go far beyond communicating in an accessible way. Those carrying out a capacity assessment need to constantly ask themselves why they have concluded the person lacks capacity and what else they could or should have done to either restore or maximise decision making ability.

For any decision there are three core components that must be in place for a valid decision: accurate information, the capacity to take the decision, and that is it voluntary (i.e. free of coercive pressures). Although the MCA focuses on capacity, whoever is assessing capacity of a person to make a decision must pay meticulous attention to giving information in the most appropriate way to meet a person's needs. For everyone, decision-making requires that we have the necessary information. It requires a person to explore all the options which may require time and opportunity to mull over, talking with others and utilising personal strengths and those of any support group. It might mean learning a new skill, having 'field visits' and often it can be helpful to talk to others who have been in the same position.

Therefore, practicable steps, as required by the MCA, might mean putting in a programme of support *before* assessing capacity. This support might be basic financial skills, a budgeting course, personal health education, a clear explanation to enhance understanding of a person's own medical condition or many more things.

A far stronger emphasis needs to be placed on asking professionals, 'Why were your practicable steps not successful?' before proceeding to assess whether the person 'can understand, retain and use and weigh the information to make a decision'. Such an emphasis needs to occur at every level, including in the Courts where it would help decision making if greater scrutiny were afforded to the ‘practicable steps’ taken around a decision that ends up being referred to the Courts.

Practicable steps to support decision-making should provide the invisible scaffolding to allow the person to be as independent as possible, living with their disability rather than restricted by it.

A real life illustration below shows how G was supported to employ a member of personal staff *(courtesy of Lorraine Currie)*:

Who should be a personal assistant (PA) to someone with seriously impaired capacity?

G, a young adult with serious brain injury, needs a team of staff round the clock. G is unable to read, has poor memory and on questioning cannot describe in detail all support needed. If those supporting G had started by assessing capacity, they may easily have concluded that G could not select staff.

But an alternative approach was taken, starting with the question ‘what practicable steps can be put in place for G to recruit the staff?’ and led to the following:

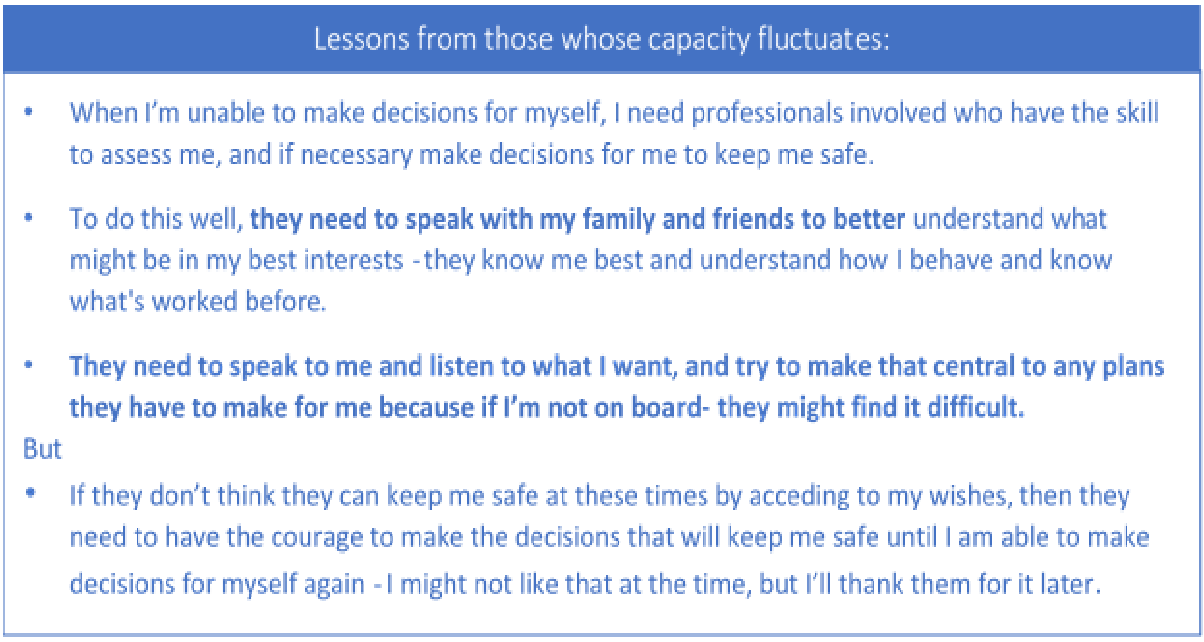
1. An online advert was placed by G’s Court Appointed Deputy.
2. Applications were screened against agreed selection criteria and then read out to G, who gave an opinion on what was described to construct a shortlist.
3. Interviews were arranged over a day, with all applicants arriving just before lunch time. Existing PAs also attended, along with G’s Deputy and G.
4. Applicants were engaged in a group discussion looking at two questions about what it means to live independently.
5. All then had lunch together. There was plenty of time during these periods for individual discussion with G, allowing G to get a ‘feel’ for each applicant.
6. Following this a more formal interview of each applicant was held by G, the Deputy, and an independent professional. Each asked two questions.
7. Existing PAs were around and spoke to the new applicants in between. A photograph of the two applicants ensures that G remembered the right one.
8. The result – everyone independently selected the same person.
9. G was fully involved in the process, utilising G’s strengths of visual clues and interpersonal communication.

By focusing on using G’s strengths,
G was central in this important decision making.

Fluctuating capacity

For those with fluctuating capacity, such as in certain types of mental illness, the support needs to be able to recognise when capacity has been lost and also as it is regained. This can be particularly difficult for family and friends who can find themselves trying to advocate for the person in an emergency, of then dealing with health and care staff who have not known the person previously. The voice of one person[18] who is willing to openly share his story, and the lessons that can be learnt from this experience, are in the box below.

One person's description of fluctuating capacity
and the need for others at times to take over decision-making.



Lessons from those whose capacity fluctuates:

- When I'm unable to make decisions for myself, I need professionals involved who have the skill to assess me, and if necessary make decisions for me to keep me safe.
- To do this well, **they need to speak with my family and friends to better** understand what might be in my best interests - they know me best and understand how I behave and know what's worked before.
- **They need to speak to me and listen to what I want, and try to make that central to any plans they have to make for me because if I'm not on board- they might find it difficult.**

But

- If they don't think they can keep me safe at these times by acceding to my wishes, then they need to have the courage to make the decisions that will keep me safe until I am able to make decisions for myself again - I might not like that at the time, but I'll thank them for it later.

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[18] Jim Poyser presentation at the MCA Action Day 2019

Best interests decision-making

Over the past year health and social care leads and legal partnerships have all worked together to provide guidance on best interests decision-making. For example, the British Medical Association (BMA) ethics committee are producing guidance that is generic, and also guidance focused at difficult clinical scenarios such as the cessation of nutrition and hydration in severe brain injury when there is no hope of any improvement.

The processes around taking major decisions on behalf of a person who lacks capacity need to be improved. The decisions must be in their best interests, not the interests of others or of the clinical and social services providing care. It is also important to always remember that a decision must never be motivated by a desire to bring about a person's death. A person has interests while alive but once dead they cease to have interests; they may have left a will or expressed a wish, but it is then up to others to decide whether to comply with those wishes or to challenge them, meaning their interests are effectively transferred on death to others.

Severe brain injury

There are many reasons for severe brain injury. In general, it is associated with traumatic head injury but the impression this gives is far too narrow. A very wide range of conditions, from stroke to infection can damage brain cells, resulting in neurological deficit.

The BMA have published guidance on the withdrawal of nutrition and hydration from those with prolonged profound disorders of consciousness. They have attempted to cover a wide range of circumstances[19].

When disaster strikes

In 1972 Jennett and Plum coined the term 'persistent vegetative state' (PVS)[20] to describe the unresponsive wakefulness syndrome (UWS) seen in survivors of catastrophic brain injury. Over time, improved care has meant that following severe anoxic brain damage some patients remain alive for years.

Following the Hillsborough Football Stadium disaster, Tony Bland was in PVS, and in a landmark case ruling in 1993, the Law Lords ruled that his feeding by nasogastric tube could cease. Last year, Lady Justice Brown judged that when complete agreement exists between clinicians, family and those important to the patient, such clinical decisions no longer require court sanction.[21]

These are patients whose brain function is profoundly and irreversibly damaged, usually in a catastrophic anoxic episode. When the disaster of brain injury strikes, the disorders of

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[19] https://www.bma.org.uk/advice/employment/ethics/mental-capacity/clinically-assisted-nutrition-and-hydration

[20] Jennett B, Plum F. Persistent vegetative state after brain damage. A syndrome in search of a name. *Lancet*. 1972; 1: 734–737.

[21] NHS Trust and others v Y. 2018 UKSC 46 https://www.supremecourt.uk/cases/docs/uksc-2017-0202-judgment.pdf

consciousness occur along a spectrum; at one end is PVS, which is diagnosed following detailed clinical assessment.

In all such patients the brain has taken a major assault but, despite this, the patients continue to have inherent personhood and their welfare will continue to matter to those who love them. The term ‘vegetative state’ itself is stigmatising and denies those close to the patient the respect for the intrinsic worth of the individual that should be afforded to each person. It also fails to recognise the potential uncertainty around such a diagnostic label.

The term ‘Prolonged Profound Disorder of Consciousness’ (or PPDoC) would be more scientifically accurate as well as far more respectful and would not stigmatise. The label ‘vegetative’ should be abandoned as an outdated and inappropriate term to use.

The interface between the Mental Health Act (MHA) and the MCA

The interface between these two pieces of legislation was examined by the Independent Review of the MHA, whose remit was to find a way to decrease the use of compulsory detention for treatment[22]. The report commended the MCA for ensuring service users' views and their choices are respected, using the less restrictive option. The review also drew on the importance of therapeutic benefit and ensuring patients are viewed and treated as rounded individuals, as core themes underpinning their recommendations. In addressing the interface between the two pieces of legislation, the review recommended amendment of the MCA to allow someone to be deprived of their liberty for a short while to allow psychiatric assessments to take place.

The report also addresses Advance Choice Documents and the role in clinical decision-making of an appointed health and welfare attorney under the MCA. The report suggested that a simplified approach to determining which piece of legislation is used to detain a person – namely if objecting - the MHA should be used; if not and the person lacks capacity, the MCA and revised deprivation of liberty processes would be appropriate.

However, this was not discussed as part of the progress of the Mental Capacity (Amendment) Act through Parliament and will require substantial alterations to the Code of Practice.

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[22] https://www.gov.uk/government/publications/modernising-the-mental-health-act-final-report-from-the-independent-review

National Institute for Health and Care Excellence (NICE) guidance on mental capacity and decision-making

In 2017 the NICE published in draft its guidance on the MCA. The National Mental Capacity Forum scrutinised this and expressed concerns relating to its clarity and potential confusion between the guideline and the Code of Practice. After extensive consultation between the guideline group and leadership group of the National Mental Capacity Forum, NICE revised and then published their guidance NG108[23] in October 2018.

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[23] https://www.nice.org.uk/guidance/ng108

The Mental Capacity (Amendment) Act 2019

Following the Law Commission's report on Mental Capacity and Deprivation of Liberty, which involved extensive consultation across England and Wales, the Department of Health and Social Care introduced the Mental Capacity (Amendment) Bill to the House of Lords on 3 July 2018. The Bill aimed to reform the processes, when a person lacks capacity, to consent to their care and treatment arrangements that give rise to a deprivation of liberty under article 5 of the Human Rights Act. Although being referred to as 'Liberty Protection Safeguards' (LPS) to replace the 'Deprivation of Liberty Safeguards' (DoLS), the term itself is not used on the face of the Bill, but will be used in the mandatory Code of Practice; it should be used long-term to change attitudes and ensure that the new system is not confused with previous processes.

The LPS seeks to:

- introduce a more efficient system which involves those close to the person who are concerned with the person's wellbeing in the process;
- give swifter access to assessments;
- allow local authorities and the National Health Service (NHS) bodies to focus on those with complex needs;
- stipulate responsibility lies with the NHS, rather than local authorities, when the arrangements are taking place mainly in an NHS hospital or in the community via NHS continuing healthcare; and
- reduce the number of repeat authorisations when for example a person moves from a hospital to a care home or supported living situations.

The Act received Royal Assent on 16 May 2019 and will be implemented on 1 October 2020. Amendments to the Act during its parliamentary passage addressed potential conflicts of interest for care home managers and strengthened protections for those in independent hospitals. The Act was also amended to enable families and staff at any grade to trigger an independent review of the arrangements in place if they have concerns about whether the person is objecting and also to require that a copy of the authorised arrangements is available to the person and to the family member or friend with responsibility for the person's wellbeing.

The Act was amended to remove the term "unsound mind" and replace it with "mental disorder".

New Schedule AA1

Schedule AA1 provides for the new administrative scheme for the authorisation of arrangements enabling care or treatment of a person who lacks capacity to consent to the arrangements, which give rise to a deprivation of that person's liberty. The scheme will apply in relation to all those aged 16 and above. The Supreme Court is currently considering precisely which 16 to 17 year olds who lack capacity are being deprived of their liberty.

Under Schedule AA1, a responsible body will be able to authorise arrangements giving rise to a deprivation of a person's liberty in any setting (and in more than one setting). In broad terms, the responsible body will be:

1. The "hospital manager" where the arrangements are carried out mainly in an NHS hospital;
2. A CCG or Local Health Board in the case of arrangements carried out through NHS continuing health care (but not mainly in a hospital); and
3. A local authority in all other cases, including for example where care is arranged by the local authority, where care is provided to people paying for their own care (self-funders) and where the arrangements are carried out mainly in an independent hospital.

Before a responsible body can authorise the arrangements, it must be satisfied that three authorisation conditions are met:

1. the person who is the subject of the arrangements lacks the capacity to consent to the arrangements;
2. the person has a mental disorder; and
3. the arrangements are necessary to prevent harm to the cared-for person and proportionate in relation to the likelihood and seriousness of harm to the cared-for person.

There is also a new requirement for the responsible body or care home to carry out consultation with the person and a range of others, to try to ascertain the cared-for person's wishes or feelings in relation to the arrangements. This was a provision which was particularly pleasing to see, after the strong emphasis on the importance of including family members in the decision-making process made in the various debates in the House of Lords. To deliver the necessary independence, there is a further requirement for an individual who is not involved in the day-to-day care of, or in providing any treatment to, the person to carry out a pre-authorisation review. This review will then determine whether it is reasonable for the responsible body to conclude that the authorisation conditions are met. In cases where the person is objecting to the proposed arrangements or someone is objecting on their behalf, an Approved Mental Capacity Professional must carry out the pre-authorisation review. In that case, the Approved Mental Capacity Professional must determine whether the authorisation conditions are met. They must also carry out such a review, if the arrangements provide for the person to receive care or treatment mainly in an independent hospital or where the case is referred by the responsible body and the AMCP accepts the referral.

The Government's original proposals for care home arrangements were significantly modified during the passage of the Bill through Parliament. Originally, the proposal was that the care home manager was to arrange the relevant assessments and take the other necessary steps before an authorisation can be given by the responsible body. However, following pressure from members of both the House of Lords and the Commons, the responsible body will in such cases have to decide whether it, itself, should carry out the assessment and consultation process, or whether it should be led by the care home manager.

Definition of ‘deprivation of liberty’

Many Parliamentarians, stakeholders and, indeed, the Government hoped that the reforms would provide clarification on the meaning of ‘deprivation of liberty’ in statute. This also followed the recommendation of the Joint Committee on Human Rights that a definition could help bring greater certainty to people and professionals. To this end, the Government explored providing a statutory clarification over several months, working with Peers, MPs across party lines and across the sector.

However, it became clear that the only way this could be achieved was to take an exclusionary approach, thereby setting out what does not constitute a deprivation of liberty and defining a deprivation of liberty as having the same meaning as in Article 5 of the European Convention on Human Rights. Parliamentarians expressed their dissatisfaction with this exclusionary approach which, they believed, provided very little clarity. The Government listened carefully to the views of Peers, Members of Parliament and other stakeholders, and decided not to insist on this definition. After several roundtable discussions, it was agreed, between Peers, stakeholders and government officials that the statutory Code of Practice will contain clarification on what kinds of arrangements amount to a deprivation of liberty. This part of the Code will give guidance to persons exercising functions under the LPS and will be formally reviewed, with a report of the review laid before Parliament, initially after three years of the Act coming into force and then every five years.

Interim/emergency deprivation of liberty

Section 4B of the MCA has also been amended to provide express authority for a person to take steps to deprive another person of their liberty in order to deliver life sustaining treatment or carry out a vital act. There must be a reasonable belief that the person lacks capacity to consent and the deprivation of liberty must be necessary to deliver life-sustaining treatment or carry out a vital act.

A person may be able to deprive another person of their liberty in the following circumstances:

1. where a decision relevant to whether there is authority to deprive the person of liberty is being sought from the Court of Protection;
2. where steps are being taken by a responsible body to obtain authorisation under Schedule AA1 (replacing the concept of urgent authorisations under DoLS); or in an emergency.

Safeguards

Once an authorisation has been given, there are several safeguards in place for the person. These include a right to information to be provided as soon as practicable after the responsible body has authorised the arrangements, regular planned reviews of the authorisation by the responsible body, and the right to challenge the authorisation before the Court of Protection.

As noted above, the Government’s intention is that, from the outset of the process of authorisation under the Schedule to the point when the authorisation comes to an end, the person is, generally, to be represented and supported either by an “appropriate person” or an Independent Mental Capacity Advocate (IMCA). The provisions are intended to work thus:

- The first port of call is for the responsible body to identify whether there is an appropriate person to represent and support the person who is not engaged in providing care or treatment to the person in a professional role. If the cared-for person has the capacity to consent, their consent is required for the appointment of the appropriate person. If the cared-for person lacks capacity, then the responsible body must be satisfied that it would be in the cared-for person's best interests to be represented and supported by that appropriate person. In both cases, the appropriate person must also agree to act;

- If there is no appropriate person, then, if the person has capacity to consent to being represented by an IMCA, the person must make a request for one, at which point the responsible body must take "all reasonable steps" to appoint an IMCA to represent and support them;
- If the person lacks the capacity to consent, the responsible body must take all reasonable steps to appoint an IMCA to represent and support them unless satisfied that this would not be in their best interests.

Priorities for the coming year

The National Mental Capacity Forum's priorities for the coming year will be determined by the workload associated with each:

1. The Code of Practice for the MCA must be revised and updated, using real-life examples from events that have occurred over the past ten years.

2. Specific guidance in the Code of Practice must be produced on the new Liberty Protection Safeguards to ensure a timely roll-out of the new assessment processes and associated areas, with evaluation of the effectiveness of the new system when a person is being deprived of liberty.

3. The rights and ability of people to form a relationship and show affection, including sexual expression of affection, between consenting adults needs review because assessment of capacity to enter into a sexual relationship is often restrictive and may be seriously impairing the Article 8 rights of some people.

4. Supporting people to make their own decisions needs promotion to ensure that the support builds on the strengths and abilities of the individual. The principle of support must not be used as a way to coerce a person into making the decision that others wish them to agree to.

5. The term Persistent Vegetative State should be abandoned in favour of Profound Persistent Disorder of Consciousness.

6. A specific report needs to be commissioned into the deterioration in culture that occurs in some care settings, particularly how it relates to ongoing training and other aspects of individual staff support provided in these settings.

Appendix 1

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

Members of the Leadership Group 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

Debbie Ho, Nationwide Building Society

James O'Sullivan, 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

Since 2018:

Sir William Charles – Former Vice President of the Court of Protection

Mark Holloway – Head First

Appendix 2

Selection of projects submitted to the fourth National Mental Capacity Action Day

The attached table highlights the projects undertaken during 2018-2019.

Name(s)	Organisation	Sector	Project Title
Susan Fitzgerald	Your Healthcare CIC	Healthcare	Development of innovative training tools for clinicians
David Rowley	NHS Lambeth CCG	Social Care	Lambeth Advance Planning Consortium
Professor Rosie Harding	Birmingham University	Academia	Research on disabled people's experience of legal services
Dr Liz Tilly	Open University	Academia	Research on access to heritage and archives
Sue Ledger	Open University	Academia	Research on access to heritage and archives for people with disabilities
Anna Duthie	RPPR = Relevant Person's Paid Representative	Social Care	Improving access to justice
Martin Humes	POhWER	Social Care	RPPR provision
Jane Kingston	Newcastle Council	Social Care	Managing independent advocates
Gav Barang	British Telecom	Utilities	Safety and peace of mind for the telecoms customers
Jo Harrison	Sheffield CCG	Healthcare	Ensuring Compliance in primary care
Marino LaTour	Wandsworth and Merton CCG	Healthcare	Disseminating safeguarding
Christine Asare-Bosompem	Harrow CCG	Healthcare	Training in primary care
David McSweeney	Hillingdon CCG	Healthcare	Safeguarding
Dawn Henderson	Guildford and Waverly NHS CCG	Healthcare	Safeguarding training
Deborah Seago	Surrey Heath CCG	Healthcare	Primary care delivery

Eve McGrath	Barking and Dagenham, Havering and Redbridge CCG	Healthcare	MCA and DoLs Lead
Jacqueline Coulton	Trafford CCG	Healthcare	Improving frontline services
Mary O'Reardon	City and Hackney CCG	Healthcare	Improving safeguarding
Mohammed Shofiuzzaman	Newham CCG	Healthcare	Safeguarding training
Noreen Gurner-Smith	Guildford and Waverly CCG	Healthcare	Safeguarding training
Rachel Blaney	Sutton CCG	Healthcare	Training and guidance
Tracey Cooper	Herts Valleys CCG	Healthcare	Training in primary care
Alan Eccles	Office of the Public Guardian	Government	Improve delivery of service and raise awareness of the OPG's safeguarding role
Nuala Attwood	Office of the Public Guardian	Government	Managing deputyship cases
Louise Jordan	Department for Education	Government	Improving Mental Capacity (Amendment) Bill
Lyndon Walters	DWP	Government	Improving appointee process
Toby Williamson	Toby Williamson Consultancy	Independent Consultant	Co-written 'The Dementia Manifesto'
Jennifer Pearl	Care Quality Commission	Independent Regulator	Raised awareness and improved quality of care
Jody Wicks	Care Quality Commission	Independent Regulator	Reviewed the Mental Health Act
Chris Watson	Care Quality Commission	Independent Regulator	Improved quality of inspection
Raphael Chichera	Care Quality Commission	Independent Regulator	Improved clinical practice, following inspection
Edmund McAddy	Care Quality Commission	Independent Regulator	Improved supported living arrangements
Gemma Berry	Care Quality Commission	Independent Regulator	Improved quality of frontline services
Hanna Cohen-Whittle	Care Quality Commission	Independent Regulator	Improved quality MCA implementation

Judy Davies	Care Quality Commission	Independent Regulator	Reviewed Mental Health Act
Marie Martin	Care Quality Commission	Independent Regulator	Monitoring use of capacity assessments
Nathalie Southgate	Care Quality Commission	Independent Regulator	Contributed to 2018 State of Care Report
Shelley Alexander-Ford	Care Quality Commission	Independent Regulator	Reviewed and monitored inspections
Sir William Charles	Retired Judge; Vice President of Court of Protection	Judiciary	Guidance for the legal sector, Court of Protection, local Government and NHS Trusts
Geri Rawlins	Penningtons Manches LLP	Law	Supporting clients on financial and property affairs
Ian Hunt	East Devon Law LLP	Law	Training for frontline services and care home managers
Alex Ruck-Keene	39 Essex Chambers	Law	Legal advice and publication of research on capacity disputes
Sara Isenberg	Royds Withy King Solicitors	Law	legal advice and acting as a financial deputy
Lorraine James	Southwark Borough Council	Local Government	Managing and supporting the multi-agency Team
Carol Redford	Essex County Council	Local Government	Raising awareness and improving mental capacity practice
Jim Poyser	Surrey County Council	Local Government	DoLS Assessment delivery
Sophy Hansford	Sheffield City Council	Local Government	MCA Talking Mats training
Jo Holloway	London Borough of Islington	Local Government	MCA Training through role-play
Ellen Munkley	Ealing Council	Local Government	Leading MCA delivery
Sara-Jayne Williams	Bedford Borough Council	Local Government	Delivery of children’s services capacity training for voluntary and independent sectors
Fiana Centala	Enfield Council	Local Government	New Audit tool

Susan Wilson	London Borough of Islington	Local Government	Simulation training
Anne Malloni	Bexley Council	Local Government	DoLS Assessment
Claire Migale	London Borough of Merton	Local Government	Social work
Hannah Everard	Thurrock Council	Local Government	Early intervention and Prevention
Henry Gilfillan	Bexley Council	Local Government	MCA training delivery
Jennifer Tengur	Barnet, Enfield & Haringey Mental Health Trust	Local Government	Delivery of training to frontline services
Jenny Gray	London Borough of Havering	Local Government	Dementia project
Jo Brady	Thurrock Council	Local Government	Exploring alternative communication methods
Jon Norris	Waltham Forest Council	Local Government	Safeguarding and DoLs delivery
Julie Greig	East Sussex Council	Local Government	Development of MCA Strategy
Liz Dickson	Islington Learning Disabilities Partnership	Social care	Improving communication tools
Liz Gale	Royal Borough of Kensington and Chelsea	Local Government	Champion programme
Marlene Cook OBE	Barnsley Met Borough Council	Local Government	MCA Compliance Records
Rachel Croft ASC	Surrey County Council	Local Government	Surrey Safeguarding practice and conference
Katie Edwards	Cheswold Park Hospital	Healthcare	Practice development, including communication passports
Johanna Turner	East London NHS Foundation Trust	Healthcare	Implementation and advice to Court of Protection
Dr Elizabeth Alton	NHS East Riding of Yorkshire CCG	Healthcare	Training and leading MCA practice
James Godber	NHS	Healthcare	E-learning package on MCA

Sophie Borrett	Portsmouth Hospitals NHS Trust	Healthcare	Speech and Language training and research
Anna Volkmer	NHS	Healthcare	Speech and Language training and resources
Theresa Renwick	Whittington Heath	Healthcare	Safeguarding training across sectors
Frank Butau	Royal Brompton & Harefield Hospital NHS Trust	Healthcare	Bespoke training for medical staff
Dr Karen Dodd	Surrey and Borders Partnership NHS Trust	Healthcare	Developing Mental capacity assessment tools
Dee Blaikie	Royal Free London NHS Foundation	Healthcare	Safeguarding training and delivery
Julie Hall	NHS Luton CCG	Healthcare	Publication of the Central Bedfordshire Mental Capacity Framework
Linda Katte	Homerton University Hospital NHS Foundation	Healthcare	Workshops to train frontline services
Micahel McHugh	London Purchased Healthcare Team	Healthcare	MCA templates
Hannah Burn	London Purchased Healthcare Team	Healthcare	MCA templates
Haidar Ramdan	Central London Community Health NHS Trust	Healthcare	Supervision and training on MCA
Angela Halsted	Royal Marsden NHS Foundation Trust	Healthcare	Monthly surgeries and publications
Kerrie Reidy	Kingston Hospital Foundation Trust	Healthcare	Training and support for clinicians
Anne Marie McEntree	Epsom and St Helier Hospitals	Healthcare	Safeguarding support and training
Anneliese Hillyer-Thake	NHS England and South West	Healthcare	Improving MCA compliance
Alison Bradshaw	North Devon NHS Trust	Healthcare	Raising awareness of MCA
Andrea Svinurai	Kent Community Health NHS Foundation	Healthcare	Driven Agenda for supporting decision-making

Florence Acquah	London North West University Healthcare NHS Trust	Healthcare	Updated policy and working with stakeholders
Francis Kudjoe	Royal National Orthopaedic Hospital NHS Trust	Healthcare	Leading MCA safeguarding and training
Hannah Watson	Community Learning Disability Team, CLCH	Healthcare	Speech and language therapy and improving capacity assessment
Helena Peros	MK Community and Mental Health Directorates Central and North-West London NHS Foundation Trust	Healthcare	Leading training delivery
Jemma Sharples	NHS England	Healthcare	Developing the national working group and resources
Jennifer Watkins	Royal Surrey County Hospitals NHS Trust	Healthcare	Supporting staff, patients and relatives in the capacity assessment process
Joy Maguire	NHS Brent CCG Wembley Centre for Health and Care	Healthcare	Safeguarding
Julia Burrows	Somerset and Taunton NHS Foundation Trusts	Healthcare	Creation of an electronic capacity assessment system
Julie Akorley	Central and NW London NHS Foundation Trust	Healthcare	Capacity assessments and supporting patients
Kate M Gray	Bart’s Health Trust	Healthcare	Capacity Assessment and supporting staff training
Lavinia Liburd	Greenbrook Healthcare delivering NHS Commissioned Urgent Care Services	Healthcare	Adult safeguarding
Makay Godelieve	Barnet, Enfield & Haringey Mental Health NHS Trust	Healthcare	Tribunals report
Margaret Smedly-Stainer	Imperial College Healthcare NHS Trust	Healthcare	Training and the development of and ‘adie memoir’
Marion Moran	Central London Community Healthcare NHS Trust	Healthcare	Rapid Response community nursing support

Nathalie Beltramo	Royal National Orthopaedic Hospital	Healthcare	Safeguarding supervision and training
Nhamo Pazvakavambwa	Barnet, Enfield and Haringey Mental Health Trust	Healthcare	MCA training and safeguarding audit
Queen Nyirenda	Homerton University Hospital NHS Foundation Trust	Healthcare	Research on the first principal of MCA
Sarah Philip	Moorfields Eye Hospital	Healthcare	Training delivery to clinicians
Tendai Mihzha	London and Central West Unscheduled Care Collaborative	Social Care	Improving client service delivery
Wendy Bennett	Kent Community Health NHS Trust	Healthcare	Coordinating mental capacity practice
Zahid Iqbal	Central London Community Healthcare NHS Trust	Healthcare	MCA guidance
Kate Tabner	Westminster adult social services, hospital discharge team	Social care	MCA Champion and support
Sandie Cox	Hounslow and Richmond Community Healthcare NHS Trust	Healthcare	“Show How to Know How’ training film
Caroline Peters	NHS Medway Clinical Commissioning Group	Healthcare	Safeguarding
Stef Lunn	OLM	Social Care	Online solution support service
Annette Kaggwa	HMP Bronzefield	Law enforcement	MCA Lead
Tracey-Jo Simpson	Challenge Consultancy	Private	Person-centred support
Joanne Howcroft LLB	Bupa	Private health	Alzheimer’s sprint project 'Lift the lid’
Joseph Samson	Bupa	Private health	Clinical nurse education
Marion Songhurst	Virgin Care Surrey	Private health	Safeguarding training and support
Holly Chantier	Morrisons Solicitors LLP	Law	Client support
Karon Walters	Hegarty Solicitors	Law	Court of Protection practice

Claire Lumb	Creative Support Ltd.	Third Sector	Research into positive behaviour support
Judy Weiner	VoiceAbility	Third Sector	Advocacy and awareness
Meg Stapleton	Independent Age	Third Sector	Concerns raised about the Mental Capacity (Amendment) Bill
Merlyn Holkar	Money and Mental Health Policy Institute	Third Sector	Researching the relationship between finances and mental health
Stephen Bartley	Older People Commissioner	Third Sector	Managing casework team regarding decision-making
Eiran O'Connell	Fundamental care Training	Education	Training for social care and health workers
David Thornicroft	St Thomas Training	Education	Training for social care and health workers
Angela Woodley	Three Cs	Education	Delivery one-day training sessions
Maureen Halford	Severus Training Ltd	Education	Training sessions for private and NHS services
Angela Allen	Funeral Consultancy Services	Undertakers	Empowering vulnerable people to make decisions about their or a loved one's funeral arrangements
Elizabeth Main-Ian	Independent Age	Voluntary Sector	Improving advice and resources for relatives
Usha Grieve	Compassion in Dying	Voluntary Sector	Lambeth Advance Care Planning Consortium
Kerry Kilburn	Independent researcher	Academia	Two phase audit into the implementation of MCA in adult social care
Valerie Dawkins	Enfield Health	Healthcare	Supporting patients and families to make informed decisions about care arrangements
Susan Fitzgerald	York Healthcare CIC	Healthcare	Safeguarding

Alternative format versions of this report are available on request from nmcf1@justice.gov.uk