

Whose decision?

Preparation for and implementation of the Mental Capacity Act
in statutory and non-statutory services in England and Wales



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with Learning Disabilities

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The people

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Contents

Foreword	3
1. Introduction	5
Background history	5
Mental Capacity Legislation	5
The Mental Capacity Act 2005	6
Implementing the MCA	7
Assessing Capacity	7
The Foundation and Mental Capacity	9
2. The Project and Method	11
Sampling	11
Final Sample	11
Measures	11
Ethical Issues	12
4. Results	13
What Staff had to Say	13
- Defining Mental Capacity–personal definitions	14
- Definitions–organisational definition	15
- Training	15
- Assessment attitudes and practice	15
- Comparisons across Service Sector	22
- Key findings from the Staff Survey	23
What service users had to say	23
- What decisions do service users make?	23
- How do service users make decisions?	23
- Do service users have enough involvement in making decisions?	24
- What encourages service users to make decisions?	25
- What hinders service users in making decisions?	27
- Key messages from service users	28

4. Results <i>(Continued)</i>	
What Carers had to say	28
- How do carers and the person they care for make decisions?	28
- How do service users communicate their wants and needs?	29
- What sources of help are available for carers?	30
- What hinders carers in supporting those they care for?	31
- What is the experience of carers and service users in mental capacity assessment?	31
- Key messages from carers	32
5. Discussion	33
The main findings	33
Implications of the findings	33
Critique	34
Conducting Mental capacity research	34
Key recommendations	35
6. References	36
7. Appendices	37



FOREWORD

The ability to make decisions and exercise control – “agency” – is key to our mental health, our happiness and the pursuit of our choices and goals. But what happens when we can’t make decisions for ourselves? A minority of people with mental health problems and some people with severe learning disabilities lack the capacity to make decisions either some of or all of the time. Historically, this group has been vulnerable to poor practice and even abuse as a result. There has also been a lack of understanding regarding the fact that many people **can** participate in decision making with the right support.

For the first time in law the Mental Capacity Act (2005) has set out a clear set of principles nationally about decision making for people who lack capacity, how capacity should be assessed and the safeguards needed. The Mental Health Foundation and the Foundation for People with Learning Disabilities supported the introduction of the Act as part of our work to encourage people’s empowerment. The piece of research work reported here shows our continuing commitment to supporting the implementation of this legislation. The report shows that there is still a way to go in raising awareness of the key principles contained in the Act.

I should like to pay tribute to the 16 sites across England and Wales that participated in the project and the service users and carers who shared their experiences with us. I hope this report fairly reflects their interests and concerns and helps inspire further efforts to empower people who may lack capacity and those close to them.

Dr Andrew McCulloch
Chief Executive

“*the problem is,*
when you are ill, people don't
keep you informed ...And they
withhold information from you.
This is not the right time to withhold
information as you can't decide
things like medication if you don't
understand all the facts, therefore you
are left with no choices.”

1. Introduction

Mental capacity

Mental capacity – the ability to make decisions – is an issue that affects everyone. We all make decisions, big and small, everyday of our lives. Most of us are able to make these decisions for ourselves, although we may seek information, advice or support for more serious or complex decisions.

However, for large numbers of people (for reasons of illness, injury or disability) their mental capacity may be affected in ways that prevents them from making certain decisions about their lives (on a temporary or permanent basis) and decisions are therefore made on their behalf. These include people with serious mental health problems, people with dementia, and people with learning disabilities (as well as people with brain injuries and other relevant illnesses or medical diagnoses).

Background history

Sadly, the history of health and social care and the treatment provided to people who may have lacked the capacity to make decisions contains many examples of how a diagnosis or disability has been used to prevent individuals from making even simple decisions for themselves. In addition, where someone genuinely could not make a decision for themselves (for example, consenting to medical treatment) their needs might have been ignored altogether or only catered for in the most basic of ways. Institutional ‘care’ in the old Victorian asylums, and the practices it resulted in for much of the 20th century, provide many examples of how people were treated in this way. Some of these practices continued even after the closure of these asylums when more individualised, community based-care was introduced, as some well-meaning professionals and families remained over-protective of individuals who they believed were not safe or able to make their own decisions about how they lived their lives.

However, in the absence of any clear legal framework, there were also a number of other problems. There were no safeguards or protections for severely disabled people who were extremely restricted in their mental capacity to make decisions and needed most decisions to be made on their behalf. Health and social care professionals and other staff were often unsure about what they could and couldn’t do in relation to providing care and treatment to people who lacked the capacity to consent. This often resulted in poor practice or neglect. Family carers were even less likely to be aware of how and when they could take decisions on a family member’s behalf, and also had no legal right to be consulted about decisions made by professionals. This meant that they were sometimes powerless to challenge poor practice. There were only limited ways in which a person with full mental capacity could plan ahead in case they lost capacity to make decisions in the future – the formal process known as Enduring Powers of Attorney (EPAs) was limited to decisions about a person’s property and financial affairs. This system was also open to potential abuse. Confusion also existed about the legal status of advance decisions in relation to health and social care.

The lack of a single legal framework for dealing with mental capacity issues, and reliance on common law, meant that addressing these issues was increasingly difficult toward the end of the last century and as the new millennium began. With estimates of up to two million people living in England and Wales who lacked the capacity (at times) to make decisions for themselves, and another six million people involved in their care, either as family carers, or part of the health and social care workforce, a formal solution was badly needed.

Mental capacity legislation

As far back as 1989 the Law Commission began a six year consultation on the issue of mental capacity. This was followed by a Green Paper, *Who Decides?* in 1997, published shortly after the Labour Government had been elected. The introduction of Scottish legislation on mental capacity, the Adults with Incapacity (Scotland) Act 2000 brought into even sharper contrast the lack of legislation south of the border, and following extensive consultation a draft Mental Incapacity Bill was published by the Government in June 2003. This was then subject to pre-legislative scrutiny which led to a number of changes being made (including the name) and a Mental Capacity Bill being introduced into Parliament a year later in 2004. On 7 April 2005, after its passage through Parliament, the Mental Capacity Act for England and Wales received the Royal Assent. Although well supported

by a wide range of stakeholders, including organisations representing people who lacked capacity, carers, and professionals, the passage through Parliament was not without controversy, particularly around end of life decisions. These debates resulted in amendments containing additional legal safeguards being added to the Act.

The Mental Capacity Act 2005

The Mental Capacity Act (MCA) came into full effect on the 1 October 2007, although some parts of it had been implemented in the previous April.

The MCA applies to anyone who is aged 16 or older (with some exceptions) in England and Wales. It begins with five principles which should be applied in any situations where mental capacity is an issue and apply to virtually any decisions, great or small (see box below)¹.

The five principles

- Every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise
- People must be supported as much as possible to make a decision before anyone concludes that they cannot make their own decision.
- People have the right to make what others might regard an unwise or eccentric decision.
- Anything done for or on behalf of a person who lacks mental capacity must be done in their best interests.
- Anything done for, or on behalf of, people without capacity should be the least restrictive of their basic rights and freedoms.

The MCA goes on to set out how to assess capacity (see below) and if a person is found to lack capacity there is a legal 'checklist' for making a decision on their behalf that is in their best interests, which includes involving the person and taking into account their wishes and feelings, written statements, etc. and consulting with others (e.g. family carers). This also includes the mandatory provision of an Independent Mental Capacity Advocate (IMCA) for people who lack capacity and have no-one else with whom the decision-maker can consult, where decisions are being made about serious medical treatment or a change in the person's residential accommodation. Local Authorities, the NHS and local health boards also have discretionary powers to extend the IMCA service to care reviews and adult protection procedures. IMCAs commenced working in England in April 2007 and in Wales in October 2007.

Where decisions or actions need to be taken on behalf of someone who lacks capacity involving care or treatment the MCA enables this to take place lawfully providing it is in the person's best interests (e.g. carrying out invasive treatment), although there are limitations contained in the MCA on the use of restraint when providing care or treatment². The MCA also contains extensive safeguards that researchers must follow when they want to involve people who lack the capacity to consent to participate in a research study.

The MCA provides several ways in which people who have capacity can plan ahead in case they lose capacity in the future. It codifies existing case law around advance decisions to refuse treatment and includes additional safeguards where advance decisions apply to life-sustaining treatment. The MCA allows people to make a Lasting

¹ Certain decisions are excluded from the MCA including decisions about marriage, divorce, sexual relationships, adoption, voting and decisions relating to the compulsory detention and treatment of someone with a mental disorder under the Mental Health Act 1983.

² The Act will be amended further in 2008 because any restraint currently used under the Act must not amount to a deprivation of liberty as this would contravene Article 5 of the European Convention on Human Rights. As a result of case law from the European Court of Human Rights in 2004 (the so-called "Bournewood" case) the Act has been amended to include new legal procedures and safeguards that will have to be used when a person who lacks capacity needs to be detained in a care home or hospital in their best interests

Power of Attorney (LPA) which replaces the existing system of Enduring Powers of Attorney (EPAs). As with EPAs in making an LPA people will still be able to appoint someone to make decisions on their behalf about their property or financial affairs but for the first time, the MCA allows people to make an LPA to cover decisions about their personal welfare and health. People must be aged 18 or over to either make an advanced decision to refuse treatment, or an LPA.

A new Court of Protection is created by the MCA which replaces the existing Court of Protection. The Court will deal with any cases brought under the MCA and is expected to adjudicate in particularly complex or disputed situations, including issues concerning whether or not someone has capacity to make a decision, and best interests determinations. It will be able to make declarations (e.g. about someone's capacity), make decisions on behalf of someone who lacks capacity, and appoint deputies to make decisions on behalf of someone. The MCA also creates a new public official, the Public Guardian, who has specific responsibilities for registering and overseeing LPAs, and supervising court-appointed deputies. The Public Guardian is supported by a new Government agency, the Office of the Public Guardian (OPG) which also provides information about the MCA.

The MCA also creates a new criminal offence of ill-treatment or wilful neglect of a person who lacks capacity by someone caring for them and this applies to people of any age, including children. The offence came into force in both England and Wales in April 2007.

Finally, the MCA requires that a Code of Practice is produced that anyone who is working in a paid or professional role with people who may lack capacity must pay attention to – the Code explains how the MCA works on a day to day basis³.

Implementing the MCA

After the Mental Capacity Act was passed by Parliament, a two year Government programme was established called the Mental Capacity Implementation Programme (MCIP). This programme was led by the Department for Constitutional Affairs (DCA), which became the Ministry of Justice (MoJ) in 2007, and included the Department of Health, Welsh Assembly Government, Public Guardianship Office (now the OPG). The implementation programme had responsibility for carrying out public consultations on the details of several aspects of the Mental Capacity Act, secondary legislation (such as regulations), establishing the new Office of the Public Guardian (OPG), the Court of Protection and IMCA (Independent Mental Capacity Advocate) services, producing the Code of Practice, preparing key groups (e.g. health and social care practitioners, the judiciary) through the provision of information and training materials, and generally communicating and maintaining engagement with stakeholders.

Assessing capacity

Historically there has never been a specific clinical or legal procedure that had to be followed when assessing capacity. Although assessments based upon outcomes or diagnosis had been used, a functional approach was increasingly preferred and recommended to professionals such as doctors (other medical practitioners) and psychologists in their professional guidance⁴. However for family carers and other unpaid carers, and the majority of the health and social care workforce there is little evidence to show what test of capacity they might have been using. It can be assumed that a whole range of factors including perceptions of a person's illness or disability, desired or perceived outcomes, perceptions of risk, or issues of control and power could and would be involved.

³ *Mental Capacity Act 2005 Code of Practice*. London: The Stationary Office, (2007).
Available online at: <http://www.publicguardian.gov.uk/mca/code-of-practice.htm>

⁴ See for example, *Assessment of mental capacity*, British Medical Association / Law Society (2004), *Assessment of Capacity in Adults: Interim Guidance for Psychologists*, The British Psychological Society (2006). See also Suto, Clare & Holland (2002).

The legal test that was usually applied prior to the MCA coming into force was that contained in the case of *Re. C*, a man with a diagnosis of schizophrenia who was deemed capable of making the decision to refuse the amputation of his gangrenous foot, and this test of capacity bears a close resemblance to that contained in the MCA⁵.

The first two principles of the MCA make it clear that irrespective of someone's diagnosis or disability they should be presumed to have capacity and that as much support as possible should be given to a person to help them make a decision before one decides they lack capacity. The third principle emphasises that assessment should be based upon the decision-making **process**, not the **content** of the decision, as what appears to be an unwise decision must not be taken as evidence that the person lacks capacity. The MCA also clearly states that a person's capacity must not be judged based solely on the age, appearance, condition or behaviour.

The MCA itself does not require any specific procedure to be followed when assessing a person's mental capacity nor does it require specific individuals, such as particular professional disciplines to be involved (in contrast to mental health legislation). There are no specific forms that must be filled in and there is no 'certificate of incapacity' that is issued (unlike in Scotland where in some cases GPs must complete a certificate). This is because the MCA covers virtually all decisions great or small, but is also time and decision-specific – this is known as the 'functional test' of capacity (see box below).

The functional test of capacity

- Does the person have an impairment of, or disturbance in, the functioning of the mind or brain (it does not matter if this is permanent or temporary)?
- If the answer is yes, does it make the person unable to make the decision? This can be found out if, after all appropriate help and support to make the decision has been given to them they cannot:
 - Understand the information relevant to that decision
 - Retain that information
 - Use or weigh up that information
 - Communicate their decision
 If any of these apply the person lacks the capacity to make decision.

The capacity test must be made on the balance of probabilities and what is known as a 'reasonable belief' – is it more likely than not that the person lacks capacity? Clearly for more complex or serious decisions it may help to involve a professional with skills and experiences of assessing capacity in order to make use of that expertise in deciding whether the person has capacity or not, although this is not a legal requirement. Involving a professional may also be helpful in determining whether a person has impairment of or disturbance in the brain, as well as advising upon their capacity.

The MCA's Code of Practice goes into a lot more detail about assessing capacity, for example, the time and place when an assessment takes place and the importance of involving others who know the person. A consistent emphasis is placed upon the specific nature of the capacity test. For example, a person with a moderate or severe

5 *Re. C (Adult: Refusal of Medical Treatment)* [1994] 1 All E.R. 819. The judge in the case said that the test of capacity had three stages:

1. Does the patient comprehend and retain treatment information?
2. Does the patient believe that information?
3. Does the patient weigh that information balancing risks and needs to arrive at a choice?

learning disability may lack the capacity to make a complex decision about medical treatment, but this must not be taken as proof of them being unable to make a simpler decision, such as what to eat. Similarly, a person with mental health problems may not have the capacity to make a simple decision one day because of the distress they are experiencing but perfectly able to make the decision when the distress diminishes. Just because a person has not had the capacity to make the particular decision in question in the past is not proof that they lack the capacity to do so now.

The absence of formal roles or procedures in the Act for assessing capacity is to ensure that the assessment process is comprehensive in the decisions it may apply to, while at the same time practical in its application. It also purposefully aims to avoid 'blanket' assessments of (in)capacity as has happened in the past (often to the detriment of service user's autonomy and self-determination). Thus a family carer may be involved in assessing a person's capacity under the MCA around everyday decisions, in the same way as a doctor might be for decisions involving medical treatment.

Although to test for capacity is a relatively simple thing, quite clearly the outcome of it could be absolutely critical in the way it might affect a person's life. If the person is found to lack capacity major decisions, including end-of-life decisions, would have to be made according to the 'best interests' principle by others on their behalf. However lack of awareness or knowledge among carers or staff of the test, pressures of work, or genuinely negligent practice could mean that the test of capacity is not done correctly. This could result in the person having to make a decision when they lack the capacity to do so, or the decision being made on their behalf when they could have made it themselves. There is certainly evidence to show inconsistencies in the way that that capacity is assessed⁶.

The Foundation and Mental Capacity

For the Foundation, issues of mental capacity and the MCA are of enormous importance. The Foundation is the only organisation of its kind in the UK to work with so many of the key groups of people affected by the MCA, together with their carers and health and social care staff.

Recognising the gap that existed in the law and the problems this caused, in 2002 the Foundation joined the Making Decisions Alliance (MDA), a coalition of almost 40 national and regional older peoples and disability organisations based in England. Including organisations such as Age Concern, Alzheimer's Society, Help the Aged, Mencap, Mind, National Autistic Society, Rethink, and Turning Point, the MDA was formed to campaign for the introduction of mental capacity legislation in England and Wales.

In 2004 the Foundation's Head of Policy became co-Chair of the MDA and represented the Alliance in numerous meetings as the Bill was going through Parliament. Early in 2006 he joined the Department for Constitutional Affairs (now the Ministry of Justice) as Stakeholder & Communications Manager for MCIP on a 15 month secondment. The Foundation also held an online conference in 2005 on the theme of values and mental capacity and has produced briefings and articles about the MCA⁷.

A key value of the Foundation is ensuring that people are supported and empowered to make their own decisions wherever possible. Additionally, ensuring the correct procedures and safeguards are applied when decisions are made on someone's behalf is an important tenet of the Foundation's ethos and also lies at the heart of the MCA. In this respect, the test of capacity represents the point at which the paths divide for an individual who may lack capacity to make a decision, either in the direction of autonomy and self-determination or towards a best interest decision made on their behalf by someone else.

In light of the MCA being passed by Parliament in 2005 the Foundation was interested in investigating how mental capacity was assessed before the MCA came into effect and again, after it had actually come into force. We were keen to explore this not only with health and social care staff who would be assessing capacity as part

⁶ The case of Re: C referred to above provides an example of doctors being found to have incorrectly assessed someone as lacking capacity (they based their decision primarily on the person's diagnosis alone). See also for example, Hotopf et al, Prevalence of mental incapacity in medical inpatients and associated risk factors: cross-sectional study, *The Lancet* (2004), 364: 1421-27, for evidence of how mental capacity can be incorrectly under-assessed by doctors.

⁷ *Mental Capacity Act Briefing*, Mental Health Foundation (2005). *Decisions, decisions*, Williamson, T, Mental Health Today (October 2007), p.27-29

of their work but also with carers who would also be assessing capacity (though perhaps often unaware of doing so) together with the experience of people using services who were having their capacity assessed. Due to the comprehensive nature of the MCA it was also important to explore the different environments in which people might be experiencing incapacity and the different reasons for needing to carry out the assessment, including community-based services, residential care settings and acute in-patient settings.

A further area of interest for the Foundation, as a research organisation, concerned the new safeguards that the MCA introduced around carrying out research that involved people who may lack the capacity to consent. While clearly put in place to protect vulnerable people from intrusive, distressing, exploitative, or dangerous research the safeguards also create a more complex series of steps to go through before research can take place. Carrying out research on mental capacity during the period that the MCA came into force therefore also enabled the Foundation to be one of the first organisations to actually test the new safeguards in practice. It also meant that researchers, in effect, had to carry out a test of capacity themselves, thereby providing a good opportunity for reflective learning that would be of considerable interest to researchers elsewhere.

“ The label of illness should not mean that people assume that you are not capable of making your own decisions

2. Project and method

The Foundation conducted a study which explored the knowledge of existing practices in services throughout England and Wales. The study assessed staff knowledge of issues surrounding mental capacity, staff awareness of the Act, and training provision prior to the Act. The study also conducted in-depth consultation with service users and carers regarding their experience of mental capacity issues and their experience in services.

Specifically, the research addressed five questions:

1. How do staff and organisations define mental capacity and decide when it needs to be assessed?
2. What training and guidance is currently available to staff regarding the Act?
3. What is the experience of service users in being able to make decisions and make their choices known?
4. What is the experience of carers in enabling those they care for to make decisions and in making their choices known?
5. What is the experience of carers and service users of mental capacity assessment?

Sampling

A sampling frame was created which fully sampled all mental health services throughout England and Wales, including every Primary Care Trust, every Mental Health Trust and every service within such Trusts that dealt with mental health or learning disability.

From this sampling frame, Trusts were split into rural and urban areas. Six Trusts were randomly drawn, three rural and three urban. A further random draw was undertaken to select services. Within each trust services were split into working age adult mental health, learning disability, and older people's mental health services. A random selection draw was then undertaken to select an adult mental health service, a learning disability service and an older people service within each of the 6 areas. Both statutory and non-statutory services were included and at least one non-statutory service was included per area, with the exception of rural Wales in which no appropriate non-statutory services were available.

Final sample

Of the 18 original sites drawn 4 were unable to participate and were replaced (by random draw). By the end of the Time 1 data collection cut off, 16 sites had been visited for data collection. 2 sites were still unreachable and had not responded to allow researchers to visit. Please see Appendix 1 for brief descriptions of each of the sites.

Measures

Staff Questionnaire

A questionnaire was created and designed for the study. The questions were developed over a period of time in consultation with a number of staff who had expertise in the field of mental capacity. The questionnaire was a mix of categorical and open questions, designed to gather data on staff training, experience and opinion regarding mental capacity assessment. (Please see Appendix 2 for the full questionnaire).

Carer and Service User Interviews

Interview questions were also developed and passed under internal and external review. A set of 10 questions (2 prompts) were developed for the carer interviews (please see Appendix 3).

A set of 6 questions (3 prompts) were developed for Service Users (please see Appendix 3 for full details). The interviews were semi-structured, with prompts to allow for some flexibility and responsiveness to new lines of thought from carers and service users.

Ethical issues

The project submitted an application to COREC (now NRES) and received a favourable ethical opinion following amendments in September 2006. The project ensured the standard and expected ethical procedures were followed (anonymity, confidentiality, right to withdraw etc.) However, in this case there was an additional issue regarding the difficulty of gaining informed consent from participants who lack capacity to consent. The project modelled the guidelines set out in the Act regarding research⁸. This included, presuming capacity of all participants, supporting them to make decisions regarding taking part (talking with participants, sometimes at considerable length to ensure they fully understood all the information documents and the implications of taking part) and involving carers or staff where appropriate. If participants, after considerable support, were unable to consent, they were excluded from the study.

“

I notice that now, since I've been unwell it's kind of like... 'do we really take that on board, because **is she really able**, does she you know what she's talking about?' you know, and that really does annoy me.

”

(Mental Health Service User)

⁸ See Code of Practice, Chapter 11 p 202 to 214 for more detail on how the Act affects research projects and guidelines for how to conduct research in light of the Act.

3. Results

The main aims of the project were to investigate staff and organisations definitions of capacity and their experience of training and practice relative to capacity and its assessment prior to the Act. In addition the project aimed to explore service user and carers' experience of making decisions and having capacity assessed. 73 staff participated in the research by filling in a questionnaire, 20 service users and 6 carers were interviewed. Please see the table below for details.

Table 1: Participation by site

Site	Sector	Staff	Service Users	Carers
Site 1	Older People Mental Health acute hospital ward	0	0	0
Site 2	Learning Disability voluntary service	1	2	2
Site 3	Mental Health acute and day care ward	6	3	1
Site 4	Learning Disability residential and day care	9	2	0
Site 5	Mental Health outreach team	8	1	2
Site 6	Older People Mental Health day ward	3	1	1
Site 7	Mental Health early intervention team	0	4	0
Site 8	Older People Mental Health, voluntary sector care home	0	0	0
Site 9	Learning Disability statutory service	0	0	0
Site 10	Mental Health voluntary residential	15	0	0
Site 11	Learning Disabilities community team	14	0	0
Site 12	Older People with Learning Disabilities voluntary residential home	7	0	0
Site 13	Community Mental Health Team	0	4	0
Site 14	Learning Disabilities community based service	0	0	0
Site 15	Older People Mental Health Team	1	3	0
Site 16	Mental Health Emergency Duty team	6	0	0

An additional 3 questionnaires were completed where site was not identified.

► What Staff had to Say

The number of questionnaires used in the analysis was 73; the range of submission per site was 1-15 with an average return of 6.3. The age of the staff sample ranged from under 20 to over 60 years old with a median cluster in the age group of 41-45. The staff sample was predominantly female (80.3%) and predominantly British in origin (88%) together with Other European (7%) and Indian (4%).

In terms of educational background, 41% of staff had degree or diploma training, 33% had NVQ training in their role, with a smaller proportion that had in house training (15%) or no training (3%) for their role.

In terms of current environment, the largest group in the sample came from the voluntary sector (35%), with 29% in statutory NHS acute (inpatient second tier services) and 16% in statutory NHS primary care sectors. The primary work location of the staff was largely community (65%), with 23% residential and 11% acute.

The questionnaire provided both quantitative and qualitative information. Quantitative responses were analysed using SPSS. Qualitative responses to each question were analysed and coded thematically. A sample of the initial codings was validated by a second researcher for consistency. The themes were then grouped into categories of response.

Defining Mental Capacity – personal definitions

Staff were asked where their own definition of mental capacity had come from, the largest group (28%) stated it had come from working experience; beyond this group 21% felt it had come from training and 21% from their own mind and views. 16% felt it had come from information or reading material and 12% from work.

A majority of respondents (83%) included an ability to make a decision in their definition of capacity. Of these, more than half linked the ability to make decisions with some form of cognitive competence. For the most part this was expressed as a person's ability to understand information or make an informed choice, but some looked for "*logical*", "*reasoned*", "*competent*", "*wrong or right*" or "*realistic and safe*" decision making as a mark of capacity.

Q: What do you personally understand by the term 'mental capacity'?	
Definition	Frequency
Decision-making and cognitive competence (some = understanding consequences)	29 (10)
Decision-making ability only	25
Cognitive competence only	10
Decision-making, cognitive competence and expressive skills	9
None/other	4

A substantial group (38%) of these respondents suggested that mental capacity also included an ability to understand the consequences of a decision or action. One supposed that:

"if someone has mental capacity they are capable of understanding the importance of making a decision and the severity of the consequences if the wrong one is made" (Student nurse; Site 4, 06)

While another believed that a person with capacity would display:

"the ability to make choices, to weigh up options and their consequences, and to come to independent conclusions - the basis for then making decisions" (Social worker; Site 2, 58).

Within the definitions offered by staff were some interesting variations. Some emphasised the autonomy of individuals in making decisions, and some made specific reference to the narrow range of issues which, they believed, capacity applied; major life decisions, consent to medical treatment and financial matters, for example.

The fullest definitions, offered by 12% of respondents, corresponded more closely with the principles underlined in the Act and supporting guidance. These definitions included references to the ability to understand, retain and weigh information combined with the ability to make a decision based on that information. Typically, this was formulated as

"the ability of an individual to understand and interpret information provided, and make a decision based upon a clear understanding of this information" (Physiotherapist; individual return, 73).

Only a few added a further element about ability to communicate such decisions:

"The ability to consent for treatment e.g. understanding information being given, retaining info, consider info and make decision, communicate to others." (Mental Health Nurse; Site 4, 08)

And in one instance, consideration was given to wider cultural influences:

"Ability to understand information within the persons own cultural setting and using their preferred language. The ability to process and react appropriately to information by making an informed choice."

(Care management assistant; Site 11, 36)

Definitions – organisational definition

Respondents were also asked to say how their employing organisation defined mental capacity. Only a small number (9%) either didn't know or were unsure. Just over half believed that the definition would be similar to their own, while 12% said that their organisations would use an official definition. Some deployed more instrumental terminology, suggesting their organisations view capacity in terms of its implications for the provision of services. Capacity was therefore associated with a person's ability to live independently, variously defined as an ability to carry out daily living tasks, to make choices for themselves or a consideration of risk factors.

Q: What do you think your organisation defines 'mental capacity' as?	
Description	Freq
Same as/similar to own definition	39
Government/MCA definition	9
Helping people make choices for themselves	8
Don't know/unsure	6
Consideration of risk factors	4
Independence	4
Tasks/daily living focus	4
Consent to treatment	1
Refer to others	1

When asked categorically if they agreed with their organisation's definition 93% did agree.

Training

When asked about what guidance or training staff had received regarding mental capacity assessment 59% stated they had received 'a little', 36% stated they had not received any and 5% that they had received 'a lot'. What guidance was received seemed to have primarily come from a formal course (44%), 13% from local training, 11% from reading information and 7% from team discussions. When asked if staff would like more training on the issue 59% said 'yes a lot', 39% 'yes a little' and only 1% said 'no'.

Assessment attitudes and practice

It is important to note that only 29% of those workers taking part in the survey had carried out a formal written assessment of capacity.

Instruments of Assessment

Staff had very varied responses when it came to the assessments they used in day-to-day practice. The most popular method of assessing capacity was stated as care plan reviews (27%), followed by a non-specified formal assessment tool (18%), and 11% specified they used the Mini Mental State Assessment. Alternative methods were to use colleagues opinions (11%), general knowledge questions (7%), pictures (3%), service user diaries/views (3%) and staff's own experience (3%). 16% stated they used no assessment.

In regard to whether the capacity assessments were recorded, the majority of staff recorded them in writing

(89%), 3% were recorded by audio taping, and 8% were not recorded at all. On the topic of involvement in assessment, 44% involved a combination of family, carers and staff in the assessment process, 31% stated they involved others (but did not specify who they involved), and 15% involved other staff with 8% stating they did not involve others in the assessment process at all.

Frequency of Assessment

When staff were asked how often a service user may have their capacity assessed responses varied, ranging from 38% responding 'more often than every week' to 11% 'at least every week' and a further 11% 'every 3 months'. In day-to-day practice frequency of assessment seems to vary a great deal over services (see below for comparison across service sector).

Q: What reason is there for this frequency of assessment?	
<i>Description</i>	<i>Freq</i>
Frequency determined by client/situation	18
To monitor change/stability of condition/needs	18
To monitor change/stability in capacity	11
To aid care planning	10
To help workers assist person with decisions/choices	7
As part of duty of care/risk analysis	5
Not applicable to us	3
Only meet client irregularly	2
Only for detention under the MHA	1

When exploring the reason for frequency of assessment, a large group of staff indicated that there was a need to monitor the stability of a person's condition or situation. While some of the responses clearly distinguished such assessments as relating to a person's capacity, for some, capacity became enmeshed with a condition, illness or an overall assessment of a person's needs. What is apparent from the testimony of staff is that assessment of capacity is rarely associated just with a specific decision or action. However, a considerable number of respondents did say that the frequency of assessments was determined either by the person's state or by a particular situation. Examples given were the need to obtain consent to treatment, admission to hospital, checking someone's ability to drive a car, or seeking an appointeeship.

Principles of Assessment

When asked about the principles staff use in dealing with capacity assessments and service users who lack capacity the largest group (30%) stated individual rights and consultation with the service user as the primary principle, with other staff citing no principles (14%), policies (12%) and colleague opinion or care plans (12%). A number of other issues were mentioned in response to this question including assumption of capacity (7%) observation (6%) confidentiality (3%) formal assessment (4%) and the history of client (2%).

Rationale of Assessment

When exploring qualitatively how staff decide when someone's capacity needs to be assessed a number of themes emerged from their responses to this question which can be grouped into 6 major categories.

Q: How do you decide whether someone's mental capacity to make a decision needs to be assessed?

<i>Primary coding for theme</i>	<i>Group Category</i>	<i>Freq</i>
Communication (understanding/retaining/expression)	Process	17
Consultation with others	Service-led response	14
Decision-making presents a risk (to selves, others, legality)	Impact	10
Altered mood/condition/health/behaviour	Change	9
Importance of the decision to be made/specific decision to be made	Situational	7
Refer responsibility to others	Service-led response	6
Understanding of consequences	Process	6
Inability to make decision	Situational	6
Presence of a condition (LD/dementia)	Personal characteristic	5
No response		5
Affects independence/autonomy	Impact	4
Irrationality	Process	4
History/precedence/pattern of behaviour	Personal characteristic	4
During formal meeting/care planning/review	Service-led response	4
Need to act in a person's best interest	Impact	3
Compliance	Impact	2
New experience/decision required (risk assessment)	Situational	2
Referral to respondent	Service-led response	2
Potential to section	Situational	1
Through assessment	Service-led response	1

Category	Brief description	Freq
Process	The need to assess is indicated by a person having problems with one or more aspect of decision-making. This may be a more or less permanent impairment.	27
Service-led	An assessment of capacity is initiated by the service or another professional. Capacity may be considered as part of a care planning process.	27
Impact	An assessment of capacity is required where a person's action or decision either places him/herself at risk of harm or abuse, or presents a risks to others.	19
Situational	The worker states that an assessment of capacity would only relate to a specific decision that needed to be made.	16
Characteristic	The issue of capacity is associated with a person's long-term condition, their history or precedence.	9
Change	The need to assess is triggered by a change in the person's ability, mental state or condition.	9

a) Service-led. One third of the respondents mentioned that an assessment of capacity was associated with some aspect of service provision. Some said that such assessment would normally be carried by service managers or another professional, while others suggested it forms part of a care planning process.

b) Individual characteristics. A small number of workers believed that the issue of capacity is associated with a person's long-term condition, their history or precedence. In other words, the presence of dementia, a learning disability, a mental health problem or previous behaviours would alert them to the potential need for an assessment of capacity.

c) The process of making decisions. Approximately one third of respondents said they would be alerted to the need for an assessment of a person's capacity if he or she appeared to have problems with one or more aspect of decision-making. In most instances, this related to a person's apparent ability to understand and retain information, or in being able to express him or herself. A few also included judgments about the rationality of people's decision-making by asking themselves, was it "*absurd*", "*sound*" or "*informed*"? Some also reported that the extent to which a person is able to understand the consequences of a decision or intended action might also be the trigger for an assessment.

d) Impact of decision-making. For many of those workers concerned about the ability of a person they care for to make decisions, the impact of those decisions and the consequences of actions arising from them could be an important factor in determining whether an assessment of capacity was required. More specifically, one quarter of all respondents said this would be the case where actions or decisions that either placed a person at risk of harm or abuse, or presented a risk to others.

e) Changing circumstances. In some instances the need to assess capacity might be triggered by a *change* in a person's ability, mental state, behaviour or their condition.

f) Situational. Just under 20% of the workers mentioned that an assessment of capacity would only take place in relation to a specific decision that needed to be made.

It is worth noting that three of these categories (service led, individual characteristics and changing circumstances of a person's condition) are inaccurate interpretations of when mental capacity should be assessed (if applied on their own) according to the Act.

Almost all of the respondents said they would make the decision about assessing capacity on their own authority, but some indicated that they would refer responsibility for assessing capacity to another person. There was also some deliberation about who should be involved in the process of deciding whether an assessment should be made, with a small number of respondents elucidating what they clearly saw as an important principle; to involve the person in any assessment of their own capacity.

There is an interesting dichotomy between those staff that do or would initiate an assessment based on behaviour (from observation and consultation with others) and those that refer to a situation or range of situations where an assessment of capacity might be required. In some cases, staff would initiate an assessment where they observed a pattern of behaviour:

"If I observe them making in my opinion a really bad decision on lots of occasions or if they can't seem to make a rational decision about anything" (Mental health support worker; Site 4, 09)

Assessment and the Act

Some staff had a greater appreciation of the provisions of the Act. However, staff were not always aware about where responsibility for acting lay:

"If there is a need identified, a practitioner becomes involved through a contact, then options will be explored, involving the service user and considering their views and opinions. The worker will consider if someone has capacity to make that decision." (Social worker; Site 11, 35)

Others said

"I would not make that decision. I would involve another professional" (Care management assistant, Site 11, 38)

"Can refer to a psychiatrist if there are issues raised regarding if person has capacity to make any decisions." (Care management assistant, Site 11, 39)

This confusion about responsibility applied even where people appeared to understand the principles underpinning the Act:

"There is generally an assumption that people - the work is with adults with learning disabilities - can make their own decisions. If there is any concern about this, the procedure would usually be to make a referral to the local learning disability service (social services/specialist health)." (Social worker; Site 2, 58)

Indicators for Assessment

To explore the question of what triggers an assessment more deeply, respondents were asked to describe the particular indicators of the need to assess someone's mental capacity. This subtly altered the pattern of responses compared to those for the previous question. The most frequently mentioned indicator was said to be a change in the person's usual pattern of behaviour, mental or physical state or their ability to make a decision. Some would look for changes in aspects of personality such as a reduction in confidence, self-esteem, interest, or engagement. However, most respondents were more specific. One third of them pointed to inadequacies in a person's key cognitive and social skills as potentially indicating a lack of capacity. One third referred to the potential or actual outcomes of actions and decisions as being a primary indicator. Risk-taking behaviour and evidence of vulnerability or abuse were cited most often. Irrational decisions and a tendency to compliance also fell into this category.

Q: What particular things would indicate to you that such an assessment is necessary?		
Primary coding for theme	Group category	Freq
Deteriorating mental state/psychosis	Change	13
Communication	Skills	11
Change from usual behaviour	Change	10
Risk-taking behaviour	Outcomes	7
Evidence of abuse/vulnerability	Outcomes	7
General ongoing/observation	Other	6
Inability to function socially	Skills	6
Dispute about capacity	Other	5
Lack of confidence/interest/engagement	Change	4
Lack of usual skills	Skills	4
Fluctuating decision-making	Outcomes	4
Concern raised by others/referral from others	Other	3
Crisis/major life change	Outcomes	3
Lack of insight into problems	Skills	3
Deteriorating physical well-being	Change	3
Compliance	Outcomes	2
Unrealistic expectations of person	Other	1
Irrationality	Outcomes	1

Category	Brief description	Freq
Changes	The primary indicator is change in a person's usual pattern of behaviour or skills.	30
Outcomes	Where the consequences of a decision or action are such that the worker believes that the person's capacity may need to be assessed. This may include risk-taking behaviour or evidence that the person is vulnerable.	24
Skills	The social or cognitive skills displayed by a person may indicate that an assessment is required.	24
Other	This would include referral from or concern raised by another professional or service, in the event of a dispute about a person's capacity or as the result of observations (where the worker has not specified the conclusions of such observations).	15

Reasons for Assessment

When asked for reasons as to why the mental capacity of a person they support might need to be assessed, workers were overwhelmingly (82%) of the opinion that such assessments were designed to serve a person's best interests. This notion of best interest was predicated either in their "*duty-of-care*" to protect vulnerable adults or the need to determine risk to others. However, this conception of 'best interest' was challenged by some as oppressive:

"best interest' often takes precedence over person's rights to take risks - particularly where we have a duty of care" (Social worker; Site 11, 41).

A considerable number of respondents agreed, preferring to define '*best interest*' as a way to empower individuals. Several also pointed out that an assessment of capacity acts as an important bulwark against coercion and uninformed consent around important decisions such as medical treatment.

Approximately 20% of respondents invested assessments of capacity with a diagnostic value. For example, one mental health support worker supposed that an assessment

"helps GPs to see at what level clients are; e.g. are they fit for work? Or if client is in trouble with police, helps [a] GP determine if they are capable of standing trial or not." (Site 4, 5)

Another felt that

"mental capacity needs to be assessed in order to know how the patient is coping with their illness & it needs to be ongoing so we know if any problems arise" (Student nurse; Site 4, 7).

Q: Why or for what reason do you think mental capacity needs to be assessed?		
Primary coding for theme	Group category	Freq
Protect individual	Best interest	29
Empower individual	Best interest	14
Best interest	Best interest	11
Incapacity (inc communication)	Diagnostic	9
Preventative	Other	5
Arrange right support/good care planning/QOL	Best interest	4
Ensure mental health/well-being	Best interest	4
Diagnostic (mental health or capacity)	Diagnostic	2
Change in circumstance	Other	2
Management of risk to society	Other	2
Irrationality	Diagnostic	2
Contribution to formal process	Other	1
Decision-specific	Other	1
Prove capacity	Diagnostic	1
New client/relationship	Diagnostic	1

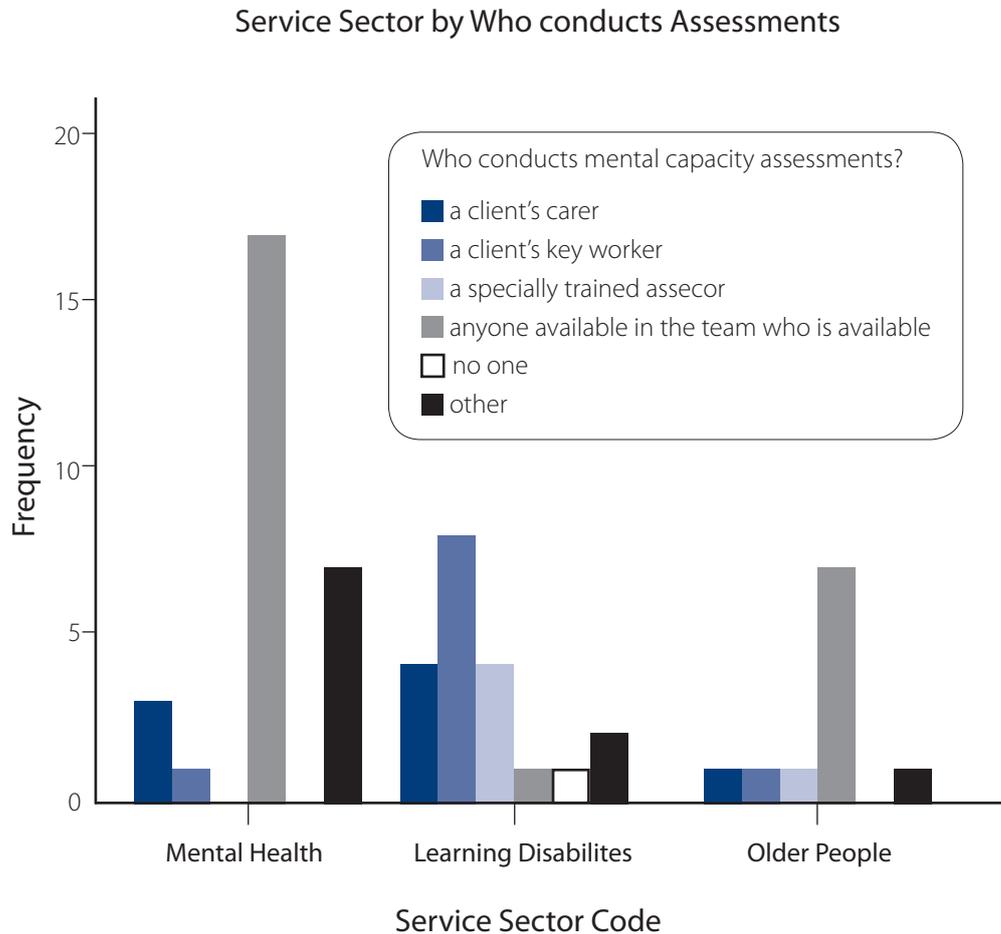
Category	Brief description	Freq
Best interest	The decision to initiate an assessment has been taken in the person's best interest. This might be to either empower or to protect the individual.	62
Diagnostic	The primary reason for carrying an assessment is the need to ascertain a person's mental capacity.	15
Other	Includes changes in circumstances	11

Some regarded assessment of capacity as part of their or their organisations '*duty of care*', typically where a person's lack of capacity might place them at risk of harm or abuse, or present a risk to others. Specific situations were mentioned where an assessment might be triggered – where sectioning under the Mental Health Act was being considered or where a referral was being made to another professional.

There was an overwhelming sense that assessment of capacity is integral to the daily working practices of the workers who were interviewed. A few did not consider assessing capacity to be part of their role so that where the issue arose responsibility for conducting an assessment would be passed to an appropriate professional. Some, such as the members of an Emergency Duty Team, also noted that the nature of their contact with clients mitigated against them becoming involved in assessments either because of its brevity or irregularity.

Comparisons across Service Sector

The services were carefully selected in order to allow researchers to make comparisons across sectors – working age adult mental health, learning disability, and older people mental health services. The staff survey results were compared between these service sectors. There were no significant differences in how frequently assessments were carried out between sectors, however there was a significant difference in who carried out the assessments ($\chi^2 = 30.06$; $df = 10$; $p = .001$). The differences between sectors are illustrated in the chart below.



Nor was there any significant differences across sector regarding desire or need for more guidance; all sectors wished for more guidance.

The range of instruments used to assess mental capacity varied greatly; however, there was no significant clustering due to sector. Each sector used a range of assessments across its services. Nor was there any significant clustering across services regarding whether family and carers were involved in assessments according to staff.

Key Findings from the Staff survey

- 98% of staff would like more guidance and training on the Mental Capacity Act and its implications for practice
- More information on standardised (or a range of) assessments recommended for use in certain groups/settings
- More guidelines on frequency, recording, and triggers for assessment
- More advice on best practice regarding who to involve in assessment
- Clearer and better communicated local policies and principles

▶ What service users had to say

Twenty service users were interviewed across eight of the services included in this study; access was problematic in some services and it was not possible for the researchers to speak with service users at the remaining eight services for a variety of reasons. It should be noted that the interviewees in this study varied widely on their ability to recall and articulate their experiences of making decisions.

What decisions do service users make?

Many of the service users interviewed talked about the range of decisions they make from day-to-day (making a cup of tea), to larger decisions about the future. Generally, people felt confident in their ability to make everyday decisions and believed that they were doing so capably. However, a number of service users talked openly about their struggles with decision-making, stating that it could sometimes be hard to make even the most basic of decisions:

"...Sometimes I'm really struggling with, you know, whether to make a cup of tea or not"
(Mental Health Service User)

"I find decision making, like even choosing what to eat or even choosing what film to go and see really, really difficult" (Mental Health Service User)

On occasion, it was felt that the struggles associated with making decisions could lead to intense feelings, which might be expressed inappropriately:

"... Sometimes really small things around the house I find really difficult and if I get overwhelmed it can even resort to self-harming" (Mental Health Service User)

A few service users gave examples of the larger or more significant decisions that they were making in their lives. For example, some people talked about making a decision to seek help for their mental health problem by choosing to take medication or by attending a mental health service, whilst another spoke of making the decision to attend a work scheme.

How do service users make decisions?

Service users were asked to think about how they make decisions. This is quite an unusual or unnatural concept for people to reflect upon and this was occasionally highlighted in their responses: *'I just get up and decide'; 'I just do it'*. However, many people were still able to consider and explore the process they go through when making a decision. A couple of people stated that decision-making was always a straightforward process. For one individual, this was because they felt they really knew their own mind - *'I know if I like something, I know if I don't'* - whilst another felt that decision making merely required *'common sense'*.

Other service users made the distinction between different types of decisions, agreeing that whilst everyday decisions can *'come naturally'*; larger decisions can require more contemplation and discussion:

"...Everyday things is just done through routine, I think you don't always have to necessarily think about it, you just do it automatically. More bigger things ... I suppose I'd use more outsiders, friends and things"
(Mental Health Service User)

This concept of supportive discussion with family, friends and staff was a common one. Such discussions were felt to be very useful, particularly for talking through options, being reminded of choices made in the past, and for receiving guidance, support and reassurance, but some people were clear that, after having these discussions, they wanted to come to the final decision themselves:

"I make decisions myself... I can ring up and talk them through, but even if I did that, I would still decide" (Mental Health Service User)

Another message was that service users need information when making decisions and need to be given all the available facts and alternative options to enable them to make an informed choice. This was particularly relevant for decisions surrounding medication. However, in some people's experience, service users were not always given the information they needed and desired:

"The problem is, when you are ill, people don't keep you informed... and they withhold information from you. This is not the right time to withhold information as you can't decide things like medication if you don't understand all the facts, therefore you are left with no choices" (Mental Health Service User)

Do service users have enough involvement in making decisions?

The majority of those interviewed felt that they had enough involvement in making decisions. Many said they were happy with their level of input in the decision making process: that they were always consulted on decisions and generally felt listened to. However, a number of individuals did not feel so involved. A couple of service users took personal responsibility for this, saying that they did not always feel able to get involved with decision-making due to a lack of confidence in communicating their wants and needs. Another felt anxious about making decisions and therefore felt it was easier to *'go along with the flow'* than make an independent decision.

Conversely, some service users held those around them responsible for not involving them enough in decisions. For example, one individual said that their community psychiatric nurse did not have the appropriate communication skills to facilitate their involvement. Others talked more generally about a lack of clarity in the decision-making process, stating that decisions are often made regardless of the service user's thoughts and feelings, and that discussions about decisions could sometimes be merely tokenistic. One service user highlighted this by stating that although her family might ask her questions about decisions and she felt, *'they've got all the answers'*. Another talked of being invited to a meeting to discuss their options and choices surrounding a decision, only to find that staff had already met beforehand and had come to decision alone:

"... Often you're made to believe you have a say in things when really a decision's already been made"
(Mental Health Service User)

Indeed, many of the service users interviewed could remember a situation in which people had made a decision on their behalf. For a few, this had been a positive experience. For example, one individual said they felt anxious about making decisions and so preferred others to make decisions for them. Another stated that it didn't concern them when people made their decisions, so long as they were making the right decisions. It was also acknowledged by one individual that, although it may feel difficult at the time, you could look back in hindsight and appreciate that someone made the right decision on your behalf:

"... At the time I didn't want the decision to be made but maybe it was the best thing for me"
(Mental Health Service User)

However, it was more usual for people to highlight negative experiences of people making decisions on their behalf and to discuss the distressing impact this had. Some service users talked of how the experience had made them feel uncomfortable, others talked about feeling powerless or useless and some talked about feeling annoyed, angry and frustrated. One individual said that their experience left them feeling *'demeaned, mad, furious, dehumanised, and patronised'*.

Usually these negative experiences had occurred while the individuals were in hospital: often when they had been sectioned. Indeed, some people talked of feeling less in control of their own decisions whilst in hospital than they did in the community:

"[In hospital] you are told what to do, told what medication to take ... They are not about involving you in care, they decide where you will be held, for how long and what you will take" (Mental Health Service User)

One person said that although they were angry with the hospital staff for making decisions on their behalf, they were too scared to question it, due to a fear that all support would be withdrawn. Another service user gave an example of feeling ignored and patronised in hospital:

"...I sat there like I was invisible and the nurse who was with me... was asked, 'can she make a decision?' and 'can she do this?' and I'm like, 'I'm not an idiot, I'm not a puppet and I can answer for myself, you know, and you're just made to feel like you're nothing'" (Mental Health Service User)

Perhaps because of these negative experiences, some service users did acknowledge that they would like more support to enable them to express their opinions, wants and needs. Very few individuals said that they always felt able to do this: most individuals said they could do this most or some of the time. Again, some service users felt held back from speaking up by a lack of confidence or by a fear of being perceived as *'a nuisance'*. Another felt restricted by the busy workloads of the staff and the feeling that they don't have the time or the inclination to hear what they have to say:

"...Sometimes you've only just got to look at someone, they give you that look as though to say, 'don't approach me, I'm busy, or 'I don't need this'" (Mental Health Service User)

It was also important that people be supported to express their wants and needs early on in the decision-making process, as some individuals had a tendency to hold back on this for as long as possible, leading to a build-up of frustration and annoyance.

What encourages service users to make decisions?

Communicating through preferred means

It was clear that people had varying preferences of how to communicate their wants and needs to others and it was important that they were able to express themselves in the way they felt most comfortable. Most service users said they could verbally communicate with others, by telling people what they need or asking for what they want. Many people found discussions helpful and talked of the benefits of being able to talk through their issues and concerns with others:

"I talk to them, I talk, talk to the staff... that sorts the problem out" (Learning Disability Service User)

However, not everyone felt comfortable expressing their wants and needs verbally. A couple of people found writing helpful, whilst another talked about expressing themselves in more creative ways, such as painting. For these individuals, writing their wants and needs down on paper felt easier than expressing them verbally, particularly if what they wanted to say was complex or in some way critical of the support they were receiving:

"... If you find it hard or intimidating to confront somebody face to face, or if it's over something quite in-depth or a bit complex and I cant work out what it is I want to say, I'll write it in a letter" (Mental Health Service User)

Being heard

Irrespective of how people chose to express their wants and needs, it was important to service users that the people around them really listened to what they had to say. By feeling listened to, they believed their opinions had been understood and were valued:

"I need someone to be here and sit down and listen" (Mental Health Service User)

However, not everyone felt that they were listened to; indeed some individuals felt that their opinion at times was ignored by staff. A couple of people felt their opinions were not valued because of their mental health diagnosis and the stigma surrounding it (see Prejudice and Stigma section below).

Familiarity and trust

Service users identified trust as an important element in the communication of their wants and needs. This included service users trusting the people around them and feeling trusted in return. Trust was often built through familiarity with others and a feeling of knowing those around you well:

"If I know them long enough, I would be able to tell [what I want], you know, if I knew them long enough" (Older People Service User)

Although service users talked about a range of people who they found helpful and supportive in their day-to-day life (e.g. partners, CPN, children, social worker, parents and colleagues), it was perhaps because of this familiarity and trust that family and friends were generally felt to be the most helpful, rather than mental health professionals. Service users also often felt more comfortable telling a friend or a member of their family what they needed, rather than members of staff. For some, this was again because of a feeling that their family members know them better than the staff do and that they could notice their non-verbal signals:

"... Because I don't wear my heart on my sleeve and because I hide things... people can't really see beneath, or they think, 'ah, yeah she's fine' and that scares me, but my husband does home in on it. I mean, we've been together 14, 15 years so he can, he can read the signs" (Mental Health Service User)

Some individuals did give positive feedback about their relationships with members of staff, stating similar experiences of trust and understanding. However, this generally occurred when service users had been in contact with a service for longer periods and these relationships had developed over time.

Service and staff qualities

A number of service users talked about what services and staff could do to help people make decisions. Once again, a key quality was that staff are good communicators: that they talk through decisions with service users and really listen to their point of view. Other factors included being down-to-earth; not 'fazed' or shocked by what service users have to say; being available when needed and quick to respond to individual needs. It was also important that staff are caring and helpful, are *'good company'*, and have a positive outlook. These are key aspects for staff to embed in their day to day practice when dealing with capacity issues.

The external environment of services also have a role to play, with one service user saying the environment should be welcoming and safe and that staff members should be introduced to service users:

"... It was a very cold situation, there was no staff introduction, no photos of the staff on the walls with names and so it is difficult to feel part of the place or know who is who if you need help" (Mental Health Service User)

The absence of crisis or out-of-hours support was also raised as an issue for one individual, who stated that it was most often in the evening - when the service was shut - that they needed help.

What hinders service users in making decisions?

Lack of confidence

It was clear that for many service users, being able to express oneself and make one's own decisions required confidence: a personal quality that some people felt they were lacking. Service users were less likely to make decisions or express their wants and needs in situations where they felt unconfident. Some talked instead of trying to hint to others about what they want, without openly expressing it:

"... It can take me a while to feel confident and so then I just hint until my confidence builds up" (Mental Health Service User)

This tension between wanting to express oneself and not having the confidence to do so had a negative impact on some individuals, leading to feelings of stress and frustration. Because of this, some people expressed a strong desire to build their confidence in order to become better equipped to make their own decisions. For one individual at least, their service was assisting them in their desire to achieve this goal.

Prejudice and stigma

Some service users felt disempowered by the prejudice and stigma they experienced because of their mental health problem, and believed this had an impact on their ability to express themselves and make decisions. Some individuals felt that mental health problems were still misunderstood within society and that people did not understand or want to understand the thoughts and experiences of people with mental health problems:

"I cannot experience this with people because they don't want to know. They're ignorant, they want to be ignorant" (Mental Health Service User)

Others felt that people with mental health problems were mistrusted or ignored, that their contributions were not respected and their decisions not valued:

"I notice that now, since I've been unwell and in the system quite some time, I notice then that people really do kind of question, or they let you speak and it's kind of like, 'do we really take that on board, because is she really able, does she know what she's talking about?' you know, and that really does annoy me" (Mental Health Service User)

"...The label of illness should not mean that people assume that you are not capable of making your own decisions" (Mental Health Service User)

Again, such experiences had a negative impact upon people's confidence and their willingness to share their wants and needs with others. One individual said they did not like to ask for help as they worried they would be perceived as a **'burden'**. Another felt that they could not ask their friends and family for assistance and believed that the only people who will help individuals with mental health problems are professionals – simply because they are paid to do so and not because they care. Such experiences and beliefs had led to feelings of isolation and loneliness, which, again, made it harder for people to build the confidence to ask for help or support or to express their opinions:

"... Really I've got no one" (Mental Health Service User)

Key messages from service users

- Service users have varying preferences of how to express their wants and needs to others. Services should allow service users to express themselves in the way they feel most comfortable
- Services should be able to demonstrate that they can ensure that service user opinions are valued and understood
- Service users are less likely to make decisions or express their wants and needs in situations where they feel unconfident. Services should encourage and support service users to grow in confidence and help develop their abilities to make decisions unsupported
- Prejudice and stigma can diminish service users' confidence and inhibit their ability to express their wants and needs. Services should work with service users and their families to tackle prejudice and stigma
- The quality of services and relationships with staff are important considerations when helping service users to make decisions. Important staff characteristics include good communication skills, flexibility and responsiveness, a positive outlook and a non-judgemental, caring disposition

▶ What carers had to say

Six carers were interviewed across four of the services included in this study; access was problematic in some services and it was not possible for the researchers to speak with carers at the remaining twelve services. It is worth noting that the group of carers interviewed were firstly involved in caring at various levels (some living with and heavily involved in caring, others involved in the service users life but not necessarily in every day life). Also, that the people they were caring for had very different levels of capacity.

How do carers and the person they care for make decisions?

Some of the carers interviewed talked about the type of decisions the person they care for makes independently, including choosing what clothes to wear, deciding what food to buy or how to spend their money. These tended to be smaller, everyday decisions or those which one carer described as *'trivial'* or with *'no serious consequences'*. Another carer described these as being more concrete decisions, explaining that if, *'you ask them about something that's not real in front of them, they can't make a decision about those things'*. Only one individual gave an example of a more significant decision made by the person they care for - the decision not to attend a day centre. Though the carer had been informed that attending a day centre would benefit her husband, she respected his decision on this matter, stating:

"I wouldn't push that, he doesn't want to do it, so leave it, you know... I mean that's his choice"

(Carer of Mental Health Service User)

Some carers also talked of mutual decisions being made between themselves and the person they care for, following discussions about the available options. It was clear that these individuals valued the input of the person they care for and endeavoured to involve them in the decision-making process:

"...People need their dignity don't they? They don't need to be taken over. So as I say, I do, I involve him in everything" (Carer of Mental Health Service User)

However, a couple of people acknowledged that they could sometimes guide or persuade the person they care for toward making a certain choice, particularly if they felt that they did not fully understand the decision to be made:

"In the main I would speak to my husband about anything that... we need to make decisions on. But possibly when it comes down to it, I probably make the decisions because he isn't quite able to maybe entirely understand" (Carer of Mental Health Service User)

"I try to let her make her own decisions but then I guide her and if I think there are things that she should buy, I'll put them in the basket for her anyway" (Carer of Older People Service User)

On occasion, some carers would also go beyond guiding and persuading and actually make a decision on behalf of the person they care for. This was particularly pertinent in situations where an **important** decision (which could have serious repercussions for the person being cared for) was to be made. Some carers felt strongly that in such situations, they did not have a **choice** as to whether or not to become involved, but instead saw their involvement as a necessity: a decision needed to be made and the person they cared for was incapable of making that decision, therefore it was their responsibility to intervene:

"When you need to make a decision, you know, you have to make it. You don't have much choice" (Carer of Learning Disability Service User)

Furthermore, some individuals stated that they made most, if not all decisions on behalf of the person they care for:

"I don't think she really makes any decisions because I think I've more or less taken that role from her" (Carer of Older People Service User)

"It's mostly me that makes decisions" (Carer of Mental Health Service User)

Only two of the carers interviewed felt that the capacity of the person they care for changes or fluctuates; others felt that the person's capacity stays the same.

How do service users communicate their wants and needs?

Carers communicated with the people they care for in a range of ways. Some said that the person they care for was able to communicate with them verbally and tell them what they want and need. Others used more non-verbal means of communication, such as using signs or showing their carer what they want. Nevertheless, regardless of how service users communicated with their carer, there was a clear message from the carers that:

"Mostly, I know what they want" (Carer of Learning Disability Service User)

This notion that a carer knows what the person they care for wants is important when exploring the way that capacity is judged. One might propose that assessment of capacity can be judged upon a continuum, ranging from formal assessments through to a more informal judgment of 'knowing' and 'understanding' a person. Within this study, it was clear that it was the more informal judgements that were most pertinent to carers. When asked how they decide if they need to make a decision on behalf of the person they care for, none of the carers interviewed talked about the outcomes of formal mental capacity assessments. Instead, they all talked about referring to and calling upon their knowledge and understanding of the person they care for.

Carers stated that knowing the person they care for makes it easier for them to communicate: that carers tend to be more aware of the person's signals and reactions and can read what the person is trying to say, even when it is not communicated verbally. A number of carers felt that this closeness and knowledge helped them to support the person they care for to make their own decisions:

"... Because I know them so well they can communicate with me and I can understand if they like something or if they don't like it" (Carer of Learning Disability Service User)

One carer also felt it important that she had known her partner before he became ill, while the service did not. She talked of how other people attributed his indecisiveness or his unwillingness to make some decisions to his diagnosed mental illness and associated 'lack' of capacity. Yet, she said he was indecisive before he became ill and it had little to do with his mental health problem. She also talked of how the person she cared for was unable to perform certain tasks around the home, but that he had never performed these tasks before he became ill. It therefore seems that services need to consider such factors when assessing a person's capacity:

"I've tried to explain to them that he's never done this so don't expect him to do it now" (Carer of Mental Health Service User)

Perhaps because of their close bonds; some of the carers interviewed believed that the person they care for trusted them enough to comply with any decisions that they made on their behalf:

"... She goes along with it, probably because she trusts us, we trust each other because we're a loving family" (Carer of Older People Service User)

Indeed, carers frequently spoke of how any decisions they did make were always in the best interest of the person they cared for:

"I just feel that as though the decisions that I make for me mum are the best decisions and decisions that she would have made if she was capable of making them" (Carer of Older People Service User)

"I wouldn't do anything that would be against him or, or you know, not good for him" (Carer of Mental Health Service User)

Some carers said that they would also consult with professionals and take their advice before making a decision on behalf of the person they care for.

What sources of help are available for carers?

Carers discussed many sources of support, including partners, friends, GPs, mental health professionals, and social services. Regardless of the type of support accessed, what carers felt most helpful was having the opportunity to talk about their problems and concerns, to hear other people's experiences and to gain their advice. There was some suggestion that being a carer could be a difficult or lonely role, therefore being able to talk through experiences with others was greatly appreciated:

"... When you talk with somebody else, you have, you know, two people, they can make a decision and it's shared isn't it, that problem is shared" (Carer of Learning Disability Service User)

Many people felt that they had adequate support for their role as a carer. Some were particularly appreciative that services kept them involved in decisions relating to the care of their loved ones. Others were grateful to have access to a carers group, though some did acknowledge that the groups could be held at inconvenient times for those in employment. One carer felt that the service offered even more support than she needed and worried that the staff would be annoyed with her for not accepting all the help they offered.

Whilst these experiences highlight a fairly positive picture of the help available for carers, it should be noted that all of the carers interviewed in this study were accessed because of their link to a service; hence, they all had at least some form of support available to them. One might propose that other carers could portray a very different picture of the levels of support available. Indeed, some individuals did talk about the difficulties they had experienced in the past when trying to locate and access supportive services for carers:

"I didn't know where the heck to turn. Or where to go" (Carer of Mental Health Service User)

"...It's not easy to find, to know where to go" (Carer of Learning Disability Service User)

One individual talked of how support for carers is most needed at an early stage but is most often provided later rather than sooner:

"Years ago, I would have loved that, to give me a warning of what sort of things to expect. But when you've been a guardian and carer for so long you know it all" (Carer of Mental Health Service User).

What hinders carers in supporting those they care for to make their own decisions?

One barrier for carers in supporting those they care for to make their own decisions were the personal fears and emotions they experienced. Many people talked frankly about the responsibility that came with being a carer and the impact this had on their own life. Some individuals talked of the **worry** and **anxiety** associated with being a carer. This was evident in an example given by one individual, who said that the person they cared for had a health concern, which had left them in a lot of pain, yet they were unable to make a personal decision as to whether or not to have an operation. This decision - and the accountability for any negative consequences relating to the decision - was therefore left to the carer:

"That was a very difficult decision to make.... She can't make a decision to say, you know, 'I want that operation' and so I'm left to decide and it's a big worry, what if something goes wrong" (Carer of Learning Disability Service User)

A number of other emotions were also linked to a carer's need to make a decision, including **guilt** and **distress**. One carer also spoke of the **frustration** of being a carer, disliking that they seemed to be **'always nagging'** the person they care for. Others spoke of how being a carer impacted upon their personal life, affecting their day-to-day living, their relationships with others and their sense of freedom:

"...I'm sort of trapped, and it's a terrible feeling, you're not going to get your own life" (Carer of Mental Health Service User)

"It's difficult... because he isn't as he was. He looks the same but he isn't. And it is a bit difficult caring for someone who is different" (Carer of Mental Health Service User)

What is the experience of carers and service users in mental capacity assessment?

It was clear from the interviews that either a) formal capacity assessments are not being conducted in the services studied or b) service users and carers are not being clearly informed that capacity assessments are being conducted. Only two of the twenty service users interviewed said that they had undergone a formal capacity assessment, while none of the carers interviewed were confident that the person they cared for had undergone a formal capacity assessment. Two of the carers said the person they cared for had had some form of assessment but they were not clear whether this was to assess capacity per se.

Some of the service users interviewed did have comments to make about the Mental Capacity Act and the changes it would bring. Those who did comment on the Act were positive in their contributions, stating that it sounded **'useful'** or **'a good idea'**. The suggestion of providing access to advocates was also supported:

"It would be a big help to have advocates" (Mental Health Service User)

"I've often said, you know, to me husband when I've been dealing with Social Services or anybody else, 'How do people who live in their own homes, you know make, make decisions and get things done for themselves, when they're not, you know, they haven't got full capacity... who does it for them?'" (Carer of Older People Service User)

The only concern was that one individual felt it might not always be practical to nominate an individual to speak on your behalf and worried that **"the wrong person could speak for you and make decisions for you that you would not like"**.

Key messages from carers

- Services should be able to demonstrate that they recognise a carers' role in the assessment of capacity and decision making process and acknowledge their familiarity and understanding of the service user.
- Many carers are appreciative of the support they receive from services and particularly value the opportunity to discuss their situation and their concerns with others, to hear other people's experiences and to gain their advice.
- Services should ensure that support groups are accessible to all carers and consider the potential barriers to attendance.
- Services should acknowledge the responsibility associated with being a carer and the impact this has on a carer's own life.

“ It would be a big help to have
advocates

(Mental Health Service User)

4. Discussion

This project addressed five main questions regarding how staff and organisations define and assess incapacity, how they trained and guided their staff in these, and how service users and carers experienced making decisions and assessment.

The main findings

The project found an overwhelming desire amongst staff for more training and guidance on the issue of mental capacity and its assessment. There was also considerable variety in individual staff and perceived organisational definitions indicating a need for more guidelines – or perhaps greater efforts at communicating existing guidelines - to provide better standardisation of the understanding of capacity, assessment of capacity (how and when to assess), and best practice regarding who and when to involve others in assessment.

Service users clearly stated that whilst good practice does exist in the sector, more attention must be paid to supporting them to express their needs appropriately, to encourage confidence and to battle stigma (both within the sector and outside it).

Carers have much to offer staff and services in their knowledge and experience of the person they care for. Services need to recognise a carer's expertise and support the carers own needs in a completely accessible way.

Implications of the findings

The wide variety of staff definitions of mental capacity and in deciding when and why to assess mental capacity is certainly worthy of note. Such a wide variety may also be a cause for concern for obvious reasons; however, the survey was conducted before the Act came fully into force so some dissimilarity may be expected throughout the sector. It can be argued that a central reason for introducing the Act was to address these variations and standardise definitions, assessment and practice across health and social care.

It is also worthy of note that the concept of 'best interests' was the most common reason given by staff to initiate a capacity assessment. The Mental Capacity Act outlines that what is in a person's best interests is decided only *after* assessing their capacity. This is an example of the confusion that has existed in the sector in the past. It is hoped now that the Act is fully in place, such confusion will be reduced.

It is also interesting that staff's personal definitions of capacity differed greatly, with only 12% giving a more complete definition (similar to the MCA) which included understanding, retaining and weighing up information. However, only a few also included communication in this definition in line with the definition in the MCA.

Also of interest is the fact that many of the key messages put forward by service users (p 28) link with the principles of Act. Service users request opportunities to be able to express themselves, to be heard, to be supported to be heard both in important and day to day decisions. This is a key component of the Act.

Assessment Issues

There is no standard test or assessment for capacity being used. The Act does introduce a standard, simple, test of capacity and the Code of Practice provides guidance on how to ensure individually tailored and appropriate tests for the person and situation. However, the great variation from staff in outlining principles of assessment needs to be addressed. The golden mean between a prescriptive or restrictive recommendation and complete lack of coherence needs to be reached. Whichever way staff may choose to assess capacity it is reassuring to find that such a large proportion of them were recorded – although needs must stress to the 8% who do not record them that such records are invaluable for both small and large decisions.

With regards to the good practice of involving families and carers in assessments, carers expressed a wish to be involved and many services did involve family and carers. However, with 23% only involving staff (and no one else), the argument for the benefits of involving families and carers is still worth pursuing.

Critique

Sample size and range

Despite best efforts to canvas a range of sectors in a range of rural and urban areas there was great difficulty in accessing sites in all areas. This reduced the sample size, a larger sample size may have allowed for more differences between the Mental Health, Learning Disability and Older People services to become apparent.

The sample was necessarily an opportunistic sample with some bias built in to this in that those who were interviewed were those with enough capacity to be able to consent (heavily supported in many cases, but still able to consent). Those who were truly unable to consent, and therefore more likely to be having decisions made for them by others at a much greater frequency were not able to be interviewed. Service staff were also involved in helping us to access service users in their area, this contact assistance was gratefully received and of great help yet may also have added a bias in that service users who were only peripherally involved in the service or had had a bad experience were unlikely to be easily reached by the team.

In terms of methodology, one of the challenges of the study involved making questions about mental capacity meaningful to service users. In order to achieve this staff, service user and carers questions varied between groups. However, this raises the possibility that slightly different but related concepts were being addressed, and that participants were relating the questions to different decision making situations. It may be that service users and carers, in keeping with the Act, were thinking of every day decision making situations more than staff were.

Conducting Mental Capacity Research – Lessons Learned

There were considerable ethical difficulties involved in the research from the beginning. Ethical approval through COREC (now NRES) was a long process that took over 6 months. The ethical committee had understandable concerns about conducting research with such a vulnerable group. The research team resolved these difficulties by modelling the guidance set out in the Act.

In terms of the practical lessons learned, the research team found that services vary greatly in their attitudes towards research involvement and consent. A researcher needs to make sure they are following the guidelines of the Act even if the service is unaware of them.

In following the guidelines teams need to allow extra time to be set aside; informed consent is not a simple procedure with this group, and extra time and resources needs to be put in place to ensure fully supported consent. Translators, carer involvement, staff involvement all may be necessary and that can make working in the service harder and longer than usual.

An extra cost to such research is the fact that access is often hard, and of the participants who do come forward, the team must accept that after spending time on full informed consent procedures the interview may not be able to proceed due to capacity (for example, just because a contact has been made and an interview set up, does not necessarily mean that the person can consent at that time to interview).

Lessons Learned - Key points

- Allow extra time and resource for ethical application, there will be issues to discuss and debate
- Allow extra time and resources for supported, sometimes heavily supported consent procedures, extra budget may be needed for translators, easy read versions and further staff time involvement.
- Involve the staff, carers and advocates in the consent procedure, be accepting that many interviews may not proceed due to difficulty of consent

These recommendations are aimed primarily at directors of social services, researchers, clinical/medical/nursing directors in NHS Trusts, chief executives of non-statutory health and social care provider organisations:

Key recommendations

- There needs to be a coherent strategy across sectors to communicate guidance and training on the Act for frontline staff. As well as training on issues such as good communication, supporting patient choice and user empowerment, person-centred care and managing risk.
- There also needs to be similar work across sectors to ensure the provision of support and mentoring for practitioners to enable them to apply the Act in their everyday practice, with a focus upon supporting patients and users of services to make as many decisions as possible for themselves.
- An audit or evaluation of knowledge and training regarding the Mental Capacity Act would be helpful to identify areas and gaps that need to be filled
- Services must be able to demonstrate how they have involved service users and their carers, in the determination of the person's best interests.
- There needs to be more resources in place to support service users to make their own decisions (staff time, carer involvement, confidence building, and time taken around decisions).

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6. Appendix 1

Brief site descriptions

Site 1 – a busy urban hospital with an acute older people’s ward, engagement with staff was difficult.

Site 2 – a voluntary service based in a busy urban area, providing support services to a range of service users with learning disabilities, mental health problems and carers of these groups. 1 staff questionnaire was completed, 2 carers and 2 service users were interviewed.

Site 3 – a suburban hospital on the edge of a busy city this service provided acute and day centre care for a variety of service users with severe and enduring mental health problems. 6 staff completed questionnaires, 1 carer and 3 service users were interviewed.

Site 4 – An urban site that was mixed residential and day care unit, the site consisted of a number of supported housing units centred around a day unit facility. The population consisted of people with learning disabilities and people with enduring mental health problems. There were 15 staff, 9 of whom completed questionnaires. Two service users from this site were interviewed

Site 5 – An urban centre based in a hospital grounds, this serviced a range of users with severe and enduring mental health problems. 8 of 9 staff completed questionnaires, and 2 carers and 1 service user were interviewed at this site.

Site 6 – An urban day ward designed to serve older people with 5 staff, 3 of whom completed questionnaires. 1 carer and 1 service user were interviewed at this site.

Site 7 – A rural early intervention team for people aged 18-35 experiencing their first onset of psychosis. No staff completed questionnaires at this site. 4 service users were interviewed.

Site 8 – A rural registered care home for older people. No staff completed questionnaires at this site and no interviews were carried out with service users or carers.

Site 9 – A rural statutory service. No staff completed questionnaires at this site and no interviews were carried out with service users or carers.

Site 10 - Questionnaires were completed by 15 mental health support workers at two community houses run by a small not-for-profit organisation that specialises in providing residential support to former residents of local psychiatric hospitals. The service covers part of a large shire county. Team members completed questionnaires during specially arranged sessions.

Site 11 - Fourteen members of a CLDT completed questionnaires following a meeting with the researcher. The joint health and social care team covers a mixed urban and rural unitary authority.

Site 12 - A residential unit supporting 10-12 older people with learning disabilities situated in the suburbs of a provincial city. The home is run by a large not-for-profit organisation that provides a range of learning disability services. Most of the residents are former patients of long-stay hospitals. Questionnaires were completed by residential support staff following a team meeting.

Site 13 – A rural community mental health team. No members of staff completed questionnaires at this site. 4 service users were interviewed.

Site 14 – A rural learning disabilities team providing community-based services to adults with learning disabilities and their carers. No members of staff completed questionnaires at this site and no service users or carers were interviewed.

Site 15 – A rural community and mental health team for older people. One member of staff completed a questionnaire at this site and three service users were interviewed.

Site 16 - Six members of an Emergency Duty Team (4 psychiatric social workers and 2 support staff) completed questionnaires during a meeting with the researcher. The Emergency Duty Team is based in a former acute hospital building in major provincial city. The team covers the city and a large tract of surrounding countryside.

Site 17 – A community support team for people with learning disabilities covering a regional city. Despite initially agreeing to participate in the project, repeated attempts to arrange an initial meeting with the team manager were unsuccessful.

Site 18 – An organisation managed by people with severe mental illness and their families that offers a range of services including housing support, drop-in facilities and advocacy, across a number of local authority areas. Agreement in principle to participate was reached, but after an initial meeting was cancelled the organisation declined further contact.

Appendix 2

Evaluating How we Measure Mental Capacity in England and Wales Staff Questionnaire Online Preview version (plain text version)

[Version 5.0, 20.07.06]

Mental Capacity Assessment Processes

The following questions seek information about how you, your team or service assesses the mental capacity of service users. You may find it useful to think of a specific example when answering:

1. How do you decide whether someone's mental capacity to make a decision needs to be assessed?
 - What would indicate to you that such an assessment is necessary?
 - Why or for what reason do you think mental capacity needs to be assessed?
2. What do you personally understand by the term 'mental capacity'?
 - Where do you think you got this definition from?
3. What do you think your organisation defines 'mental capacity' as?
 - Do you agree with this definition?
4. During someone's time in care with you or your team (where appropriate), how often might they have their mental capacity assessed?
 - What reason is there for this frequency?
5. Who conducts mental capacity assessments in your team/service?
 - Have you received any guidance or training about this?
 - If you have, please briefly describe what guidance or training you received?
 - Would you like more guidance or training on these issues?
6. Are there any principles you use to inform/underpin the assessment process?
 - Are there particular stages you or your team/service would ordinarily go through?
 - Who sets out these principles?
 - Are they formal or informal?
 - Please state here any specific instrument(s) you use:
7. Are assessments recorded?
 - If they are, by whom and where?
8. Is assessment data readily available for others to see and understand e.g. carers/advocates?
9. Do you involve or consult any other persons in your capacity assessment (e.g. family, carers? Support workers?)
 - If you do, how do you involve others in your assessment?

Appendix 3

Evaluating How we Measure Mental Capacity in England and Wales Interview Schedule and Prompts

[Version 5.0, 08.08.06]

Carers/Supporters

How we make decisions

We'd like you to tell us a bit about how things are for you everyday and the person you look after.

1. How do you and the person you look after make decisions? (this could be decisions about major things like where you live or little decisions about what to wear today)
2. How do you decide when you need to make a decision for the person you care for?
3. How do you decide when the person you care for can make a decision for themselves or not?
4. Do you feel you have enough help in guiding you to what you should be doing and saying for the person you care for? (where did that help come from?)
5. What have been the best sources of help or guidelines for you?
6. How does the person you care for communicate their wants and needs to you?
7. Does the person you care for have days when they can make decisions for themselves and days when they can't?
 - If they do, how do you decide how much you need to have a say in it?

Finally,

8. Has the person you care for gone through a formal assessment of their capacity? (what was this?)
9. Was this recorded in some way?
10. Were you, as carer, involved in this process in any way?
 - If you were, how did you find that experience?

Evaluating How we Measure Mental Capacity in England and Wales

Interview Schedule and Prompts

[Version 5.0, 08.08.06]

Service Users

How you make decisions

Interview schedule

1. How do you decide things everyday?
2. Do you feel you have enough say in the way things are decided concerning you?
 - How do you let them know if you want more say?
3. Who do you find is most helpful in your day to day life?
 - How is this person helpful to you?
4. How do you let people know what you want to say or do?
5. Do you feel you are able to tell people what you need?
 - All the time? Or just some of the time?
6. How do you feel when people make decisions for you?

About the Mental Health Foundation

Founded in 1949, the Mental Health Foundation is the leading UK charity working in mental health and learning disabilities.

We are unique in the way we work. We bring together teams that undertake research, develop services, design training, influence policy and raise public awareness within one organisation. We are keen to tackle difficult issues and try different approaches, many of them led by service users themselves. We use our findings to promote survival, recovery and prevention. We do this by working with statutory and voluntary organisations, from GP practices to primary schools. We enable them to provide better help for people with mental health problems or learning disabilities, and promote mental well-being.

We also work to influence policy, including Government at the highest levels. We use our knowledge to raise awareness and to help tackle stigma attached to mental illness and learning disabilities. We reach millions of people every year through our media work, information booklets and online services. We can only continue our work with the support of many individuals, charitable trusts and companies. If you would like to make a donation, please call us on 020 7803 1121.

If you would like to find out more about our work, please contact us.

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