Mental Capacity and the Mental Capacity Act 2005
A literature review
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Mental capacity and the Mental Capacity Act 2005 - A literature review

1.0 SUMMARY

This literature review was carried out to collate academic literature relating to mental capacity issues and to the implementation of the Mental Capacity Act 2005. Mental capacity is the ability to make one’s own decisions. The Mental Capacity Act (MCA), which came into force in 2007 and covers England and Wales, provides a statutory framework for supporting people to make decisions for themselves wherever possible as well as processes and safeguards for decision-making involving people who lack capacity to make their own decisions because of illness, injury or disability. According to the MCA, if a person is unable to understand information given to them about a particular decision, retain the information long enough to make the decision, weigh up the information available to make the decision, and/or communicate their decision they may lack capacity to make the decision. The MCA is based on existing legal principles while clarifying and improving upon these principles. The law prescribes the legal protocol for any decision-making situation, including care and treatment issues, property and financial affairs, and research participation. It applies to all types of decisions ranging from complex health care decisions through to everyday decisions, involving people who may lack capacity to make these decisions. It has a far-reaching effect on well over a million people across the UK, service-users and service-providers, relatives and carers alike. The MCA should be followed by anyone involved with someone who may lack capacity to make a decision.

The MCA is based upon five primary principles.

1. A person must be assumed to have capacity unless it is established that s/he lacks capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him or her to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because s/he makes an unwise decision.
4. An action done or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his or her best interests.
5. Before the action is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is least restrictive of the person’s rights and freedom of action.

These five governing principles serve as the basis for the detailed, complex piece of legislation which is supported by a Code of Practice. The Code lends practical guidance on how the MCA is applied across various settings on a day-to-day basis for professionals and other staff involved in the care or treatment of people who may lack capacity, as well as for unpaid carers and relatives of people who lack capacity.
This review has collated a broad range of literature investigating various issues relating to mental capacity and the implementation of the MCA with the aim of identifying consistent themes, problem areas and any gaps in the existing literature. The largest proportion of literature relating to the MCA in England and Wales relates more specifically to issues with older people and people who have dementia.

Several other countries have their own mental capacity legislation (including Scotland) and this review includes studies from outside England and Wales but does not look in detail at other legislative frameworks.

2.0 INTRODUCTION

Mental capacity refers to a person’s ability to make their own decision and, if this ability is hindered because of some impairment of the mind or brain, the MCA ensures the individual remains involved in any decision making process and that decisions are based upon their best interests. As it has been four years since full implementation of the MCA, it was of interest to the Mental Health Foundation (incorporating the Foundation for People with Learning Disabilities) to obtain an accurate account of how the MCA is working in practice as evaluated by existing research. As MCA legislation only covers England and Wales, these countries were of particular interest but research from other countries that have legislation analogous to the MCA were included in the review for comparative purposes. Mental capacity legislation outside England and Wales differs in specifics but aims to serve a similar purpose of empowering people to make decisions about their own lives and providing safeguards for those who lack capacity to make their own decisions.

2.1 Methodology

This aims of this literature review were to identify mental capacity issues, problem areas and successes in the practical application of mental capacity legislation as well as identify gaps in the research. Emergent themes were derived from the body of literature which may contribute to an understanding of the application of mental capacity legislation at the ground level, as well as from more theoretical perspectives. The main focus was to obtain meta-reviews and high quality peer-reviewed papers on issues related to the MCA. These were obtained by searching a number of databases which relate from varying disciplines to issues within implementing the MCA. These disciplines included law, psychology, medicine, psychiatry and social work.

Most of the articles were obtained through searches in September 2011 and the following databases were used:

- Cochrane Database of Systematic Reviews
- JSTOR
- MEDLINE
Although we were primarily interested in the implementation of the MCA, which applies solely to England and Wales, current literature from other countries was included where they contribute learning about mental capacity issues. Reviews published before 2006 were not included in the review because the MCA had not been implemented.

Search terms included:
- “mental capacity”
- “mental competence”
- “consent/treatment consent”
- “advance directives/ statements/ decisions”
- “patient decision-making”

The substantial body of literature that has been collated for this review have been presented according to the service-user groups that were identified or included in the research paper. These service-user groups include people with learning disabilities (sometimes referred to in the literature as ‘intellectual disabilities’); people with mental health problems; and people with dementia, but also including issues relevant to the care of older people. The categorisation according to service-user groups was chosen as these groups of service-users are of particular interest to the Mental Health Foundation because the organisation’s applied research is focused on these three groups. They are also three of the main groups most commonly affected by mental capacity issues. The literature was also categorised into subgroups according to specific mental capacity issues that most frequently occurred throughout the literature. These issues were:

- shared decision-making
- assessment of capacity
- best interests decisions
- advance directives, including advance care planning and advance decisions to refuse treatment (see note on terminology)
- research involving people who may lack capacity to consent to participation

Table 1 gives a breakdown of the number of articles in each category.
Table 1: Categorisation of articles

<table>
<thead>
<tr>
<th></th>
<th>Dementia</th>
<th>Mental Health Problems</th>
<th>Learning Disabilities</th>
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<th>Total</th>
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<tr>
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<td>15/1</td>
<td>34/17</td>
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The articles are reviewed in sections according to the service-user groups involved in the study with subsection divisions according to the specific issues raised by that body of research. These are followed by a review of more general articles pertaining to the MCA and any specific issues they identified. Each section separately included any collated articles from outside England and Wales. Finally, consistent themes emerged, regarding mental capacity issues, the level of success in implementing the MCA and the Code of Practice, and an evaluation of where further research may be needed.

2.2 A note on terminology

For the sake of brevity, the author may refer to a person as “lacking capacity” to make a decision although it is fully understood that, in accordance with MCA principles, any lack of capacity is situation- and decision-specific. Additionally, the term advance directives (ADs) will be used throughout this article to refer to any “living will” or statement of preference made in advance, unless reference is made specifically to advance decisions to refuse treatment. This distinction is important as, in the UK, only advance decisions to refuse treatment are legally binding, while an advance directive refers to a broader set of documents and is not necessarily binding but should be referred to when making best
interests decisions. The legal status of advance directives, advance decisions to refuse treatment and advance care planning vary from one country to another.

3.0 MENTAL CAPACITY

The sections presented below contain a brief breakdown of the main aspects of the mental capacity issues that were identified in the research. They are listed in order of presentation in the MCA and Code of Practice.

3.1 Shared decision-making

Shared decision-making refers to the continuous involvement of an individual in the decision-making process, whether or not they lack capacity to make the decision alone. It is perhaps the most commonplace aspect of the changes brought about by the MCA as it is used in everyday decision-making situations as well as in more complex decisions. The Code of Practice emphasises the importance of including individuals with and without capacity in the decision-making process and thus, all decisions should be made with the aim of engaging in a shared decision-making process.

3.2 Assessment of Capacity

The MCA and Code of Practice explain how and when capacity is to be assessed, which is through a two-stage process. Firstly, the cause of the inability to make the decision must be established as being due to a disturbance of the mind or brain, regardless of whether it is permanent or temporary. Secondly, in establishing an individual’s capacity, their ability to understand, retain, use and weigh up the relevant information presented to them should be assessed. Incapacity to make a decision can only be established if all practicable steps to help the individual to make the decision autonomously have been attempted without success. The individual must be unable to make the decision at the time the decision is required. A medical or psychological professional is not required to ascertain capacity but they are often involved in the assessment process. An assessment of capacity must not be done solely on the basis of a person’s age, appearance, condition or behaviour.

3.3 Best interests decisions, advocacy and surrogate decision-making

Best interests decisions relate to the method and focus of decision-making for an individual who lacks capacity to make a particular decision. Best interests decisions are one of the five primary principles of the MCA and are guided by the MCA and Code of Practice. The MCA specifies that any best interests decision must be made to reflect the views, opinions and cultural beliefs of the individual who lacks capacity to make the
decision, without the influence of personal preferences, beliefs or judgements of the decision-maker. The Code of Practice prescribes the continued involvement of the individual who lacks decision-making capacity, even if they are unable to make the decision autonomously. The decision-maker should also seek the advice of others who may know more about the individual's beliefs and wishes, such as relatives and friends, to inform the decision outcomes. All decisions made on behalf of another person should be made with as little restriction, or deprivation of individual liberties, as is practicable and any restriction must be proportionate to the degree of risk to the individual and/or others.

If the best interests process has been followed correctly by professionals the MCA gives them legal protection if they are providing care or treatments to an individual. Additional safeguards apply if this involves depriving the individual of their liberty (e.g. keeping them in hospital or a care home), known as the Deprivation of Liberty Safeguards (DOLS). Similar to assessments of capacity, best interests decisions must not be done solely on the basis of a person's age, appearance, condition or behaviour. In situations where there are no relatives or close friends who can provide advice on the individual's beliefs or wishes, the MCA requires the involvement of the Independent Mental Capacity Advocacy (IMCA) service.

The IMCA was created under the MCA to assist in important decision-making for vulnerable people who are unable to make the decision on their own and who have no one who can act as advocate for their best interests. Situations requiring IMCA services include decisions about change of accommodation and serious medical decisions. The IMCA's role is to find out and represent the views of the individual who lacks capacity. The MCA also established a Court of Protection which can deal with complex or disputed cases involving mental capacity. It has the power to appoint a 'deputy' who can be authorised to make decisions on behalf of someone who lacks mental capacity but they must do these in accordance with the best interests principle and procedures.

There is a mental capacity assessment and best interests online tool for professionals to retrospectively ensure mental capacity assessments and best interests decisions were done in line with the MCA (www.amcat.org.uk; www.bestinterest.org.uk). In addition to these websites, there is also an online forum (www.communities.idea.gov.uk) that provides a platform for discussions with other professionals that are involved to any extent with mental capacity issues, including issues with Deprivation of Liberty Safeguards.

3.4 Advance Directives, Written Statements and Lasting Powers of Attorney

Mental capacity legislation has provided the option for people to create an advance directive (also known as 'living wills') to prepare for the future possibility of incapacity. The MCA enables people to make advance decisions to refuse treatment, allowing an individual to make legally binding treatment-refusal decisions while they have capacity, relating to a situation that might arise in the future when they lack capacity. They can also be helpful to carers or relatives by clearly outlining personal wishes. They do not need to be made out in writing unless they dictate refusal of life-sustaining treatment.
The MCA also allows an individual to appoint someone else to make decisions on their behalf in preparation for future loss of capacity, known as a Lasting Power of Attorney (LPA). This is a legal document that must be registered with the Office of the Public Guardian allowing an individual to choose someone else (known as the ‘attorney’) to make specific decisions regarding financial, health and/or personal welfare matters. The chosen attorney must make any decisions according to the best interest principles.

Written statements are more general statements about preferences for care or treatment and are also made in preparation for a time when the individual may lack capacity. They can include preferences about day-to-day matters, as well as housing and care or medical treatment preferences. They are not legally binding in the same way as advance decisions to refuse treatment but they should be taken into account when making best interests decisions.

3.5 Research with people who lack capacity to consent

The MCA and the Code of Practice provide guidance on conducting research with people who lack capacity to consent to participation. It outlines the required ethical approval process and the respective responsibilities of researchers and the ethics approval bodies so that researchers and regulatory bodies are expected to balance the benefits of carrying out the research against the burden of effect on the participating individuals. They are required to consult the relevant carers or relatives on their views regarding the participation of the individual who lacks capacity to consent. While carers and relatives’ views are to be respected, they cannot provide consent or assent on another person’s behalf. Researchers are required to respect the wishes and feelings of participating individuals continuously throughout the research process, placing greater importance on the wishes of the participant than on the research needs of wider science and society.

4.0 DEMENTIA

Dementia affects around 750,000 people in the UK (Alzheimer’s Society 2007) and with an increasing ageing population, numbers are likely to rise. Dementia is a progressive neurological condition which entails a gradual overall decline in cognitive function, such as memory and reasoning abilities. It may include impairment of communicative abilities and mood disturbance and people in the later stages of dementia require additional care and support. As such, it may have a broad overall effect on the individual and their capacity to make decisions. The treatment and care of people with dementia has been greatly affected by the MCA.

4.1 Dementia and shared decision-making

Livingston et al (2010) collated family carers’ accounts of shared decision-making experiences which revealed problems with accessing help and difficulties in the consideration of care home placement. Problems were also reported by family carers in
dealing with legal and financial matters and in making health care decisions unrelated to dementia. Carers faced difficulties with making contingency plans should the carer fall ill themselves. Livingston et al’s methodology, presentation of findings, ethical process and discussions were thorough and some important questions were raised by the researchers as a result of these findings, such as whether doctors should always ask about gaining allowance to share medical information with relatives and how/when ADs should be introduced as part of standard practice. Livingston et al reported that advance directives were always adhered to but a recurring problem was late diagnosis so that creating an advance directive was often no longer feasible as the patient had already lost capacity to make such decisions. (Also relevant to advance directives. See section 4.4.1 for review of literature on advance directives.) The underlying difficulty throughout is that there is a need for far greater information and support for people with dementia and their families.

Conclusions - Dementia and Shared Decision-Making

Only one article related to dementia and shared decision-making was obtained for this review.

4.2 Dementia and Capacity Assessments

Two UK-based articles examined issues in capacity assessments for people with dementia. Menezes and Tadros (2008) surveyed care home residents which revealed that a large proportion of residents lacked capacity to make treatment decisions. They also found a high level of trust in the decisions made by medical professionals so that residents did not feel it necessary to question and discuss issues, such as treatment side effects. Menezes and Tadros reported a ‘paternalistic’ style of medical practice which failed to include residents in discussions on treatment options and decision-making.

Gregory et al (2007) identified correlations between specific cognitive functions and an individual’s capacity to create an Enduring Power of Attorney (EPA, a legal document that pre-dated Lasting Powers of Attorney but related exclusively to property and financial matters). The Mini Mental State Examination (MMSE), a standardised test of cognitive function, was administered and an EPA-specific capacity assessment was carried out which revealed positive correlations between the MMSE scores and the capacity assessment outcomes. While the MMSE is insufficient as a capacity assessment tool, strong positive correlations indicated that MMSE scores can be used as a measure of cognitive function in cases of disputed capacity to create an EPA (or Lasting Powers of Attorney).

McDonald (2010) provided a discursive evaluation of three approaches to carrying out risk assessments with people who may lack decision-making capacity. Under examination were legalistic, actuarial and rights-based approaches, and difficulties in practice were identified with the aim of contributing towards good assessment protocol. An issue identified was that the significance attached to a diagnosis was greater for junior professionals, who often perceived a diagnosis as supportive of their decision to assess capacity. More senior professionals, however, welcomed the freedom to assess patients,
irrespective of the patient’s diagnosis. Assessment of capacity was found to be largely used when assessing the individual’s capacity to make higher-risk decisions. They were also used in residential decisions, sometimes inappropriately overriding relatives’ wishes or decisions.

Social workers had been using capacity assessments outcomes to ensure patients’ rights and views were upheld, thereby acting as a mediator between patient autonomy and relatives’ views. Dilemmas in best interests decisions were primarily due to contradictions between views of the patient and the wishes of relatives. The authors concluded by ascertaining that MCA implementation can only be quality-assured if risk in decision-making is properly evaluated. They argued that implementing legislation on its own is insufficient to ensure good practice but that increased and regular training for professionals will bring about a cultural shift, inherently improving the way in which capacity assessments are made as well as any resultant action. Crucially, organisational pressures must be monitored to ensure they do not override more important legal and ethical principles in practice.

4.2.1 Dementia and Capacity Assessments - Non-UK

Braun and Moye (2010) presented a case study as an example of a thorough and accurate assessment of capacity to make medical decisions for a patient with moderate dementia and to outline the appropriate actions to be taken following capacity assessments. They emphasised relatives’ role in reporting unusual behaviours so that uncharacteristic decision-making can be identified. The patient’s ability to understand, appreciate, reason and express a choice regarding medical treatment was assessed and a standardised functional assessment of medical consent capacity was completed. Based primarily on impairments in judgement and reasoning, the patient was deemed to lack capacity to refuse treatment. Braun and Moye argued that the assessment outcome prompted a chain of events which demonstrated the optimal protocol for such an assessment outcome. Powers of attorney were enacted, the family were referred to the Alzheimer’s Society to improve their understanding and support, the patient’s mild depression was treated to improve medication adherence and finally, a neuropsychological evaluation was repeated a year later to provide updated recommendations.

An earlier study by Martin et al (2008) compared the higher order functioning skills of patients with Parkinson’s disease (PD) with and without dementia, in relation to mental capacity. Findings indicated that patients with PD, both with and without dementia, had some deficits in higher order functioning, suggesting that all PD patients’ mental capacity should be assessed so that appropriate support can be provided. Moye et al (2006) identified cognitive predictors of mental capacity in people with mild-to-moderate dementia. One in ten lacked mental capacity when seen initially and a quarter had impaired capacity nine months later. The method of assessment minimised demands on memory ability and aimed to maximise capacity performance as participants were able to refer to written information while making decisions. Problems were identified in understanding and reasoning, but not in appreciation. All participants with dementia were
able to express a choice and almost all communicated trust in doctors’ treatment decisions.

Similarly, Okonkwo et al (2008) investigated changes over time in the mental capacity of patients with mild cognitive impairment, which causes memory loss. A high proportion eventually developed dementia, causing functional impairment. Patients with mild cognitive impairment had significantly poorer appreciation, reasoning and understanding abilities but they did not differ from controls in expressing a reasonable choice. Declines emerged over time only in understanding, probably because understanding relies heavily on short-term verbal memory, which shows decline early on in most dementia-related illnesses.

A final study by Dreer et al (2008) identified the cognitive predictors of mental capacity relating to medical and legal decisions in patients with traumatic brain injury (TBI) compared to people with dementia. Understanding was the most clinically relevant measure of capacity to consent to medical treatment and was most likely to be impaired in patients with traumatic brain injury and dementia. The authors concluded that loss of short-term verbal memory appeared to be strongly associated with impaired consent capacity in moderately and severely injured TBI patients at the time of hospitalisation.

Conclusions - Dementia and Capacity Assessments

A study on capacity assessments for people with dementia revealed a ‘paternalistic’ style of medical care, indicating a need for cultural reform among many geriatric services. The Mini Mental State Examination was positively correlated with capacity assessments which indicated it may be used as an assessment of cognitive function in cases of disputed capacity. Caution was called for so that institutional pressures do not override legal principles, with training recommended as the route to ethical practice. Non-UK-based articles identified the cognitive predictors of mental capacity, with particular difficulties in understanding and reasoning associated with dementia. An example of good practice was presented which emphasised the importance of family in identifying unusual behaviours and outlined the correct procedure depending on capacity assessment outcomes.

4.3 Dementia, Best Interests Decisions and Advocacy

Boyle (2008a) provided discursive arguments against the use of neuroleptic drugs as a treatment for dementia symptoms. According to Boyle, neuroleptic drugs are over-prescribed, without consideration for best interest principles and in contravention of the MCA’s Deprivation of Liberty Safeguards (DOLS). Any deprivation of personal liberty must be proportionate to the level of risk posed if liberties were not deprived. Further, a person’s freedom of movement may be deprived only while it is needed. Boyle suggested that neuroleptic drugs are prescribed to control undesirable behaviour and for long periods of time but without the absolute necessity that would render it lawful, and therefore, that the rights of patient’s with dementia are frequently contravened.
Mapes (2009) evaluated, the Mental Capacity Advocacy Project, a volunteer-based service, which identified the difficulties in implementing advocacy services, such as confusion around when and how to assess capacity and who should make the assessment. Staff were not sure of their responsibilities, as outlined in the MCA, and they expressed confusion about service-user rights, entitlement and service provision so that patients often did not receive full quality care. Mapes called for more stringent processes to check that councils were appropriately using resources to ensure adequate care provision. It was suggested that there may be a significant divide between policy and practice so that policy does not necessarily reflect the reality of care provision and becomes difficult to implement in practice.

Manthorpe et al’s (2012) study explored staff difficulties in offering advice and information related to decision-making capacity. This qualitative study highlighted experiences, challenges and expectations faced by carers of people with dementia. Voluntary organisations such as the Alzheimer’s Society were the main providers of information and support. Issues for family carers with the Mental Capacity Act included “unhelpful” legal advisors and the cost of setting up Legal Powers of Attorney. Family carers were more aware of patient empowerment but were less aware of protection issues covered by the MCA. Suggestions were made that separate provision of support and advice would be warranted for carers and service-users as their needs differ greatly.

Boyle (2008b) evaluated how the MCA impacted on the health and social care of people with dementia, with particular focus on choice in residential decisions. Boyle differentiated between civil rights, propounded effectively by the MCA, and social rights. Boyle argued that if access to social rights are not enshrined in mental capacity laws, people with dementia will remain unable to demand access to civil rights. Specifically, this was applied to choice in care and accommodation which is often limited for people with dementia due to a lack of state provision for those who would choose to stay at home. Additionally, Boyle argued that the cultural tendency to view people with dementia as ‘incapacitated’ allows for overriding the decisions of people with dementia, particularly where resources are too limited to support autonomous choice.

Herring (2009) focused on the impact of mental capacity laws for people with dementia who have borderline scores on capacity assessments. He argued that best interests principles are more stringently followed with dementia patients who clearly lack decision-making capacity while those just on either side of the cut-off points are more likely to have their views and interests over-ridden. Herring argued this is due to inexact aspects of the MCA. Using hypothetical scenarios to illustrate, Herring highlighted difficulties and subtleties in making capacity assessments and the resultant decisions based on assessment outcomes. He argued that the wishes of a patient who lacks capacity are entirely disregarded and that this conduct is codified in law. Herring’s critical views on best interests principles serve to highlight gaps in the law which aim to protect vulnerable people who lack capacity.

Rather than focus on the effects or impact of the MCA, Hope et al (2010) focused instead on the approach taken in designing the MCA with arguments that it is incomplete. They suggested that best interests decisions are not defined sufficiently in the MCA and Code
of Practice, leaving too much room for personal interpretation. In this light, the interpretation of what is accounted for in best interests decisions is left to the substituted decision-maker. They argued that this approach cannot yield consistently positive results due to the reliance on any known facts about the patient’s beliefs and wishes prior to them losing capacity. The respective wishes and beliefs of the patient that are upheld is the prerogative of the decision-maker and may no longer reflect the feelings or wishes of the patient.

Put another way, if a patient’s wishes change following reduction in mental capacity, is it right to hold those wishes as less important than the out-dated but perhaps more socially acceptable wishes? Respecting present desires, Hope et al argued, should be the starting point from which decisions are made rather than those wishes made known prior to diminishing capacity. They asserted that professionals would benefit from guidance in the MCA about marrying best interests decisions with laws on advance directives and that information given in advance directives should be accounted for when making best interests decisions.

Martin (2009) argued that a ‘recovery’ approach to treatment has been popularised in recent years and should form the basis from which the MCA is implemented. He suggested that even in degenerative conditions, such as dementia, recovery should remain the focus of professionals' approach to health care. He suggested that if nursing practice follows this principle of recovery, the MCA will be more effectively assimilated into the culture of care delivery, with the views of those who lack capacity being more accurately represented. The Alzheimer’s Society (2009) produced guidance on the MCA specific to anyone who has received some level of training in the MCA and is in a health or social care role for a person with dementia. This comprehensive guide included examples of good practice and exercises to demonstrate how to go about making assessments and decisions.

Examples included how to support autonomous decision-making and promoting an understanding of the experiences of people living with dementia. The issues included how and when to assess mental capacity, supporting decision-making, making best interests decisions and making legal and medical preparations for future care. Forms and checklists, filled in according to fictitious case studies, demonstrated how to go about making assessments, best interests decisions and assigning Lasting Powers of Attorney to a person. In addition, a glossary of terms was provided to those less familiar with the MCA and further resources were listed.

Conclusions - Dementia, Best Interests Decisions and Advocacy

Articles that specifically investigated dementia-specific issues surrounding best interests decisions produced calls for more stringent checking systems for the medical treatment plans for people with dementia and for advocacy services. It was suggested that there is a divide between policy and practice though it appeared that the divide only exists between the expectations on staff and their level of training, which lends hope for bridging the gap with updated training and education. Suggestions included having separate dementia support and advisory bodies for carers and patients due their greatly differing
support needs. It was argued that the MCA may be incomplete in its ability to ensure social rights, as well as civil, are being applied. It would seem a greater emphasis on shared decision-making and patient involvement would assist in resolving many dilemmas. Several research papers lent support for this view, having argued that there is too much room for personal interpretation. However, it could be argued that more stringent guidance would leave less room for personalised, situation-specific judgements by professionals. Lastly, the Alzheimer’s Society provided an illustrative dementia-specific guide through the MCA.

4.4 Dementia and Advance Directives

Tillyard (2007) conducted a comparative review of the use of advance directives in the UK and the USA, revealing difficulties in evaluating UK practice as large gaps were found in the available research. Much of the information reviewed by Tillyard dealt with findings from the USA which allowed for comparative insight into problematic areas and successful methods of increasing the use of advance directives. A recurrent issue was that patients’ relatives did not always make existing advance directives available to medical professionals, indicating a need for a regulatory body that would ensure advance directives were made available to medical professionals and that they are followed to whatever extent is possible.

A further two articles investigated medical professionals’ experience and understanding of the MCA (Schiff et al, 2006; Wilson et al, 2010). Schiff and colleagues obtained the views and experiences of geriatricians in working with living wills which indicated overall satisfaction with advance directives as they simplified decision-making, removing the onus of sole decision-making responsibility from geriatricians. However, concerns were also reported as some doctors were apprehensive about being obliged to follow an advance directive if it was seen to be to the detriment of the patients’ long-term wellbeing. The most frequent concern expressed by geriatricians was that patients’ wishes would become inconsistent over time, and may later contradict their wishes laid out in a living will.

Unlike Schiff et al participant selection in Wilson et al’s investigation was not randomised and researchers recruited from a sample of people that were recommended by senior staff. Staff found it difficult to relate the content of patients’ ADs to relatives as the content sometimes contradicted family views, causing upset and difficulties between professionals and relatives. Nurses and other health care staff lacked confidence in explaining advance directives and Lasting Powers of Attorney (LPAs) to patients and their relatives and reported difficulties in understanding which best interests decisions should be documented, but they believed their current practice already reflected best interests principles.

4.4.1 Dementia and Advance Directives - Non-UK

Bird (2006) provided case studies to illustrate a breakdown of Australian law for medical practitioners. Suggestions were provided for medical practitioners regarding the
assessment of decision-making capacity prior to completing AD and Power of Attorney documents. Black et al (2009) examined how surrogate decision-makers for dementia patients in the USA developed an understanding of patient care preferences. Content analysis of semi-structured interviews revealed that the primary factor that promoted the creation of ADs or formally outlining End-of-Life care was to remove the burden of making difficult decisions from loved ones.

Black et al’s findings indicated that many patients did not realise the importance of ADs until it was too late, highlighting the importance of finding opportune moments to raise relevant issues with patients and their families. In practice, ADs seemed to act primarily as restrictions to health care provision, rather than documentation outlining what health care is desirable. For instance, the most common subject matter of ADs in this American study was to refuse life-sustaining treatment by “extraordinary measures”, referring to the more aggressive or invasive life-sustaining treatment options.

Lacey (2006) described nursing home social care staff roles and perceptions related to EOL medical decision-making with residents who had dementia. Almost all nursing home care staff were responsible for introducing ADs. More than three quarters of care staff perceived that they extended themselves beyond legal requirements and helped patients and families clarify their thoughts about life-sustaining treatment. 50% said they often or always discuss artificial nutrition and hydration options on admission but only 36% of staff divulged accurate knowledge of the risk of aspiration pneumonia with tube feedings, which indicated that nursing home social care staff need on-going training to function effectively as educators and provide support.

ADs and EOL care plans were highly valued by staff (91%) but the study revealed that the timing of introducing ADs can be problematic during the admissions process. Only 25% agreed that newly admitted residents have the cognitive capacity to complete health care proxy forms (similar to a powers of attorney document, granting decision-making responsibility to another person). Almost 50% of nursing home staff agreed that families are too overwhelmed at admissions to fully understand ADs. This diminished the value of early AD introductions, prompting recommendations for follow-up discussions which would produce better results, leaving more time from the initial introduction of ADs to the time when relatives and patients decide on the content of their ADs. 97% of social care staff took full responsibility for introducing and discussing ADs with dementia patients but only 45% agreed or strongly agreed that theirs was the discipline most suited to discussing ADs with residents.

Triplett et al (2008) identified the most common preferences outlined in ADs created by people with dementia. The most commonly expressed requests were for supportive treatments rather than aggressive treatments. Most ADs were advanced decisions to refuse life-sustaining treatment if in a persistent vegetative state, terminal condition or end-stage condition but ADs did not specifically state the treatments that were not wanted. Pain relief treatment requests were found in 48% of ADs; these were made even in cases where pain treatment would shorten their life expectancy. Triplett et al’s findings indicated that ADs are not comprehensive enough to cover many frequently encountered scenarios, further propounding the involvement of advocates or surrogate decision-
makers. In 41% of medical charts, a do-not-resuscitate (DNR) order was made but these were not included in the corresponding ADs. It would seem that only a minority of ADs addressed commonly encountered and important EOL issues faced by people with dementia. Recommendations were made for several scenarios, as a checklist, to be presented to the patient so that they are made aware of the various instances they can prepare for.

Volandes et al (2007) developed an intervention to assist in creating ADs by using video images along with discussions of advanced dementia to help patients to imagine scenarios that may require pre-planning. The use of videos was associated with dramatic changes in stated preferences for medical care. Participants reported feeling comfortable with watching the video and they indicated greater understanding of dementia and what to expect. Patients’ ability to accurately envision scenarios altered the content of their ADs so that uncertainty about EOL care was drastically reduced and comfort care requests (i.e.: palliative care) were significantly increased.

Volandes et al urged that the video images used in this way should be monitored and undergo an ethical approval process to prevent undue distress to the viewers. An additional suggestion was that video recordings could be taken to document ADs, rather than relying solely on written documentation. They suggested that using video recordings may increase the number of directives made and demonstrate the emotive context and particular emphases of the patient’s expressed wishes. In support of this assertion, Volandes et al (2009) found that agreement between doctors and surrogates predictions of patient wishes and actual patient wishes rose from 33% to 100% with the use of video documentation rather than written AD documentation.

Conclusions - Dementia and Advance Directives

The literature on ADs for people with dementia revealed that health and social care staff provided the main introduction to AD but they lacked the confidence and necessary training to deal with this role. Initial introduction of ADs was problematic and ineffectual so continuous discussion was recommended. The most common requests in ADs were pain relief preferences and refusal of life-sustaining treatment. The content of ADs was often inadequate which dictated the necessity for advocates or surrogate decision-makers. Video images to assist in creating ADs were highly useful, as was the use of video recordings to document ADs.

4.5 Dementia and Research Participation

Only non-UK articles were obtained which explored the involvement of people with dementia in research participation. Jefferson et al (2008) revealed that scores on neuropsychological tests were associated with mental capacity assessment scores. Differences in understanding between people with mild cognitive impairment (MCI) and people without MCI were identified, primarily in understanding the nature of the research project and its procedures. Memory was not associated with capacity to consent to research participation, possibly because memory was aided by encouraging participants
to refer back to the consent statement throughout the assessment. Executive functioning and information processing were more strongly associated with understanding, indicating that strategies to improve these functions would bolster capacity assessment outcomes.

Ravina et al (2010) evaluated research participants’ understanding of research consent information over the course of a clinical study. The relationship between consent information and participant behaviour was measured which revealed that the majority of participants with dementia understood the key aspects of the study, including random allocation and the chance of receiving placebos. Compliance and satisfaction were very high and years in education and cognitive function were associated with comprehension. It was suggested that participants’ understanding of the research process and design were increased through involvement in the research process. Striking discrepancies were identified between the excellent performances on 7 out of 9 items on the questionnaire. The latter two items on which performance was poorer related to the differences between research and routine care and the understanding of risks. A particular difficulty was in understanding the risks of participating in clinical trials and difference between standard treatment and clinical trials, raising important ethical issues about the inclusion of people with dementia in clinical research trials.

Conclusions - Dementia and Research Participation

Executive functioning and information processing abilities were most closely associated with impaired decision-making capacity in people with dementia. Consent information was a particular difficulty, prompting suggestions that interventions aiming to improve mental capacity should focus on these particular concepts. Research findings revealed that patients had a good understanding of most research-related concepts. It was proposed that patients may experience cognitive benefits through participating in research.

5.0 MENTAL HEALTH PROBLEMS

Mental health problems affect one in four people in the UK and can range from mild mental disturbance to severe and prolonged dysfunction. Some specific aspects of the MCA are particularly salient for people who have mental health problems such as the available option of (psychiatric) advance directives and the emphasis on shared decision-making and best interests decisions.

5.1 Mental Health Problems and Shared Decision-Making

Only non-UK articles were obtained which explained mental health problems and shared decision-making. An Italian paper by Goss et al (2008) evaluated patient involvement in treatment decisions within an out-patient psychiatric population sample. Patient involvement scores were poor with minimally attempted or minimally achieved patient involvement. Performance was dependent on patient and psychiatrist characteristics but
improved with the length of the consultation. Patient involvement was more likely when the psychiatrist was female, in a younger age group and/or had fewer years of experience in psychiatric practice. Patient gender was the only patient-based factor that was associated with patient involvement, with women being more eager to be involved in shared decision-making.

Psychiatrists’ scores on patient involvement were parallel with general practitioners scores on patient involvement. Some differences did emerge, however, between GP and psychiatrist patient involvement. GPs were more likely to explore patient concerns although demonstrating less skill than psychiatrists as psychiatrists explored patient concerns less often but with greater skill. It is worth noting that the researchers did not provide information on how ‘skill’ in exploring patient concerns was measured. The researchers identified an ‘idiosyncratic’ approach to involving patient in treatment decisions so that personal differences were more likely to have effects on care standards and styles, indicating a lack of specific patient-involvement training for psychiatrists.

Hamann et al (2009) carried out an evaluation of German psychiatrists’ views in shared decision-making, specific to the treatment of patients with schizophrenia. A self-report survey was conducted which revealed that more than half of the respondents regularly used a participatory style of decision-making and that they tailored their participatory approach to the individual patient needs. Contrasted with the findings from Goss et al, German psychiatrists’ expressed strong approval for involving patients and viewed patient participation as effective in achieving positive change within patients who exhibited poor compliance or had reservations about their treatment. The primary obstacle to shared decision-making was the patients’ impaired capacity. Increased likelihood of patient involvement was associated with decisions that related to psychiatric factors such as choice of antipsychotic medication (involving side effects), readiness for discharge and the use of antidepressants as additional or supportive medication. Psycho-education, decision aids, communication skills programmes and individual preparation of the patient for decisions allowed for increased patient participation in treatment decisions.

An American study by Mahone (2007) examined the medication-related decision-making experiences of people with severe mental health problems, rather than focusing on psychiatrists’ reports as the previous two studies. Mahone explored situations involving perceived coercion, mental capacity, preferences for involvement, actual participation, the outcomes of medication adherence and quality of life. 82% preferred a collaborative relationship with the prescriber while only 70% reported experiencing a collaborative participation. Encouragingly, 69% reported receiving the type of care they wanted, showing some level of effective patient participation which seemed in contrast with patient reports of their own amount of involvement.

An American study by Patel and Bakken (2010) explored anxiety and depression treatment preferences. Most patients chose a shared decision-making approach with women showing stronger preferences for involvement in decision-making (in line with the Italian findings by Goss et al, 2008). Cultural differences also emerged with Hispanics preferring a more passive role than non-Hispanic participants. Suggestions were made for reassessing preferences for the level of involvement in decision-making as it may vary
over time and dependent on the nature of the decision concerned. By offering the level of participation that the patient is comfortable with, communication is likely to improve, along with congruence and expectations about recovery by both patients and physicians.

Conclusions - Mental Health Problems and Shared Decision-Making

Articles relating to shared decision-making with people who have mental health problems were not UK-based but they nonetheless revealed potentially useful information for UK practice. The Italian study showed poor patient involvement, contrasted with the German study which found very high levels of patient involvement in treatment decision-making. Both studies evaluated patient involvement from the perspective of psychiatric professionals but the differences in findings between countries indicated strong cultural differences for psychiatric practice and the way they relate to patients. This was supported by an American study which found differences between ethnicities in the level of desired involvement by patients in their treatment decisions, with Hispanics desiring less involvement than non-Hispanics. The fourth study evaluated patient involvement from the perspective of the patients. High levels of patient involvement were found but patients’ participated in decision-making less with doctors than with nurses, suggesting that nurses are well-suited to the role of facilitating shared decision-making.

5.2 Mental Health Problems and Capacity Assessments

Overlap between the Mental Health Act 1 and the MCA pose ethical and legal dilemmas for many mental health practitioners and has been a topic of discussion throughout articles on mental health problems and mental capacity. The prevalence of psychiatric inpatients that lack mental capacity was measured by Owen et al (2008) which revealed that approximately 60% of inpatients lacked capacity according to outcomes on the MacArthur Competence Assessment Tool for Treatment (MacCAT-T), a standardised tool for assessing capacity to make treatment decisions. The prevalence of incapacity varied according to diagnostic category and was correlated with hospital admission status. Admission status refers to the reason for entry into hospital, either voluntarily or via compulsory detention under the MHA.

A further investigation by Owen et al (2009) also identified positive correlations between admission status and mental capacity but identified correlated characteristics of people refusing treatment. The MacCAT-T was administered and findings revealed that 37% of psychiatric inpatients that were admitted voluntarily had capacity; 24% of voluntarily admitted inpatients lacked capacity; 34% of detained inpatients lacked capacity; only 5% of involuntarily detained patients had mental capacity. Thus this study revealed higher numbers of inpatients who retained capacity to make treatment decisions compared to the earlier study by Owen and colleagues (2008). This further highlighted the necessity

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1 The Mental Health Act 1983 (covering England and Wales) was subject to a long process of reform that began in 1999 and culminated in Parliament passing the Mental Health Act 2007 which made significant amendments to the 1983 Act. The new legislation came fully into force in 2009.
for assumption-free capacity assessments to be carried out as standard procedure, regardless of admission and diagnostic status. It also highlighted the challenges faced by clinicians when overlap occurs between MHA and MCA legislation. Associations were identified between admission and capacity status so that those who were detained under the MHA were less likely to have capacity to make treatment decisions.

Maxmin et al (2009) investigated correlates of capacity assessment outcomes but focused on older psychiatric inpatients. The MacCAT-T was again used as a standardised assessment tool although additional clinical assessments were conducted, increasing the real-life relevance of these findings. The study revealed that diagnostic category was the most important predictor of incapacity. Psychosis proved a stronger predictor of incapacity compared to depression and patients with dementia all lacked capacity, with the exception of one patient. The authors suggested that as many as 75% of inpatients were unlawfully detained as they were there voluntarily but lacked capacity to make treatment decisions. A potential issue with this study was that as the participant sample contained older inpatients, many of whom had severe mental health problems, comorbidity was likely to be fairly high (e.g. Jeste et al, 1996, identified high rates of comorbid disorders among older people with mental health problems) and may have impacted on mental capacity assessment outcomes.

A study investigating capacity assessments for psychiatric inpatients identified contextual factors that influenced assessment outcomes (Olumoroti et al, 2007) but differed from the aforementioned research in that it focused on psychiatric practitioner factors, rather than inpatient factors, that are associated with assessment outcomes. Psychiatric practitioners were asked to make a capacity judgement about a self-harming patient described in a hypothetical vignette. The primary factor influencing outcome decisions was psychiatric specialty, with specialist old-age practitioners least likely to find in capacity and psychotherapists most likely to find mental incapacity. These findings indicated there is a culture or trend within psychiatric practice that varies according to the area of specialisation. An issue which may have affected the real-life relevance of the results was that the capacity judgements were made based on vignettes and no opportunity for consultation was given. In real life settings, practitioners would likely seek second and third opinions should there be any doubt about capacity judgements. A potentially disquieting finding was that psychiatrists made surgery-based treatment decisions without the specialist knowledge required to make such a decision.

More recently, Lepping (2011) examined the use and outcomes of mental capacity assessments which revealed that senior medical and psychiatric staff frequently overestimated their patients’ mental capacity. Lepping argued that the MCA is insufficient in its effects on practice within healthcare service delivery and called for more stringent tests of mental capacity. However, Okai et al (2007) determined that mental capacity constructs can be reliably assessed using standardised assessment tools after having carried out a literature review of 37 research papers which identified the reliability of mental capacity assessments. They identified high inter-rater reliability, indicating that the use of capacity assessments had been sufficiently standardised to ensure consistency between those carrying out assessments. Although, Okai et al also found that standardised assessments lacked specificity and tended to produce false positives; in
other words, they were more likely to find someone lacked capacity when they in fact retained mental capacity. Clinicians were less likely to find a patient lacked capacity compared to other professional groups.

Perhaps surprisingly, occurrences of incapacity were no more common among psychiatric patients as among general medical patients. This indicated most psychiatric patients retain capacity to make their own treatment decisions. Highlighting important implications for mental health legislation, many patients detained under the Mental Health Act 1983 maintained capacity to accept or refuse hospital admission. The high frequency of psychiatric patients who retained mental capacity suggested the need for careful examination of mental health laws and the assumptions they make about the extent of impairment that accompanies mental illness. Suggestions were made for further research into the frequency and consequence of "overriding capable decisions regarding treatment". Finally, only clinical factors were associated with incapacity, such as psychosis and symptom severity.

Shah et al's (2009) pilot study offered a snapshot picture of successful implementation of the MCA within geriatric psychiatry. Findings were encouraging, with assessment protocol largely following the guidance in the Code of Practice. Senior consultants carried out most mental capacity assessments which led to concerns that this may increase the workload of consultants. Most assessments procedures were well-documented and due consideration was given to the wishes of the patients and their relatives. In making best interests decisions, consultants largely propounded the least restrictive and least invasive treatment options and in cases with patients from BME groups, cultural and linguistic barriers were catered for. Shah et al advised caution in the interpretation of these positive results due to the non-systematic approach taken with participant sampling. It may be concluded, however, that in the field of geriatric psychiatry, the MCA has been effectively implemented and professionals demonstrated understanding of the underlying principles to apply the less defined concepts with the MCA into ethical practice.

Shah et al (2010) reproduced similar findings to those above as they found consultants carried out most assessments, again prompting concern about the resultant increase in their workload and consequently, the quality of care delivery. While the majority of professionals participating in this study had received some training, training was mandatory for less than 50% of professionals. This raised questions about the generalizability of the knowledge and good practice of professionals demonstrated in this study. As in the previous study, the four primary concepts of mental capacity listed in the MCA were given consideration in assessment protocol, demonstrating that professionals hold good understanding of MCA principles.

5.2.1 Mental Health Problems and Capacity Assessments - Non-UK

Kornfeld et al (2009) evaluated mental capacity assessments within American psychiatric hospitals and revealed that 64% of requests for capacity assessments were due to the patient threatening to leave the hospital against medical advice, or refusing treatment or procedures. This raises questions about the predominant uses of capacity assessments
as a means for controlling 'unruly' patients. Psychiatric consultants suggested that 44% of referrals for capacity assessments were due to patient behaviours that reflected fear, anger or both.

Schneider and Bramstedt (2006) investigated instances of disputes over mental capacity assessment outcomes. They argued that differences in the meaning of ‘competency’ (American terminology, roughly equivalent to the UK term ‘capacity’) between bioethicists and psychiatrists were the cause of differing assessment outcomes. Disagreements were more likely to occur following an assessment outcome of impaired capacity and when determining the protocol that should follow. Disagreement was particularly salient when decisions were about involuntary detention. Schneider and Bramstedt concluded with recommendations that the skills sets and perspectives of both bioethicists and psychiatrists should be utilised which will ultimately lead to a more sound ethical practice. Recommendations were made for bioethical training for psychiatrists in care teams where bioethicists are not included to increase knowledge and concepts of healthcare values.

Conclusions - Mental Health Problems and Capacity Assessments

The above articles revealed a high proportion of mental health inpatients lacked capacity and those detained under the MHA were more likely to lack mental capacity. Diagnostic category was strongly associated with incapacity, as were psychiatrist factors, such as their field of specialisation. A literature review determined the high reliability of standardised capacity assessment tools, with factors of psychosis and symptom severity most closely associated with mental incapacity. Professionals’ training in the MCA was not mandatory for approximately half of professionals involved in assessments but the findings indicated that professionals made appropriate decisions regarding assessments and the resultant actions taken. Suggestions were made for coordinating discussions between bioethicists and psychiatrists to ensure that good medical practice and ethics combine effectively.

5.3 Mental Health Problems and Best Interests Decisions

Sen et al, 2006 investigated best interests decisions for people with severe mental health problems. They analysed two case studies that provided a platform for discussions on ethical dilemmas that accompany best interests judgements within psychiatric care. The use of physical restraints was ethically evaluated with discussions on balancing potential risk against the benefits of treatment for the patient. It was suggested that while psychiatric care principles may be sufficient for most care situations, they fall short in the practice of forensic psychiatry where the considerations for public and patient welfare are particularly compelling and problematic.

Fennell (2008) discussed difficulties for practice in marrying the responsibilities laid out in the MHA and those of the MCA, including a difference in emphasis on patient rights and autonomy between the two pieces of legislation. Best interests principles were said to be regrettably open to personal interpretation. Fennell acknowledged that while personal interpretation of best interests principles allows room for more individualised health care,
it also leaves ample room for replacing patient interests with public interests, particularly in judicial cases where the MHA may be invoked to detain patients or enforce treatment against patient wishes. The similarities between the two laws were presented in light of how much room the MCA yet allows for compulsory detention or treatment, suggesting that best interests principles leave excessive room for decision-making that is culturally biased and could be argued to not concur with the patients' best interests.

Owino (2008) carried out an examination of the use of lawful restraint and particular attention was given to what is meant by proportionate response as the law dictates that any restraint deemed necessary must be proportionate to the risk of harm. Owino clarifies that ‘harm’ in this legal sense does not necessarily imply physical harm but can also be risk of financial or psychological harm. Further, the MCA dictates that restraint may only be used for “the shortest possible time”. The European Convention on Human Rights and the MCA have made distinctions between restriction of liberties and deprivation of liberties, though the distinction can be quite subtle, causing difficulties for people required to make decisions concerning restraint. Owino cautioned professionals in ensuring any use of drug treatments to restrain a person is appropriate as such actions may result in charges of illegal conduct. Professionals are liable for the length of time and the effects (however unpredictable) of any drug induced restraints, such as deep sedation which may become unexpectedly prolonged.

Owino suggested that the MCA has not made fundamental changes to psychiatric practice and cautioned professionals that the MCA does not make allowance for the deprivation of liberties of a patient who lacks capacity. Further, he argued that as the MCA is based in abstract ethical principles, such as ‘best interests’ and ‘proportionality’, it lies with vulnerable patients and their representatives to ensure professionals make lawful use of legal provisions for restraint through access to the justice system and increased dispersal of education in patient rights.

Webb et al’s (2009) case study provided a platform for discussion related to ethical issues arising during treatment of mental illness. In this case study the patient (who had an eating disorder) refused life-sustaining treatment but patient wishes were unheeded as legislation under the Mental Health Act, which allows for compulsory feeding, overrode mental capacity legislation. The article highlighted specific difficulties in treating people with eating disorders who refuse life-sustaining treatment, including questions about the patient’s capacity to make such a decision. As the patient in this case study had not made an advance directive, doctors were reluctant to face the legal consequences of following the patients’ treatment-refusal decision. It was suggested that many problems would be resolved if PADs were created beforehand, leading to calls for more emphasis on encouraging patients to create PAD during periods of remission. Further research is needed which investigates the interaction between ethical issues in treating patients detained under the MHA, patient rights and practitioner responsibilities.

Conclusions - Mental Health Problems and Best Interests Decisions

The four articles included in this section evaluated the area of restraint and compulsory treatment, with arguments that the differences between the MCA and the MHA are subtle
enough to cause confusion for professionals. Greater emphasis on patient rights was advised with cautionary advice that unlawful restraint of a patient, including that induced though medication (e.g.; sedatives), may result in legal liability if inappropriately prescribed. These highlighted the importance of thorough training, both for the sake of professionals and the patients they care for. It was advised that greater emphasis should be placed by professionals on creating psychiatric advance directives during periods of remission or recovery to assist decision-making when complex ethical dilemmas arise.

5.4 Mental Health Problems and Advance Directives

A mental health advance directive or psychiatric advance directive (PAD) is a document outlining health care preferences specific to psychiatric treatments and can be created during periods of remission or improved mental capacity. Reilly and Atkinson (2010) examined the content of mental health advance directives that were used in mental health tribunal hearings in Scotland. They found that the majority (96%) of advance directives included at least one specific refusal of a treatment option. Almost half also stated the preferred treatment options but many did not state the reasoning behind their preference. Many of the advance directives were used to detail medication history in relation to their treatment refusals and 55% gave information about preferences not directly related to ‘treatment’, in its medical definition. This raised questions about what is meant by the term ‘treatment’. It appeared that advance directives are used for broader purposes than strictly stating medical treatment preferences and were being used to include preferences about setting and support. This has the potential for difficulties as, on the one hand, advance statements provided a personalised history for health and social care professionals; on the other hand, clinicians and tribunal hearings faced difficulties in honouring advance statements that detailed an increased complexity and range of stated preferences.

5.4.1 Mental Health Problems and Advance Directives - Non UK

Campbell and Kisely (2009) conducted a review from Canada of the effects having PADs compared to standard care for people with mental health problems which revealed that PADs are most often used in End-of-Life care decisions. A small study revealed fewer admissions in the PAD group, offering encouragement for further study. Patients with PADs were less likely to be involuntarily detained and were less likely to commit an act of violence. One study identified in the review indicated that PADs acted as tools for empowerment and self-determination but that limited knowledge of PADs among service providers and difficulty communicating PAD information to inpatients limited their value. Campbell and Kisely lamented that there were too few studies which investigated the effects of PADs, prompting calls for further research. Findings from the review indicated a need for more intensive interventions, such as joint crisis planning for people with mental health problems, which may reduce involuntary admissions.

A study by Elbogen et al (2006) elicited attitudes towards PADs from mental health professionals, including psychiatrists, psychologists and social workers in the USA. 47% viewed PADs as helpful and attitudes became more positive once it was reiterated that
psychiatric professionals were not required by (American) law to follow PADs if they request refusal of appropriate and unnecessary treatment. Respecting PADs was associated with professionals’ high regard for patient autonomy, legal knowledge and valuing family opinions about treatment decisions.

Elbogen et al suggested that increased knowledge of legal processes would assist psychiatric professionals in dealing with scenarios involving disputed prioritisation of patient care values. PADs may also promote self-determination in patients, producing a therapeutically rich opportunity in which to engage in shared decision-making between professionals and patients, which itself may enhance working alliances and treatment adherence. Differences were also found between three psychiatric-based professions; psychiatrists placed greater value on family opinions, therapeutic alliance and patient insight than the other two professional groups. Psychologists and social workers were more likely to endorse respect for patient autonomy compared to psychiatrists. This highlights difficulties and varied emphases considered by professionals, which is dependent on their area of specialist training and experience.

A further study by Elbogen et al (2007) measured the effects of PADs according to doctor and patient perceptions. PADs were found to assist doctors with medically relevant information which proved useful in instances of crises. Patients reported high levels of satisfaction with PAD intervention and expressed appreciation with receiving assistance in completing PADs. PADs increased a sense of autonomy at 1-year follow-up. The strongest predictor of perceived self-determination was ethnicity so that African-American groups reported a significantly increased sense of autonomy at the end of the study period. PADs also served to alter clinician treatment decisions as they had a better understanding of the patient which went beyond specific mental health issues. A point of weakness in the use of PADs was that patients sometimes failed to inform their clinician of an existing PAD. This led to recommendations that doctors should routinely check for any existing PADs, prior to making treatment decisions.

Another American study by Srebnik and Russo (2007) examined the consistency of crisis care with PADs. They found that care was consistent with ADs and PADs in two thirds of cases. Inconsistencies between PADs and actual treatment usually related to preferences between hospitals, alternatives to hospitalisation and preferences regarding seclusion, restraint and sedation. However, in regards to medication, pre-emergency de-escalation methods and types of hospital-based alternatives, PADs were more likely to be followed. Non-treatment-related preferences were generally respected as well. However, advance directives were only accessed in 20% of cases. When surrogate decision-maker were involved, ADs were more likely to be accessed but less likely to be followed.

Van Citters et al (2007) produced an exploration of methods to improve the use of PADs by using hypothetical scenarios as a means of eliciting treatment preferences in compulsory care. Involuntary treatments, such as medication, injections and seclusion or restraint were supported by over two thirds of participants. ECT (electroconvulsive therapy), however, was supported by less than a third of participants. A barrier to creating PADs was the high number of patients who required non-technical assistance with creating PADs (44%) and 35% wanted help from a case manager. It was suggested that
by using hypothetical scenarios, psychiatric patients held greater insight into the various treatment options. Patients were able to ask questions which assisted in psychoeducation and facilitated active discussion about treatment options and preferences.

It was suggested that this method can serve to reduce patient anxiety and set the stage for deciding on an appropriate surrogate decision-maker. Patients predominantly preferred methods for de-escalating crises over ECT (32%) although patients were more likely to accept ECT treatment if their life was in danger (60%). Other means of involuntary treatment were deemed acceptable such as medication injection (76%) and seclusion and restraint (73%). The authors concluded that that PADs provide a feasible, acceptable and useful standardised approach and that people with severe mental illness are able to designate treatment preferences in response to hypothetical scenarios.

Van Dorn et al (2010) produced a more recent review of the ways in which social workers can facilitate the use of PADs. The authors suggested that as the training given to social workers remains outside the traditional medical model of care, they are well-suited to a role of advocacy for patients. The role of facilitating and creating PADs requires skills in advocacy and negotiating the PAD content within settings where the traditional medical model is more common. Social workers were in need of training in PADs which should be included in the standard social work training curriculum. Course content should emphasise patient-centred care within the context of a therapeutic alliance, discussed as a crisis planning tool and also as a tool for social justice.

A final study from the USA by Wilder et al (2007) examined the reasons for refusal of treatment in PADs and whether the reasons given in PADs influenced doctors’ adherence to PADs. Based on hypothetical scenarios, 22% of clinicians said they would follow a PAD, even if the reason for treatment refusal was bizarre or delusional. When reasons given were deemed reasonable, 72% said they would comply. The authors suggested that reasoning behind treatment refusals may explain the low rate of PAD compliance identified in other research. If patients are seen as having failed to take factual issues into account, such as side effects or personal safety, their requests are less likely to be respected.

Conclusions - Mental Health Problems and Advance Directives

One UK study carried out research into Scottish ADs which raised questions about the degree of specificity of information that should be included in an AD as too many specifics have been difficult to adhere to. Too few specifics, on the other hand, meant that ADs were not used to their full extent, leaving many of the patient’s wishes unknown. American research evaluated crisis planning in relation to creating PADs and found that interventions should be more intensive. PADs promoted a well-rounded understanding of patient needs and a sense of autonomy in patients, who reported high satisfaction ratings in their experience with PADs. Four articles identified a lack of legal knowledge in psychiatric and social work professionals, leading to calls for increased legal training. Social care staff were perceived as highly suited to a role of introducing and facilitating completion of PADs.
5.5 Mental Health Problems and Research Participation

Only non-UK articles were obtained which evaluated research participation of people with mental health problems. American researchers Candilis et al (2008) obtained comparative data between psychiatric patients, medical patients and healthy participants in their capacity to consent to research. Cognitive capacity, physical functioning and diagnostic outcomes had the greatest impact on mental capacity. 69-89% of severely mentally ill participants demonstrated good mental capacity. Cognition, education and psychosis remained the primary factors related to mental capacity for consent to research participation. The authors suggested that assessments should consider the effects of emotional and physical functioning on capacity. Common vulnerabilities among psychiatric groups warrant the continued attention of investigators to identify the full range of variables that impact on mental capacity.

Kim et al (2007) evaluated a standardised method of assessing capacity to consent to research participation with people who have schizophrenia. This produced calls for a higher cut off point in capacity assessments when consent is given to participate in clinical research trials, compared to non-clinical research participation. Flexible but stringent methods were advised that meet the ethical requirements of the situation and Kim et al argued that rigid adherence to a formula will not yield desirable results.

A study from the Netherlands was carried out by Welie and Berghman (2006) which made comparisons between the Dutch and the UK system of research participation protocol. They argued that the Dutch system is clearer and more straightforward than that used in England and Wales. This is because in the Netherlands, research involving people who lack capacity to consent is not allowed, except in two specific types of research; when the research is therapeutic in its effects on participants and when the research could only be carried out with people of a particular group who lack capacity. Proxy consent is allowed under Dutch law and they may include a legal representative, immediate family members, or an attorney (not dissimilar to the MCA Powers of Attorney). However, refusal by the patient takes precedence over proxy approval.

The authors suggested that, at least theoretically, there is no reason that ADs could not also extend to preferences for involvement in clinical trials or any form of research. Welie and Berghman suggested the MCA is further complicated by having no definition of legal guardians for healthcare purposes. Relatives are not in a position to give valid consent on behalf of the patient and the general criterion for substitute decision-making lies in the best interests principles, which is difficult to interpret. Contrasting Kim et al, Welie and Berghman suggested that the standards for establishing mental capacity are too high and should be lowered for participation in scientific research, as even important decisions that people with capacity have to make are not always made systematically and with accurate information processing.

The high standards for participation in research seem to be due to the assumption that research is not primarily towards the interests of the participant and the information regarding the research protocol and consent may be more abstract and so requires higher levels of reasoning and understanding. Suggestions were made for enhancing
participants’ capacity, which would then provide direct benefits to participation in research. As capacity status is not a static measure, it would ensure that a larger number of mental health patients are able to participate in research. To promote transparency, Welie and Berghman called for full description in research publications of the informed consent process, the capacity assessment tools and protocol, as well as issues around risks and burden for participants. They argued that transparency is crucial due to public concern over research with vulnerable people and they emphasised that public support is essential for the protection of research participation and for the progress of science.

Conclusions - Mental Health Problems and Research Participation

Only non-UK-based articles were obtained relating to the recruitment of participants who have mental health problems. They revealed that almost 90% of mental health patients had mental capacity, which was associated with cognition, education and psychosis. Suggestions to include emotional state and physical functioning in capacity assessments were made as these factors are likely to impact on capacity status and may influence fluctuating capacity. Differing cut-off points for capacity assessments were suggested for clinical and non-clinical experimental research participation. It was suggested that ADs could include advance refusal or acceptance of research participation. The provision of exercises to enhance mental capacity as part of the consent process would allow for more eligible participants who can then receive direct benefit from participation.

6.0 LEARNING DISABILITIES

Learning disability is an umbrella term that describes the difficulties faced by 1.5 million people in the UK who present differences in brain development, causing difficulties in learning, understanding and/or communicating (www.learning-disabilities.org.uk). The organisation, Mencap, revealed that 58,000 people with learning disabilities are supported by day care services while less than half have a choice of where they live. 75% of general practitioners receive no training to help them treat people with learning disabilities and the population percentage of people with learning disabilities is expected to rise by 8% within the next 5 years. As such, people with learning disabilities make up a large proportion of the UK’s vulnerable population and their care is guided significantly by mental capacity legislation.

6.1 Learning Disabilities and Shared Decision-Making

Antaki et al (2008) investigated the processes of involving people with learning disabilities in everyday decision-making. Several problematic areas were identified in shared decision-making processes in residential care homes but for the most part, staff made every attempt to include residents in the decision-making process. In accordance with the second statutory principle outlined in the MCA, all practicable steps were taken to assist residents to make the decision autonomously. However, Antaki et al suggested, that regularly offering choice wherever possible may conflict with staff responsibilities to meet
institutional requirements, such as keeping to a timed schedule and acting in line with health and safety regulations.

Some potentially problematic practices were identified such as ambiguity in the choices available to care home residents and, when clarifying choices, staff may have been leading or influencing the resident’s answer. This report provided a good description of the style used in shared decision-making in care homes. However, it was not systematic enough to be generalisable and the sample size was very small (five participants). Conclusions highlighted the difficulties often faced by care home staff as the ideals outlined in policy are sometimes not translatable into practice and staff practices are likely to fall short of ideal practice.

More recently, Dunn et al (2010) examined everyday decision-making in residential support scenarios involving people with intellectual disabilities. Attention was drawn to gaps occurring between procedure and principle, an echo of the difficulties identified by Antaki et al. Dunn et al suggested that the problem with personalised care lies within the institutionalised nature of care homes rather than due to insufficient training of staff. So-called ‘person-centred’ planning was lamented by staff as producing an environment where a person’s whole life and person is summarised into a 10-page document from which all decisions are to be made. The ‘person-centred’ approach was viewed by support workers as a reflection of, rather than a challenge to, the institutional nature of care home life which has historically been characterised by a poverty of experience.

Frustration at the institutionalisation of care homes which disallows genuine efforts to provide more ‘normal’ experiences for care home residents was reflected in an example of a trip to the local pub that was prevented due to stringent health and safety regulations. Staff argued that normal experiences in life should include an element of risk-taking, less repetition and more opportunity for socialising. Dunn et al argued for a reconfiguration of the MCA framework, which is aimed at being broadly generalisable across situations and therefore often producing contextually inappropriate decisions. In addition, calls were made for a continuous revision of care plans which should be relationship-centred and focus on the quality of the support provision process.

A study relating to the shared decision-making process with people with intellectual disabilities cross-culturally examined the sufficiency of communication training received by social care staff in the UK and Canada (Rowland & McDonald, 2009). Efficiency of training was specific to care of aphasia patients. Aphasia is a moderate to severe language disorder that can develop as a result of brain injury or illness such as stroke or dementia. Findings indicated that standard communication training was sufficient and should be incorporated as part of health and social care training, either at pre-qualification level or perhaps as part of an in-work training programme. This would reduce the number of best interest decisions required as efforts to communicate by patients would be better understood.

Finlay et al (2008a) argued that residential services for people with learning disabilities experience a divide between policy and practice so that they are not mutually reflective. Finlay et al focused on the “power” element of communication, suggesting that good
practice which promotes inclusion and autonomy can only be achieved by eliminating the power imbalance reportedly observed as routine in interactions between residential staff and residents. It was evident that the disempowerment of residents with learning disabilities was influenced by policy which was target-based and offered limited time-constraints. These, Finlay et al argued, were barriers to good practice which should allow residents as much time and choice in how they spend their time as is afforded to anyone without a learning disability.

It would appear that policy stands as the biggest obstacle to genuinely shared decision-making, largely because it fails to reflect realistic or naturalistic environments and are evidence-based, focussed on record-keeping. The authors argued that steering choice, offering deliberately limited choice and asserting time constraints on the decision-making process of residents serves to implement an unnecessary and unethical power imbalance. Finlay suggested further training as residential staff often lacked awareness of the effects of their communicative style and strict adherence to policy.

Scope (2009a) investigated the experiences of young adults with multiple and profound learning disabilities with aims of identifying the MCA’s impact on decision-making processes. Findings demonstrated an over-reliance by social care staff on determining capacity based on the complexity of support needs of an individual. Despite this, staff clearly understood their role in making best interests decisions and the underlying principles when making best interests decisions. Most staff had received training in the MCA but issues remained regarding effectively applying it. Staff often gave precedence to parents’ or carers’ views over the individual, sometimes irrespective of the individuals’ capacity to decide autonomously.

Doctors’ instructions were also enforced or supported by social care staff which often overrode or did not account for the resident’s decision. Staff did not use assessments as frequently as might have been preferable, viewing best interests decisions as the inevitable next-step if an individual showed signs of being unable to decide on their own. Staff usually had good working relationships with the individuals they supported and would benefit most from gaining further understanding of assessment requirements and protocol as it was suggested that likely many individuals with learning disabilities had decisions made on their behalf which they could have made for themselves, or with some level of assistance.

It was argued that the MCA will only be fully implemented if service-users are made aware of their rights and have access to the justice system so that service-user training in the MCA was recommended. This would also serve to further empower service-users, leading to greater autonomy. The authors noted that as the sample of service-users were young adults, transitioning from adolescence to adulthood, there may likely have been an increased tendency to ‘baby’ the service-user, with both parents and staff maintaining their protective relationship. This highlighted inherent difficulties specific to people with complex support needs who are undergoing the transition into adulthood.

Stanley et al (2008) explored how the five primary principles of the MCA have been applied in day-to-day decision-making and how they impact on everyday experiences for
people who have learning disabilities. They reported that many health and social care agencies have introduced record-keeping of capacity assessments, best interests decisions and other details about individual care preferences into standard practice. This demonstrated an overall shift in the way in which the opinions of people who lack capacity are considered. Challenges identified by staff reiterated findings that time, training and resource constraints prevented full implementation and acted as barriers to placing greater importance on service-users rights and wishes.

Stanley et al suggested that instilling greater openness to scrutiny will allow for improved practice. Decisions about day-to-day care, the authors concluded, will only become more inclusive of service-users views through increased awareness and a cultural shift rather than through strict adherence to policy or the Code of Practice. They suggested that as everyday interactions and decision-making rely more on having good interpersonal relationships and understanding the individual, public discourse about autonomy will likely be the most effective route to a greater personalisation in service-provision for people with learning disabilities.

An in-depth exploration of the dynamics involved in decision-making with people who have learning disabilities was produced by Smyth and Bell (2006), with particular focus given to choices about food. They identified how carer-based factors and past experiences influenced decision-making outcomes, including affecting what ‘choices’ were offered to decision-makers with learning disabilities. The main service-user-based factors that were found to impact on decision-making were cognitive ability, lifestyle, past experience of making choices, degree of dependency, physical ability, oral health and genetic and physiological factors. Some of these factors impacted decision-making abilities indirectly, such as high rates of poor oral health in people with learning disabilities. Poor oral health indirectly affects choice about what to eat and may cause difficulties for carers if service-users routinely choose sweetened snacks or other unhealthy eating choices.

Of heightened importance was the necessity for staff to have training and understanding in ensuring choices are fully explained in a way that the decision-maker can assimilate, with careful explanation and teaching extended to the decision-making process. Smyth and Bell suggested that by incorporating a teaching element to decision-making, people with learning disabilities who are cared for will increase their own knowledge of healthy decision-making. This may serve to prevent difficulties in marrying duty of care with facilitating autonomous decision-making. Further, in respect of food choices specifically, by providing an environment that is predominantly facilitative of healthier choice, education and good habits can be encouraged without eliminating the element of choice from daily interactions.

Williams et al (2008) used a novel approach to investigating the views and experiences of people with learning disabilities by recruiting an individual with learning disabilities to assist in designing and delivering workshops, from which data was extracted on the experiences of participants, all of whom had learning disabilities. Focus group-type discussions were held throughout 3 day-long workshops and participants were also provided with information on the MCA and how it affects them. Visual maps were created
by participants through the collation of participant experiences. Participants related experiences of needing to ‘prove’ they had capacity before being ‘allowed’ to make major decisions, with incapacity as the presumptive viewpoint of professionals and relatives. Participants, however, told of major decisions they were able to make when given the chance. In addition, when decisions could not be made independently, rather than supporting the individual to decide, the decision was instead taken away from the individuals with learning disabilities and made on their behalf, sometimes without reflecting their views.

Crucially, these surrogate decisions were often not made in the best interests of the individuals with learning disabilities and were sometimes not aimed at achieving the least restrictive option. Unwise decisions were frequently confused with incapacity to decide and opportunities for supported, independent living were overlooked. The authors demonstrated that each of the 5 primary principles of the MCA were starkly contrasted with actual practice, prompting the assertion that attitudinal barriers to promoting right to autonomy and independence “lie at the heart of Learning Disability services” (p. 21). Participants highlighted the many smaller decisions that are often inherent in any major decision which emphasised how breaking down major decisions can enable people with profound support needs to continue making decisions about their own lives.

**Conclusions - Learning Disabilities and Shared Decision-Making**

Recommendations were made for continuous reviews of care plans to ensure individualised care is provided and for communication and teaching training to be incorporated into training for paid carers. It was suggested that service-users would benefit from the introduction of a teaching element into shared decision-making processes so that the service-user can gradually achieve greater autonomy in making decisions. A divide between policy and practice was observed in all the above reports, which was reflected in frustration expressed by staff who evidently aimed to provide a stimulating and varied environment. It was argued that more regulation is not needed but rather more freedom for staff to act and make allowances with their time and provision of activities. In addition, a cultural shift will bring about the necessary personalisation and sensitivity required to enable people with complex support needs to maintain a supported but independent lifestyle. Time, resource and training constraints were repeatedly presented as the main barriers to good practice in shared decision-making processes. Workshops with service-users who had learning disabilities provided learning about their views and experiences when making decisions. Service-users reported that shared decision-making was not promoted sufficiently and surrogate decisions were made unnecessarily. They suggested that shared decision-making processes should focus on breaking down larger decisions which would ultimately enhance independent decision-making abilities.

**6.2 Learning Disabilities and Capacity Assessments**

Willner et al (2010) found that even highly qualified social care professionals lacked confidence in assessing mental capacity, with 15% believing that a specialist would be
required to make a capacity assessment. 80% were unable or unwilling to make a capacity decision in a hypothetical situation and of those that did make a capacity decision, only 17% provided correct justification for assessing. 57.5% believed that the outcome of an individual’s decision should be considered when assessing capacity which contravenes the MCA. Willner et al asserted that these are common misunderstandings among clinical practitioners.

37.5% were unaware that after an assessment has determined that a person lacks capacity, any resulting financial decisions must be made in the individual’s best interests. With medical decisions, the percentage of practitioners who were unaware of the requirement to make best interests decisions lowered to 12.5%. Recommendations to improve the application of MCA principles included the designation of a team member to act as a mentor on mental capacity issues, easier access to legal advice for professionals and wider advertising of local and online forums for discussing mental capacity practice dilemmas as they arise.

Based on practical issues in assessing mental capacity for people with intellectual disabilities, Waight and Oldreive (2011) outlined gaps in professionals’ knowledge in assessing mental capacity. Issues identified in the report included a lack of recognised assessment pathways to follow, a lack of precise criteria for impaired capacity, aside from the four general criteria included in the legal statute and no requirements for evaluation of literacy skills. In response to issues in implementation, Oldreive and Waight developed a capacity assessment, specific to people with intellectual disabilities who need to be assessed for the capacity to decide on a tenancy agreement. An initial screening evaluation was designed which assessed a very basic level of language comprehension and the use of functional ‘yes’ and ‘no’ answers. Provisions were made for a variety of impairments, such as sight and hearing impairment and functional illiteracy. If participants were unable to perform on these initial evaluations, they were deemed to lack capacity to make a decision about their tenancy.

Those who performed well on the initial evaluations were further assessed in literacy, understanding of monetary concepts (i.e.: the value of money, basic budgeting) and understanding information related to the tenancy agreement. Thirteen participants passed the initial screening but failed on further tests of understanding or in communicating their decision sufficiently so that only one had mental capacity. Further investigation is required before this thorough method of capacity assessment can be instigated into widespread practice but the careful consideration of ethical and practical issues in mental capacity assessments may be useful to professionals involved in assessing mental capacity. This study highlighted some valuable implications for practice; professionals were urged to carefully document their assessment and write case studies wherever possible to create an evidence base for best practice. A library of useful resources should be developed to facilitate further developments in capacity assessment practice. Strategies to improve mental capacity must be continuously considered and multi-agency meetings should explore specific criteria and tools for assessment so that consistency is achieved.

In an exploration of how the MCA impacts on social and health care professionals, Jepson (2008) provided guidance notes on assessment of capacity and what follows,
depending on assessment outcomes. Brief explanations were given on how to make best interests decisions, including factors that must be taken into consideration. Presented as answers to potential questions about the MCA, Jepson offered simplified, generalisable information for professionals who may be unsure how the implementation of the MCA impacts on their practice. To conclude, Jepson offered recommendations for implementation, such as on-going training for relevant professionals. He explained that the principles of the MCA, rather than a dogmatic adherence, should be at the backdrop of any assessments and/or best interests decisions. A final suggestion was made to organisational improvements so that institutions should aim to provide guidance and protocol aids to their staff to diminish the potential for unnecessary confusion.

Conclusions - Learning Disabilities and Assessment Issues

A lack of confidence and knowledge in assessment protocol was identified, leading to recommendations for the appointment of a designated care team mentor who has specific training in the MCA. Calls were made for increased ease of access to legal advice and a local forum to share ideas for good practice. In addition, suggestions were made for accurate recording of assessment protocol, leading to improved knowledge and good practice. In guidance notes on implementing the MCA, on-going training was recommended for relevant health and social care professionals. It was suggested that relevant organisations could provide training and information notes for staff to prevent confusion about correct protocol.

6.3 Learning Disabilities and Best Interests Decisions

Tuffrey-Wijne et al (2009) explored the health care experiences of people with learning disabilities who have cancer. Findings presented in this report highlighted the need for increased support for people with learning disabilities and a disregard for patient’s best interests was identified. Diagnosis was late in the majority of participants as complaints about physical pain were often attributed to attention-seeking behaviour. Misdiagnosis was a recurring problem due to the patients’ communication difficulties. Doctors’ showed an overreliance on carer’s reports, instead of communicating directly with the patients wherever possible. GPs were more likely to ‘give up’ on patients when the illness was found to be progressive and often patients, and even carers, were not consulted in deciding a treatment plan.

In some tragic cases, patients were not even informed of the terminal nature of their illness causing heightened distress arising from not understanding their deteriorating health. Pain relief was sometimes insufficient as complaints were put down to attention-seeking behaviour. This was the case even with patients who had severe communication difficulties. One case example was presented which was highlighted to demonstrate the overall nature of health care delivery identified by this study in which a doctor did not look at or engage the patient at any point prior to and following medical examinations and left the room without any confirmation that the patient understood what was happening with their health. Carers’ complaints of maltreatment were difficult to substantiate, and carers
often did not know about complaints procedures and as such, issues with negligent treatment were not followed up.

It is worth mentioning that the ethical procedures followed in the development of this research project were very rigorous as the researchers made every attempt to ensure that all participating members were happy with their continued involvement in the research. Pictorial aids and various other means were used to ensure participants’ full understanding. Relatives and/or carers’ assent was obtained although assent was not taken as a proxy decision and participants were only included when all parties involved were happy with continued involvement. A process consent procedure was used which entailed re-checking and ensuring throughout the assessment process that participants were still happy to continue.

Finlay et al (2008b) investigated the effects of a “culture of care and dependency” on service-users experiences when refusing to engage in an activity or action. Analyses of video recordings were carried out, supported by ethnographic backgrounds of the participants. Finlay and colleagues also explored the difficulties faced by staff in matching up the ‘duty of care’ with patient choice, so that they held opposing objectives. Residents of care homes faced greater difficulty in expressing a choice and were further frustrated by frequent occurrences of staff coercion or overriding residents’ wishes. Refusal by a resident in one illustrated instance was for a routine but ultimately unnecessary institutional practice which staff continued to insist upon despite clear refusal by the resident.

A further study by Dunn et al (2008) outlined two different forms of substitute decision-making as observed in a home for people with intellectual disabilities--strategic and relational decision-making. Strategic decision-making was detached from everyday interactions and made in a consultative manner and in conjunction with care planning so that all the relevant and knowledgeable staff and relatives can contribute to the final decision, in parallel with MCA procedures. Relational decision-making was far more common as it reflected the type of decisions made on a daily basis and was characterised by a series of interconnected, smaller decisions. Relational decisions were made very much based on the relationship already established between carer and the person being cared for, and were based on existing knowledge about the person and related past decisions.

Care plans became ultimately redundant when making every day or relational decisions, despite staff being urged to consult care plans frequently when making substitute decisions. Most day-to-day decisions appeared to be made in a genuine attempt to represent the residents’ best interests. These were often based on a personal relationship and understanding the resident as an individual. Decisions made in this way were not made entirely in accordance with the protocol outlined in the MCA but MCA protocol has apparently affected the culture sufficiently to promote instantaneous, personalised decisions that were aimed at genuinely representing what the individual wanted.
Conclusions - Learning Disabilities and Best Interest Decisions

An investigation into health care provision for people with learning disabilities showed a lack of patient consideration by doctors. Recommendations included training social care staff in complaints procedures so they can better represent and protect their client’s interests. Other studies highlighted the divide between policy and good practice. Indeed, in some instances it was institutional policies that prevented staff’s best intentions for good practice. Overall, the research demonstrated staff’s genuine and concerted efforts to ensure best interests decisions were made appropriately to represent the individuals with learning disabilities.

6.4 Learning Disabilities and Research Participation

Dye et al (2007) explored various methods, such as a standardised consent form, to assist participants’ understanding of the research process and their potential involvement. This study contributed to the possibility of a standardised form to assess capacity to consent to research participation. In addition, it highlighted questions about the arbitrary cut off points at which a person is deemed to hold or lack mental capacity as Dye et al manipulated results based on varying degrees of stringency in the criteria for having mental capacity.

6.4.1 Learning Disabilities and Research Participation - Non-UK

Fisher et al (2006) developed a standardised assessment of mental capacity to give consent for research participation which provided a platform to evaluate arbitrary cut-off points in mental capacity assessments. Participants showed good ability to express a choice but performed poorer on explaining the reasoning behind their decision. Capacity to consent to this research trial required a high level of understanding as there were potential risk factors involved. The majority of participants scored higher than initially anticipated; one third to one half scored within the range of controls (i.e. participants without learning disabilities) on understanding research procedures, appreciating the nature of the problem and the potential consequences of participating in the clinical trial. High performance levels may have been facilitated by the methods employed by researchers, which were specifically adjusted for difficulties in language, memory and attention.

An important factor to be considered was that less than half understood their right to withdraw after research had begun, although the majority understood that they had the right to refuse to participate from the beginning. This would indicate that participants with moderate to severe learning disabilities should be given reminders throughout their participation that they are able to stop any time they want without fear of penalties or causing upset. Confidentiality was another difficult concept for participants to understand. These issues raised ethical debate about including people with profound learning disabilities in research trials, particularly where the research holds potential risks or where benefits derived from participating are less likely.
Conclusions - Learning Disabilities and Research Participation

The above papers explored the use of standardised capacity assessments for people with learning disabilities who participate in research. Adapting assessment tools to specific difficulties and adding an element of teaching into assessment protocol were suggestions which could add benefits to participants and improve capacity assessment scores. Difficulties in understanding specific concepts were also identified, such as the right to withdraw.

7.0 GENERAL ISSUES IN MENTAL CAPACITY

The articles in this section related generally to mental capacity issues, without specific reference to a particular group of service-users. These were categorised according to the specific aspect of the MCA under focus.

7.1 Mental Capacity Assessments

Evans et al (2007) evaluated health professionals’ understanding of mental capacity assessments, including when to assess and what criteria is used in assessing capacity. A multiple choice questionnaire was used which may have prevented acquiring more in-depth understanding of health professionals’ knowledge of the MCA. Doctors, nurses and emergency health care workers were assessed but very few questions were included in the questionnaire so that the information gained from this research was limited. Findings revealed that only 10% of nurses had a general understanding of the MCA and no emergency health care workers gave a majority of correct responses. However, “general understanding” was loosely defined and it was unclear what the criteria were for this.

60% of senior house officers (i.e. doctors) answered the majority of questions correctly and 13% of these believed that they could treat a patient against their will even if they had capacity to refuse treatment. Evans et al argued that medical professionals could be opening themselves up to serious legal consequences and may even face criminal charges of assault as well as civil action due to a lack of legal understanding. Conclusions drawn from this study indicated that increased training is necessary for medical professionals who lack thorough understanding of the legal principles that serve to protect the rights of the patient and it was suggested that more in-depth training should be the remit of government implementation strategy rather than the responsibility of independent organisations.

Shah et al (2009) identified issues for Black, Asian and minority ethnic (BAME) groups in the delivery of medical care. A survey of medical consultants was conducted across England and Wales. 80-90% of consultants from varying areas of specialisation considered cultural factors in assessing decision-making capacity and 80% considered religious beliefs. A troubling finding is that only half of non-English speakers received an interpreter during assessments and 40% of non-geriatric consultants reported that no
patients received an interpreter during assessments, indicating that all practicable steps to assist decision making were not taken. Conclusions drawn from this study indicated that cultural factors prevalent in BAME groups were likely to be considered by most medical consultants but that greater steps could be taken to ensure linguistic barriers are accounted for in capacity assessments.

Hotopf (2006) evaluated the ability of health professionals to accurately determine decision-making capacity in patients, particularly in regards to psychiatric patients. However, the article was published prior to complete implementation of MCA. Difficulties were foreseen with assessments as decision-making capacity was focused on the patient’s response to risks which may be difficult to quantify. This was particularly evidenced by the use of the MacCAT-T and other assessment tools for use with clinical population samples. Standardised assessments may prove problematic as factors that may impair decision-making ability, such as severe pain, alcohol or drug influence, withdrawals or powerful emotional responses to life-threatening situations, are not detected. Past research has shown, however, that reliability ratings are high and assessments have been shown to have good construct validity (so that it accurately measured what it was designed to measure). Proposed benefits due to mental capacity legislation included a clarification of the role of professionals, as it ensures that precise reasons must be given if a patient’s wishes are not followed.

Mackenzie and Watts (2011) highlighted the lack of knowledge of many professionals that are involved in capacity assessments. They suggested that only cognitive factors are accounted for in current clinical capacity assessments, including but not limited to the MacCAT-T, but that emotionality should also be included as an influencing factor. Various examples illustrated their argument, the most salient of which may be cases involving an eating disorder or a neurodiverse condition characterized by atypical brain development (such as people with Autism or Aspergers syndrome). In such cases decisions by people who have unusual emotional responses to situations may be incorrectly assessed because differences in emotionality are not accounted for in clinical capacity assessments.

An investigation by Ripley et al (2008) aimed to establish the feasibility of a clinical algorithm (mathematical formulas which use assessment outcomes to inform treatment decisions) to assess capacity. Capacity was assessed with the newly designed algorithm along with a Mini Mental State Exam (MMSE). In addition, nursing, social work and medical documentation was examined for evidence of formal or informal capacity assessments. A modest sample size limits generalizability but primary findings revealed that there was a lack of documentation of capacity to give or withhold consent to admission to a care home in over a third of cases. When more than one assessment was carried out, assessment outcomes were not always in agreement which may well have been due to fluctuating mental capacity. The determined feasibility of the new algorithm was unclear but Ripley et al were hopeful for the prospect of improvements to its accuracy.

In response to issues raised throughout 6 conferences commissioned by the Department of Health, the National Care Association (2008) provided a thorough investigation into the
experience, views and expectations of capacity assessment according to professionals’, carers’ and service-users’ perspectives. They developed the Mental Capacity Act Functions of Daily Living Assessment as part of a toolkit, for use in conjunction with care planning. Findings revealed that 60% of managers believed their staff did not understand their legal responsibilities in relation to mental capacity. Further training and the provision of booklets and leaflets were recommended by managers, as well as credit card-sized reminders for care staff of their legal responsibilities and protocol. Dementia-specific training for professional carers in residential settings was recommended.

Prior to the MCA coming into force, Myron et al (2008) collated staff expectations, experiences and opinions of capacity assessments and reviewed carer and service-users' experiences with assessment protocol. Semi-structured interviews revealed that 83% of staff understood “capacity” in terms of the ability to make decisions and most gained their knowledge of capacity definitions through work or training experience. Their understanding of the term “capacity” sometimes included an element of the service-user understanding the consequences of a decision. Only 5% self-reported “a lot” of training in capacity assessment with the largest majority (59%) reporting having “a little” training. 36% reported receiving no training in conducting or referring for capacity assessments.

Assessments were most frequently assessed during care plan reviews, although other non-standardised assessment methods were also employed. 16% had never carried out a capacity assessment. Of those who had, 89% recorded the assessment in writing but 8% of reported assessments were not recorded in any way. Most staff brought in the involvement of relatives, carers and other staff members when conducting assessments. Assessments were only rarely carried out for a specific decision and were often done in conjunction with reviewing care and alongside other tests of functioning. Encouragingly though, staff appeared to use MCA principles in their capacity assessment rationale and protocol, even if not specifically or extensively trained in assessment protocol.

6 main reasons for carrying out assessments were reported; where behaviour was characteristic of failing to understand the consequences, where difficulties were observed in many aspects of decision-making and where circumstantial change required it. In only 20% of cases, reasons for assessing were decision-specific. 98% of staff wanted more training in the use of capacity assessment and protocol and suggestions were made for illness-specific assessment tools. Calls were made for more readily and clearly available guidance on assessment protocol including who to involve, how to keep accurate records, how frequently they are required and local/organisational assessment policies. Further staff training was required to improve communicative skills, to promote patient autonomy and person-centred care as well as effective risk management.

Service-user views were collected and an understanding was gained into how service-users made decisions. They usually involved people who provided supportive relationships to guide more complex decision-making. Complaints were made that all relevant information was not readily presented, making it more difficult for service-users’ to reach a decision. Lack of confidence played a role in service-users finding it difficult to express their decision and some felt the decision was already made for them beforehand. The main issues for service-users were in feeling comfortable enough to express
opinions; feeling listened to; and in a position to trust staff members. Investigating carers’ experiences revealed that they felt insufficiently acknowledge and uninvolved in service-users’ decision-making. They felt they were best placed to assist in decision-making due to their experience and familiarity with the service-user. Support groups provided a good source of advice and calls were made for service-providers to fully acknowledge carers’ time constraints and other difficulties in attending support and training groups.

7.1.1 Mental Capacity Assessments - Non-UK

Dunn et al (2006) carried out an American-based review of standardised mental capacity assessment tools. 23 standardised tests were identified for assessing capacity to consent to research participation and most focused on the Understanding component of capacity. Findings indicated that there was no consensus on the appropriate definitions and standards for measuring each domain of mental capacity. Suggestions were made that the threshold for capacity should vary according to the potential risk derived from participating in the research. The MacCAT-T and MacCAT-Revised were the most reliable assessment tools although each assessment tool had some limitations. Specifically, these assessments lacked a predetermined cut-off point separating capacity from incapacity because they were designed for use as assessments aids rather than as definitive assessments of capacity.

A Swiss study by Fassassi et al (2009) identified the prevalence of impaired capacity of acute medical patients. 26.7% lacked capacity to consent to treatment and of these, 19.5% exhibited obvious incapacity to consent (i.e. unconscious). 7.2% of patients that were assessed were found to have impaired mental incapacity. Clinical assessments by multidisciplinary teams proved more accurate than standardised assessment tools. The Mini Mental State Examination also proved a highly accurate assessment tool when scores were compared against multidisciplinary clinical assessment outcomes. Disagreements between professionals on assessment outcomes were partly due to the fluctuating capacity of patients. General practitioners required improvements in knowledge and experience in assessing patients and many seemed surprised that they were sometimes required to assess capacity. Fassassi et al made recommendations for pre- and post-qualification training to include assessment of professionals’ understanding of capacity to consent and appropriate assessment protocol.

Conclusions - Mental Capacity Assessments

Surveyed health care practitioners’ knowledge of the MCA showed a low level of training and understanding in MCA principles. Emergency health care workers, in particular, did not give correct answers to any questions about the MCA. Calls were made for more in-depth training across health care providers as part of government strategy, which may serve to ensure consistency across organisations. Another study, however, found that health care staff had a good understanding of MCA principles, which was reflected in their practice, even though some had not received MCA-specific training. It was also found that assessments were carried out infrequently and were often not decision-specific, although good protocol was followed when capacity assessments were made. Health care staff
called for further training and suggestions were made for training in communication skills, which would serve to promote service-user autonomy.

Service-users and their carers reported feeling excluded from decision-making. Service-users often lacked confidence to assert themselves and carers groups were suggested to promote the sharing of tips, experiences and support between carers. Consultants gave good consideration to cultural and religious preferences when making capacity assessments with service users from BAME groups. Improvements were called for in making provision for potential linguistic barriers as this was not sufficiently provided for. A cautious approach was taken to risk-assessment and standardised assessments. They argued that standardised assessments cannot account for emotional factors and states of mind which may temporarily affect decision-making.

7.2 Best Interests Decisions

Luke et al (2008) investigated clinicians’ perspectives on the implementation of pilot IMCA services before the MCA came into force. 127 hospital-based referrals were obtained, 29 of which were related to serious medical decisions. Half of these serious decisions were made on behalf of patients with severe learning disabilities. 98 out of the 127 referrals were related to accommodation; 62% of these were providing advocacy for patients with dementia, who were between 80-90 years of age. In 65 cases, friends or relatives were unable or unwilling to make the decision or decisions were disputed by family and/or friends. 83% of referrals were English-speakers; 14% used alternative (i.e.: non-verbal) communicative means while 3% had no obvious means of communication. In 45% of completed cases, advocates were confident they had ascertained a clear indication of patient’s wishes and communicated these effectively to managers or clinicians. Only five clinicians at this time had experience in working with IMCAs and these cases involved hospital discharge decisions.

In addition to statistical information, qualitative reports were obtained from clinicians on their perceptions of IMCA involvement in decision-making. Benefits identified by clinicians were that the service brought a holistic perspective to decision-making and their involvement made clinicians more accountable for any decisions made. Clinicians expressed the value of IMCAs in determining patient’s wishes in decision-making and they were pleased in IMCA involvement due to their increased legal knowledge. IMCA involvement also allowed for more time to gather personal information; advocates held greater credibility with patients and patients found them easier to talk to. They also proved highly useful in situations with ethical complications, although these situations were in the minority of cases, such as in making decisions about withdrawing life-sustaining treatment or organ transplant decisions. Geriatric clinicians were most supportive of the involvement of IMCA services. IMCA involvement was seen as particularly valuable in cases involving discharge from hospital as clinicians hoped advocacy would serve to minimise delays and ensure the safety and contentment of patients following transferral.
Concerns were expressed over advocates’ lack of medical training and were just as likely as clinicians to be subjective but without the added benefit of medical expertise. Clinicians expressed regret that the service was only available within office hours, so that it would not be efficient enough emergency decisions. Clinicians with experience of IMCA involvement said that advocates were unable to relinquish strong personal views about when medical intervention was appropriate. In addition, clinicians felt it was unclear precisely when IMCA involvement was required, such as in cases requiring emergency resuscitation. Clinicians had difficulties judging when it was appropriate to consult relatives. Some clinicians and nurses rejected outright the need for an advocacy service as they felt that multidisciplinary teams already made strenuous efforts to make best interests decisions. In addition, serious medical decisions that would typically involve IMCAs were made over several meetings, starting with a general practitioner. Clinicians felt it was unrealistic to expect advocates to be present at all meetings and so to have all necessary information on the patient.

Luke et al reported significant attitudinal barriers to the IMCA. Concerns were expressed that clinicians may interpret “serious” and “urgent” idiosyncratically to avoid what may be viewed as unnecessary meddling or involvement of advocacy services. Clinical training should address concerns about advocacy and assurances should be made that clinical expertise will not be undermined. Clinicians should be made aware that advocacy can allow for increased patient involvement and shared decision-making without over-taxing clinicians’ time. Findings indicated that implementation should be continuously monitored to ensure appropriate acceptance and inclusion of IMCA services.

An investigation by Redley et al (2008) into IMCA implementation revealed that 20% of family and/or friends could not make best interests decisions due to conflicted interests. Processing and completing referrals was delayed at times, but this may have affected the relative complexity of the decision. To ensure that referrals are made appropriately, increased monitoring of the reasons for IMCA involvement was suggested. Manthorpe and Martineau (2010) indicated the need for social workers to be better informed about their legal responsibilities to refer to an IMCA and to be more assertive about ensuring that referrals are made. Social workers’ ability to meet the expectations of people requesting care home placement was difficult. It was argued that this difficulty will likely increase as funding for care homes becomes reduced. There was insufficient practical guidance available for social workers and advocates on how to demonstrate that a care home would be in the client’s best interests. Manthorpe and Martineau argued there was a lack of research to explore and evaluate services so that few studies were available for review. They suggested there was a need for social workers to return to their original role as advocates and that IMCA services should be utilised as one of several ways in which older people’s choices can be represented.

Dunn et al (2007) provided a predictive account of potential difficulties with the implementation of the best interests principles of the MCA, including decision-making by family/friends who hold strong religious or moral positions. In settings where best interests decisions related to accommodation or social settings, maximising the best interests of one individual may not be beneficial, and even detrimental, to the best interests of others involved within the same setting. Dunn et al suggested that due to the
need for generalisability, the best interests ‘checklist’ loses sensitivity with specific scenarios and its relevance for practitioners was called into question. For instance, it was argued that in cases where an individual has dementia, and their previous views and wishes were made known to family and friends, a best interests judgement may be quite straightforward. However, in cases where the individual never had capacity to make a complex decision, determinations of best interests become more provisional. This in turn may lead to decisions based on the carers’/relatives’ values, and/or social or cultural stereotypes based on age, gender or disability. It was acknowledged that the MCA has provided guidance to prevent such occurrences but Dunn et al argued that this could still potentially occur.

Another potential issue could occur when the role of those making best interests decisions goes beyond the professional’s duty of care, for instance where social care staff are very personally involved over long periods of time. Dunn et al argued that in such instances, there may be conflict in practice as a best interests determination should ideally be “a detached and reflective procedure that is potentially incompatible” with a personalised relationship. It was suggested that the Code of Practice is insufficient to resolve disputes about everyday decisions where mediation, advocacy and complaints may not be practicable. Little practical advice is given to the actual process of undertaking best interests decisions. Hence, it was suggested that the best interests decision will then be defensively oriented, so that it is used to justify decisions in retrospect, rather than to guide the decision-making process from the outset. They suggested that the successful implementation of the MCA in relation to best interests judgements will depend on refining the Code of Practice or on the introduction of further training programmes for those responsible for making everyday best interests decisions.

Gorczynska and Thompson (2007) provided a breakdown of the 270 referrals made in the first six months of launching IMCA services. 75% of referrals concerned decisions about accommodation, 7% of which were specific to adult protection decisions regarding accommodation. Only 9% of referrals were regarding serious medical decisions, which reflected the pattern found in Luke et al’s evaluation of IMCA pilots. The largest client groups referred to the IMCA were people who had dementia (53%) and learning disabilities (21%). Family members were identified as the alleged perpetrators in 58% of adult protection related referrals, highlighting the role of independent advocates. Difficulties with assessments were due to problems accessing an individual, such as in cases of domestic abuse, and due to lack of previous knowledge of the person by professionals.

IMCAs reported difficulties with time constraints. It was suggested that local authorities should be responsible for ensuring adequate discretionary powers are available to advocates in their IMCA service contracts. Gorczynska and Thompson recommended that adult protection training should be extended to include IMCA involvement and other advocates to ensure good working relationships between services. In addition, further evaluation of the role of the IMCA in adult protection cases was advised. Conclusions indicated that IMCA resources are limited and as such, cooperation between service providers and local authorities was necessary to ensure adults vulnerable to abuse receive appropriate safeguards. Another article by Gorczynska (2007) discussed IMCA
services following completion of pilot programmes which provided a breakdown of the training undertaken by IMCAs and the extent of the services they provide. Gorczyńska suggested that NHS staff would need to be made aware of the changes to the services provided, and sufficiently informed about the necessity for involving IMCAs when family and/or friends were unavailable to make decisions on behalf of another individual.

Lee-Foster (2010) presented an evaluation of a training programme for independent advocates of people who had sight- and hearing-impairment. The training course entailed one full day of training followed by the delivery of a post-course study kit. Trainees submitted an assignment two months later, which allowed learning in the practical relevance of the course content. The programme covered ethical issues, the development of communication and the role of advocacy services. Feedback from the advocates highlighted the benefits of the programme to their practice and they reported an increased understanding in the MCA. Joyce (2007) provided detailed guidance on scenario-specific dilemmas for professionals making best interests decisions. The article offers a breakdown of good practice in making best interests decisions as defined by precedent and the guidance offered in the Code of Practice. Good protocol was detailed and illustrated by case studies; decisions that cannot be made under the MCA were listed as well as decisions that can only be made within a court of law. Brown and Marchant (2011) described complex cases referred for judiciary guidance for best interests judgements. They suggested that only a small number of cases were straightforward enough to be easily guided by the Code of Practice and that most decisions were more complex. In such complex cases, the ‘spirit’ of the MCA should enlighten practice and consideration given more carefully to ensuring the underlying best interests principles are upheld, rather than following rules dogmatically. This report echoed what other papers have detailed; that is, confusion around complex best interests decisions will be resolved only through a deeper understanding of the MCA which will in turn allow for a cultural shift that inherently considers service-user rights and dignity as paramount.

Donnelly (2009) suggested that treating patients with their best interests in mind has been reflected in UK healthcare for over a decade but only in the detailing of best interests principles has actual change occurred in the extent to which patients are involved in their health and social care decisions. Donnelly argued this is due to the inclusion of people who lack capacity in decisions that concern them, where previously it was not considered ethically deviant to exclude those lacking mental capacity from decision-making. Donnelly provided case law history to illustrate the gradual change in legal judgements that were advanced further with the implementation of the MCA, and in particular, with the introduction of best interests principles into general practice. The concept of best interests, suggested Donnelly, has since been acculturated into the judicial system, altering the factors considered in legal judgements involving people who lack decision-making capacity.

Wrigley (2007) conducted an evaluation of the underlying concepts behind best interests decisions, proxy decision-makers and consent. He argued that proxy consent can never be viewed as a reasonable substitute to autonomous decision-making arguing that proxy decision-makers should fill the role of advisor only, without allowance for consenting on behalf of another. Limitations to proxies’ powers to decide on another’s’ behalf, as
instated with the MCA, were supported by Wrigley who argued that a professional best interests judgement, with advice contributed by any existing proxy, is the only way to make decisions that most closely align with the patients’ wishes and bests interests combined.

7.2.1 Best Interests Decisions - Non-UK

An American study by Torke et al (2009) described physician experiences with surrogate decision-makers. Overt disagreement was rare but 20% of the time physicians reported ineffective communication, lack of satisfaction with the outcome and high levels of stress when interacting with surrogates. Results indicated low levels of continuity between inpatient and outpatient settings, low numbers of ADs although living wills were often created (which differ in content from ADs in the USA). A high proportion of physicians were unaware of ADs or pre-expressed preferences, whether stated verbally or in writing. Physicians’ perceptions of good agreement were more likely to occur with patients who had previously expressed wishes for care. Agreement became easier as the age of the patient increased; additionally, setting limits on aggressive life sustaining treatment may be more culturally acceptable for families of older adults.

A further study by Torke et al (2010) examined the degree to which physicians place importance on patient preferences when making medical decisions for patients with impaired mental capacity. Physicians rated patient preferences and best interests as very or extremely important and one third reported patient preferences as the most important factor. Even when patient preferences were outlined in living wills or prior discussion, less than half still chose patient preferences as the most important factor. This raised serious questions about discordance between ethical standards and clinical practice. Explanations for the low number of ADs included lack of availability of information, often affected by time constraints. Patient preferences were more highly rated in intensive care settings and were rated lower in importance with older patients, potentially indicative of ageist cultural biases. An alternative explanation, however, is that some physicians may have a “natural life span” approach to health care, viewing certain treatment options as unnecessarily invasive for older patients.

Conclusions - Best Interest Decisions

IMCA evaluations revealed significant attitudinal barriers and calls were made for social workers, clinicians and nurses to undergo increased training in working with advocacy services. A gap in available literature for evaluations of advocacy services indicated the need for more focus on monitoring the implementation of advocacy services. Reports lamented the requirement for generalizability in the best interests principles as it denotes a loss of sensitivity for variations between individual cases. Researchers recommended communication training for advocates as many cases were referred due to a patient’s communication difficulties. Other, more discursive articles, used case studies to illustrate general areas of difficulty or good practice. These produced evidence of improvements in practice due to changes in ethical considerations across health, social and legal systems. Non-UK based articles revealed reports by doctors of poor communication, dissatisfaction
with the outcomes of best interests decisions and high stress levels when dealing with surrogate decision makers.

7.3 Mental Capacity and Advance Directives

Bisson et al (2009) developed a care pathway for the introduction and completion of advance decisions (ADs), using Huntington’s disease as a case example. A qualitative pilot phase involved completing an AD followed by in-depth interviews and focus groups with individuals who had Huntington’s disease. Findings highlighted the difficulties of introducing ADs because of adverse emotional consequences, especially for at the later stages of the illness. Discussions should ideally take place in clinical settings but all individuals should be offered a home visit from an AD advisor and ADs should be introduced as early as practicable. Participants suggested adding statements in AD information packs on organ donation, whether independent legal advice had been received, and disease-specific care information.

7.3.1 Mental Capacity and Advance Directives - Non-UK

A recent American review by Guo et al (2010) explored the use of ADs and do-not-resuscitate (DNR) orders in a medical population with high mortality rates. 23% of patients reported having a living will, 31% had a health care proxy (roughly equivalent to the UK powers of attorney), 6% had an out-of-hospital DNR order made and 9% had a hospital-based DNR order. They often found a very short length of time between the date the DNR order was made and the time of death, averaging at 16.5 days, which indicated a significant need for improved doctor-patient communication and more widespread End-of-Life care planning. The short length of time between appointing a proxy, End-of-Life decision-making and patient death was associated with relatives experiencing complicated bereavement. One study found that 60% of family members that had short time periods between planning End-of-Life care and the death of their relative suffered from post-traumatic symptoms.

Johnson (2006) suggested that many people will outline their End-of-Life care but opinions will change when they are confronted with the actual likelihood of dying if life-sustaining care is withheld, as per their AD. In some cases, people will be unable to state their change in preferences, causing profound ethical predicaments. Johnson further argued that medical professionals do not, as yet, make every practicable attempt to communicate with patients who have impaired communication abilities. In 2009, Johnson produced a further discussion on the bioethical underpinnings of ADs. Recommendations were made for social workers to provide detailed explanations on advance directives to clients and their families, acting as a mediator when disagreements arise. Additionally, Johnson suggested that social workers should contribute their expertise to hospitals, nursing homes and community ethics committees that frequently address decisions related to End-of-Life care. Social workers should also ensure that a decision to not make an AD should be respected and that alternatives, such as creating a power of attorney are offered to the patient. Johnson proposed that social workers are the professional
group most suited to introducing and dealing with AD creation due to their more ‘friendly’, informal style of service delivery.

A cross-sectional study of older Latino-American preferences for End-of-Life care was carried out by Kelley et al (2010), which identified a heightened preference for comfort-focused End-of-Life care in Older Latino-American adults. Participants preferred a family-centred, group decision-making model and limited patient autonomy, which is not supported by American legislation which places great emphasis on individual patient autonomy. Peck (2009) examined the extent to which the death anxiety (level of anxiety about dying) of oncology social workers impacts on the completion of ADs and their communication about ADs with patients. No significant differences were found between the death anxiety scores of social workers who had completed ADs for themselves and those who had not. Self-reported reasons for not having completed an AD were lack of time, being too afraid, denial and laziness. However, it is worth noting that a higher than average percentage had completed an AD (68%), suggesting that the experience of oncology social workers contributed to their increased awareness and experience, leading to increased likelihood of completing an AD. Rich et al (2009) evaluated disparities in the number of ADs created between ethnic groups in the USA which identified differences in the number of ADs created by white and non-white residents. This indicated a need for better communication about ADs. Suggestions were made to provide continuous discussions with nursing home residents and their families.

An additional American study by Schmid et al (2009) examined ethnicity and cultural context within hypothetical End-of-Life medical decisions and the influence of cultural context on patient-proxy agreement. Pairs of one older adult and one family member, typically an adult child, were surveyed. African-Americans displayed better patient-proxy agreement than Caucasians. Low levels of advance care planning were associated with lower patient-proxy agreement in which African American proxies tended to suggest less treatment and Caucasian proxies tended to want excessive treatment. One finding lending insight was that the pairs of relatives commonly requested to see the other’s responses and expressed concern about wanting feedback and understanding the patient’s End-of-Life wishes.

Robichaux and Clarke (2006) conducted an in-depth investigation into the experience of disagreements in End-of-Life care for critical care nurses. This qualitative investigation revealed that expert nurses shaped the processes surrounding End-of-Life decision-making. Nurses acted as advocates for the patients, conveying wishes and explanations to families. Many nurses demonstrated active resistance to aggressive life sustaining treatment, even when their stance did not influence the outcome for treatment decisions. Nurses regretted that life sustaining treatment, in being referred to as ‘treatment’, gives “false hope” to patients’ families.

Robinson et al (2006) explored health practitioners’ attitudes towards disabilities and how they affect End-of-Life care for people with disabilities. They suggested that by merely taking account of medical facts about the patient, good ethical practice is obscured and high-functioning clinicians (i.e. not having any physical or intellectual difficulties) are likely to make mistaken assumptions about disabled patients’ quality of life. This could lead to
treatment decisions that are contrary to patients’ wishes. Two components of good ethical practice were put forward; firstly, referred to as “good facts”, the authors suggested coming to know the patient and his/her wishes as well as the clinical facts. Secondly, clinicians should apply theoretical ethical approaches to patient cases to provide clarity, validation of what is important in the case analysis, and direction in weighing treatment alternatives. Robinson et al suggested that feelings about cases should be elevated to be considered alongside medical facts, producing much more ethical practice. Roscoe et al (2006) suggested that conflict and stress are inherent in the decision-making process within families, especially in the absence of ADs. They found that 54% of terminally ill patients would rather select their surrogate decision-maker’s treatment decision rather than the treatment outlined in their own AD. Studies revealed that only 8% of families who decided to withhold life sustaining treatment reported inter-family conflict but 40% reported conflict between family and staff in their decision-making process. It would seem then, that conflict is more pronounced between professionals and relatives. Conflict may have been due to perceptual differences or it may have been related to longer-standing issues, such as sibling rivalry or a need for control.

A Saudi Arabian cross-sectional study on ADs by Al-Jahdali et al (2009) determined the resuscitation preferences of Saudi dialysis patients. Cultural norms denoted that ADs were rarely discussed and cultural/religious beliefs encouraged withholding treatment if it was perceived as futile. The level of knowledge in prognosis and the possible effects of CPR (cardiopulmonary resuscitation) and chances of recovery affected resuscitation decisions so that when patients were informed about the low success rate of CPR for people with their condition, requests for life-sustaining treatment were reduced in number. Patients’ decisions were based primarily on intuition rather than on religious belief, family size, quality of life or previous hospitalisation experiences. Recommendations were made for doctors to provide patients with information about what life sustaining treatment entails and what the likelihood of the resulting outcomes are expected to be.

Schickedanz et al (2009) explored obstacles to multiple advance care planning steps and identified common barriers that impeded older adults from engaging in the process as a whole. Steps to making an AD were contemplation, discussions with family or friends, discussions with clinicians, and documentation. Six months after initial discussion, participants’ views were collated and categorised into 6 themes which outlined the existing barriers to advance care planning. These were that ADs were viewed as irrelevant; personal barriers and relationship concerns; information needs; time constraints on health encounters; and problems with ADs. Perceived irrelevance was the most common barrier to creating an AD. Factors facilitating ADs included exposure to simplified AD information, exposure to video images that describe ADs, having clinicians initiate discussions with patients and extensive clinician-led discussions about patient values. The strongest evidence of barriers was at the stage linking initial discussion to discussions with friends and/or families – this could be mediated by providing information that ADs reduce the stress experienced by surrogate decision-makers.

Silveira et al (2010) identified differences in patient and proxy treatment decisions. Surrogate decision-making was required 42.5% of the time for older Americans. It was revealed that cognitive impairment, cerebrovascular disease (affecting blood supply to the
brain and includes stroke) and residency in nursing homes were associated with impaired mental capacity but these characteristics were also present in 76.6% of the total sample. Of those who needed a surrogate decision-maker, 67.7% had an AD. This high number suggested that older Americans find AD documents familiar, available and acceptable and that elderly patients and other involved in their care perceived ADs as having value. Those who requested all possible care were more likely to receive the maximum level of care compared to those who made no such specific requests. Supporting the suggestions that ADs are commonly used to deny healthcare, among participants who wanted aggressive care some did not receive it despite their specific requests.

Conclusions - Mental Capacity and Advance Directives

The majority of articles obtained for this review related to advance directives and end-of-life care although much of the research in this field was carried out in the USA. Barriers to creating ADs were also identified and included patients perceiving them as irrelevant, having further information needs and time constraints. Recommendations for early introduction, accompanied by continuous follow-up discussions would promote the creation of ADs. Another suggestion was to increase the range of what is involved in creating an AD, such as organ donation preferences and disease-specific care pathway options. Social workers and nurses were the professional groups most suited to facilitating discussions around and the creation of ADs.

Two articles called for greater efforts to increase minority groups’ use of ADs. Differences were identified between ethnicities in the doctor-patient relationship, patient expectations and trust in doctors. Not having ADs was associated with low life-satisfaction and high stress levels of patients’ relatives. Poor agreement between patient and proxy decision-making demonstrated the usefulness of ADs, even in situations where surrogate decision-makers are available.

7.4 Research Participation

An evaluation of Research Ethics Committees (REC) was conducted by Dixon-Woods and Angell (2009) which analysed REC decision letters about applications for research with people who may lack capacity to consent to research participation. Out of 45 decision letters, 38 gave provisional ethical consent. With 25 of those letters explicit concern for compliance with MCA was shown, demonstrating good prior understanding of MCA requirements and 11 letters were concerned with how capacity would be assessed. 15 out of 21 RECs gave unclear or incorrect advice about the MCA, especially in relation to justifying the need to include people who lack capacity. Eight decision letters commented specifically on justification and five on the benefits derived from participating in research. The authors suggested that the small number of letters that gave consideration to such important issues may be because researchers had already given sufficient justification and clearly stated beneficial aspects of participation in the research projects. However, Dixon-Woods and Angell suggested that RECs need to be “consistently explicit” in endorsing the applicant’s proposal by stating specifically that justifications were sound and benefits sufficient to allow for participant inclusion.
Findings indicated that some researchers lacked understanding of their legal requirements as two letters rejected proposals because they stated that “proxies” would be used to provide consent on another individual’s behalf. Six letters corrected applications that proposed to seek “assent” by proxy. 27 REC letters made reference to a consultee process, only one of which gave correct information or advice that was in line with the MCA. These findings indicated there researchers and REC were confused about how the MCA impacts on research. Due to the findings presented by Dixon-Woods and Angell, however, the National Research Ethics Service has taken steps to address the issues highlighted and on-going training courses were implemented to ensure comprehensive understanding of the MCA in RECs. Dixon-Woods and Angell called for researchers to better inform themselves on MCA research requirements.

An additional qualitative review of Research Ethics Committees was conducted by Parker et al (2010) which focused on university RECs (URECs) and researchers. Their findings also indicated some level of misunderstandings about how the MCA will impact on research proposals. However, none of the researchers had at the time of writing submitted any applications for research with participants who might lack capacity since the implementation of the MCA. Researchers expressed the view that URECs lack rigour in their ethical approval process and viewed NHS RECs as setting the “gold” standard for the ethical approval process.

A final study by Lecouterier et al (2008) reviewed public views on carrying out research without consent (RWC) with the aims of identifying if legislation is reflective of public opinion. RWC would only be undertaken where the time constraints are highly stringent so that advocate decision-makers cannot be obtained and where consent is impossible. Findings revealed that the outpatient sample responded more favourably to the idea than people who did not regularly attend hospital, presumably because irregular attendants in hospital were less likely to be confronted with considering participation in research without their consent. While regular outpatients were largely in favour of RWC, they were also overwhelmingly in favour of obtaining consent from a relative (82%) and that consent should be obtained from the patient as soon as is possible (90%). Findings also identified very high levels of trusts in doctors’ intentions to make decisions in the best interests of the patient (91-97%) but the same level of trust did not extend to clinical researchers’ intentions.

An interesting theme that emerged from participant views was that there should be an “advance opt-out” process for people who felt strongly against participating in emergency RWC. A large proportion of participants said they would be willing to give consent in the first person but favourability towards the idea was reduced when they considered RWC becoming common practice. Low favourability may be explained as due to gaps in public understanding of the research process so that terms such as “placebo” and “randomisation” may have created cause for concern in the public views.

7.4.1 Research Participation - Non-UK

Bravo et al (2008) compared researchers’ performance in Quebec and France on knowledge of mental capacity legislation relating to research participation. Results
revealed a general lack of knowledge regarding legislation that serves to protect vulnerable people who are participating in research. This was especially so among French researchers, possibly due to the increased complexity of French legislation compared to Canadian legislation. Younger, less experienced researchers had better knowledge of legislation but opinions on ethical considerations did not differ between groups.

Mody et al (2008) explored recruitment and retention techniques for including older adults in research. Strategies to address concerns and overcome barriers to older adults’ participation in clinical research should be implemented at the earliest stages of planning. Strategies included minimising exclusion criteria, securing cooperation from all relevant parties (i.e. relatives and professionals), using advisory boards, timely screening and carefully reviewing the risk-to-benefit ratio. Targeting specific strategies to the condition, site and population of interest were also identified as key strategies.

Conclusions - Research Participation

Evaluations of RECs indicated poor knowledge of the changes to research ethics due to mental capacity legislation; however, these findings led to increased and on-going training instituted by RECs to improve practice in accordance with the principles and processes of the MCA. Outpatient views were also collected which showed that the public’s perception of being involved in research without their consent was largely favourable although researchers lamented the low level of understanding held by the public on research concepts, which may lead to mistrust of researchers. Key strategies were identified to increase the number of older people who participate in research.

7.5 Mental Capacity – Other Issues

Shah et al (2010) designed and evaluated awareness training of MCA legislation in BAME groups. Two one-day events were organised to raise awareness with representatives of BAME groups and evaluations indicated that awareness was significantly raised. Awareness training involved the delivery of documents outlining legislation, accompanied by illustrated case studies. Seminars and direct teaching was provided and a workshop format was used to allow for discussion amongst attendees. Shah et al suggested that awareness training was simple yet sufficient and could be used as a model for awareness training among social and health care providers.

Rappaport et al (2009) provided a discursive analysis of implications for social work practice arising from MCA implementation. It was suggested that social care staff may have difficulty, if not sufficiently informed, with reconciling legislation in the Mental Health Act and the Mental Capacity Act, particularly in relation to psychiatric care. Rappaport et al made appeals for effective monitoring of service-delivery, particularly while changes due to MCA legislation were being implemented.

Manthorpe et al (2009a) presented an overview of the MCA and the changes it has entailed in social and health care services. Recommendations included raising public
awareness; on-going training for staff to ensure continued and updated understanding; and effective monitoring arrangements and procedures to be implemented. The authors point out that the MCA has been criticised as “very ‘New Labour’ in tone because of its re-distribution of decision-making power to government and the court system. However, Manthorpe et al argued that the people that it has directly affected both personally and professionally believe that it has the greatest potential to enhance practice and patient autonomy and empowerment. Manthorpe et al urged employers to ensure staff will be allocated sufficient time provision to allow complete implementation of MCA principles.

Manthorpe et al provided an insightful discussion aimed at informing social workers and other professionals of the views and experiences of lay people concerning MCA-implementation. They suggested there yet remains room for abusive proxy decision-making and funding was a concern, both for service-provision and for adequate training. Insufficient training of staff in assessing capacity may lead to incorrect decisions such as sensory impairment mistakenly perceived as mental incapacity. Thus it was suggested that many health and social care staff may be inadequately trained in effective uses of alternative communication techniques to determine mental capacity. Manthorpe et al also suggested that the best interests principles leaves room for decisions to be made according to personally vested or conflicting interests.

In reference to advance decisions (ADs), it was argued that attorneys may lack the required skills and/or commitment to fill the necessary role of implementing ADs and there may be difficulty for patients who later change their minds about the content of their ADs. In addition, small but important wishes not included in ADs may be ignored. Manthorpe et al suggested a broadening of IMCA services to cases involving disputes and to backdate cases where decisions were already made prior to MCA implementation. It was also suggested that as the IMCA is a government-commissioned service, IMCAs will be more likely than friends or relatives of patients to yield to difficulties in carrying out patients’ wishes, such as agreeing to the first care home available rather than finding the best one for the patient. It was argued that there are insufficient processes in place to monitor the decision-making of those with Lasting Powers of Attorney (LPA) and that legal advisors involved in LPA creation need to be regulated to ensure accountability.

Manthorpe et al (2009b) carried out a small-scale study which obtained the views of adult safeguarding co-ordinators following MCA implementation. People acting within a professional safeguarding role felt that the MCA fundamentally affected their work. Sources of advice, when they were in doubt about what action should be taken, included heads of departments, senior practitioners and consultants. Helpful resources included the Code of Practice, internet resources such as the Department of Health website, consulting with the Office of Public Guardian, and people who deliver MCA training. All participants stated that their practice has been altered since implementation of the MCA.

It was suggested by participants that members of the public may seek advice on the MCA from social care staff, who have insufficient knowledge to fill an advisory role. Reports were made of the misuse of Lasting Powers of Attorney though no specifics were included. Findings indicated that participants had good overall understanding of MCA principles in practice. Hewitt (2009) provided a critique of mental capacity legislation
which argued that although it sufficiently protects those who are most vulnerable from physical abuse, neglect, sexual abuse and exploitation, it fails to protect vulnerable adults from financial abuse. It was suggested that alterations to specifics in legislation may serve to correct this, though particular recommendations were not given.

Reilly and Atkinson (2011) provided a comparative breakdown of the mental health and mental capacity laws across England and Wales, Scotland and Northern Ireland. Scottish mental health legislation was derived from capacity-based considerations while English and Welsh legislation is risk-based, which attempts to bridge the divide between patient rights with patient and public safety. Northern Ireland remains within the early stages of developing sufficient mental health legislation which may allow for more comprehensive considerations, gaining insight from the earlier developments in the other British countries. Scottish law takes account of ‘impaired ability’ within mental health legislation, which is a concept related to, but less comprehensive than, mental capacity. It was suggested this allows for a more ethical and less discriminatory practice in the treatment of people with mental health problems. The authors viewed the Mental Capacity Act to be sufficient in its ability to promote autonomy and provide safeguards against unnecessary compulsory treatment for people who lack capacity.

Emmett (2007) provided a model of good practice in capacity assessments specific to dental care. Using case studies to illustrate potential pitfalls in practice, Emmett explored the extent to which dental practice has been affected by mental capacity legislation. It was asserted that if effective training is not delivered as part of instating new legislation, it renders legal improvement for people who lack capacity less effective. An article by Johns (2007) promoted reflection on the impact of the MCA and detailed how professionals may be affected by reformed practice. In a comparison with other nations holding similar legislation, Johns provided justification for the difficulties in accounting for intricacies in the protection of people who lack capacity. Johns praised the instatement of the MCA but suggested that various practical difficulties will arise for professionals in needing to assess capacity decision-specifically.

Published prior to the implementation of the MCA in 2007, White and Baldwin (2006) investigated how the MCA will potentially impact on the delivery of critical care, with particular focus on anaesthetics. White et al asserted that the MCA may not alter practice in these particular fields in an overt way as the legislation builds on existing principles already known to anaesthetist and intensive care specialists. However, they recommended initiative in training and self-development to gain an understanding of the MCA to ensure changes enacted through implementation are well-received and assimilated by professionals in the field of critical care.

Alonzi (2008) devised a comprehensive guide for community practitioners in all aspects of the MCA and how it impacts on practice. The Code of Practice was reiterated as the primary reference when a service-user’s mental capacity is under question. Alonzi’s guide offered service-providers specific step-by-step guidance, including checklists to be referred to. A glossary of terms was included for further clarification as well as detailed advice of how to proceed in situations involving disputes. A later study by Alonzi et al (2009) explored nursing staff’s needs for guidance in appropriately practicing under the
MCA. Guidance needs of nursing staff across various PCTS were obtained via questionnaires which revealed that the primary request (78.4%) was for guidance on assessing capacity. Other needs included help with decision-making (72.5%) and understanding and applying the five primary principles of the MCA (70.6%). These findings indicated that training received by nursing staff on the MCA was insufficient to equip them for good practice. Nursing staff lacked confidence in how to best proceed in virtually every aspect of the MCA, from making assessments to decisions involving disputes. Each aspect of the MCA that nursing staff wanted further guidance on was briefly explained in the article, with explanations on why confusion can arise and how it might be avoided. The paper was concluded by a case study used to illustrate the challenges faced by nursing staff and how they can be adequately met.

Scope (2009b) investigated the involvement in decision-making of people who have a disability, with both pre- and post-implementation measures. This paper detailed case study analyses of six people, four of whom had a relative or other advocate involved in their care. Two participants did not have capacity to consent to participate in research but appropriate ethical deliberation between those involved in their care was carried out to determine the suitability of their participation. This research was carried out too soon after the implementation of the MCA so that no effect of implementation was observed. However, findings contributed to the body of research that has identified specific changes to the care of people with complex support needs. These findings were also supported by later research which identified the need for a cultural shift within health and social care in light of the MCA, before actual change can be observed. This was particularly true of everyday decisions and of determining mental capacity, despite all staff having had training in the MCA.

Choices, when offered, were unnecessarily restricted and the authors revealed attitudinal barriers to implementing the MCA on a cultural level. Recommendations for thorough implementation included increased and continued training for staff and making specific and detailed guidance on assessment of capacity available to care staff. Training for staff was called for in how to support service-users to gain confidence in decision-making, as well as a more inclusive approach to care that includes family carer decisions. A recommendation was for staff training to be delivered by family members as it would facilitate a deeper understanding of person-centred care and promoting empowerment for service-users and their families. Changes were also recommended on an institutional level and improvements in access to advocacy services were cited as necessary to ensuring service-users views and wishes are appropriately represented.

Conclusions - Mental Capacity: General Issues

Awareness training programmes for the public demonstrated a simple but effective means of providing accessible information across large groups which may be easily applicable to a professional level of awareness training (e.g. social workers). Effective monitoring procedures were repeatedly called for as some researchers argued there remains scope for abusive proxy decision-making, personally vested interests in best interest decisions and funding-driven IMCA decisions. Funding remained a concern, for both training and for adequate service-provision. Concerns with ADs reiterated fears that
people will change their mind about their AD content, causing practical and ethical dilemmas. Encouragingly though, health and social care staff said the core of their practice has changed since the implementation of the MCA which would indicate that positive changes are being enacted across the country, although they did request further training in the MCA.

A comparative look at the various mental health laws between UK countries led to suggestions that more clarity is needed in capacity assessment cut-off points to avoid inconsistency across professional groups. Several guides were outlined in this section, many of which detailed checklists and field-specific or disease-specific guidance on good practice. Further change will likely be achieved with time, continued evaluative research, effective monitoring and the implementation of evidence-based recommendations.

8.0 EMERGING THEMES

The themes identified in this review reflected consistent findings across more than one service user group and/or across more than one aspect of MCA principles.

8.1 Capacity Assessments

- Factors associated with impaired capacity were illness/disability-specific so that they varied according to the service-user group participating in the studies.
- It was suggested that standardised capacity assessments do not account for factors involving a patient’s emotional state and the effect that physical functioning may have on mental capacity.

8.2 Best Interests Decisions

- Substitute decision-makers were unable to accurately predict the wishes of the person who lacked capacity.
- Suggestions emerged that substitute decision-makers should fill the role of advisor and should not be relied upon to represent a service user’s wishes.

8.3 Advance Directives

- Advance directives were often limited and views were divided about how specific and detailed they should be. Advance directives that were too specific became difficult to adhere to. If they included a broad range of specific preferences, it may reduce the number of best interests decisions and dilemmas for practitioners.
- The creation of advance directives was facilitated through early introduction by practitioners and continuous discussion between practitioners and service users.

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8.4 Research Participation

- Suggestions were made that service-users who lack capacity could benefit from participating in research.
- By enhancing understanding about research within capacity assessment protocol, participants who lack capacity to consent would derive greater benefits from research participation and mental capacity may be enhanced.

8.5 Implementation and Practice - General

- A divide between policy and practice, often at the institutional level, acted as a barrier to good practice in health and social care settings.
- There was evidence of a cultural shift towards more ethical practice under the MCA within social, health and legal systems but further improvements were called for within social and health care settings.
- Changes towards more ethical practice will result from a cultural shift, according to the principles of the MCA, rather than through dogmatic adherence to policy.
- More stringent safeguarding procedures and systems were called for in monitoring important health and social care decisions.
- A greater level of family involvement in making various decisions was called for, such as in creating an advance directive or making a capacity assessment.
- The sharing of experience and advice was promoted in the form of local forums, online forums and group discussions for practitioners and family carers, which would promote learning and good practice.
- Findings reflected that substitute decisions were sometimes made unnecessarily. These occurrences could have been prevented by greater emphasis on shared decision-making, more detailed advance directives (including psychiatric advance directives) and cultural changes through further training, which would lead to a greater emphasis on service-user rights.

8.6 Training

- It was suggested that social and health care staff and mental capacity advocates should receive specific training in communication skills.
- There were calls for increased and on-going training for psychiatric, health and social care professionals in various aspects of the MCA, such as how to appropriately make best interests decisions or capacity assessments. Views were divided on whether standardised training should be implemented at the organisational level or via national training strategies.
- Social care and nursing staff were often involved in the introduction of advance directives and they were well-suited to a role that is focused on service-user involvement. They often lacked sufficient knowledge to fill these roles, however, and suggestions were made for further training.
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About the Mental Health Foundation

The Mental Health Foundation is the UK’s leading mental health and learning disability charity. A leading policy, research and service improvement charity for over 60 years, the Foundation is recognised as a leading expert on all aspects of mental capacity. The Mental Health Foundation incorporates the Foundation for People with Learning Disabilities.

The Mental Health Foundation is unique in that its work focuses on the three main groups of people affected by mental capacity issues - people with serious mental health problems, people with dementia, and people with learning disabilities (through the Foundation for People with Learning Disabilities). The Foundation is broadly supportive of existing mental capacity legislation and wishes to see it properly implemented in order that the rights of people who may lack capacity respected, and those who care or work with them are supported to understand their roles and responsibilities.

Since 2006 the Foundation has successfully carried out a number of projects on mental capacity issues as well as doing extensive policy and public affairs work in the field. We are seen as being the leading third sector organisation with expertise in the mental capacity field from the perspective of many key policy makers, health and social care services, other third sector organisations, the media and other stakeholder organisations.

Best Interests Decisions Study (BIDS)

The Mental Health Foundation was a research partner on a major study of the Mental Capacity Act 2005 (MCA) that was led by the Norah Fry Research Centre at the University of Bristol and also involved the University of Bradford. The study looked at best interests decisions made under the MCA and published its final report in 2012 – Making Best Interests Decisions: People and Processes (Mental Health Foundation 2012).

The study investigated best interests decisions in health, social care, and property and financial affairs. It involved an online survey that had 385 responses, 68 telephone interviews and 25 face to face interviews with health care, social care and legal practitioners as well as staff in care homes, advocates, some family carers and others involved in best interests decision making. Decisions ranged from end of life decisions though to everyday care decisions involving people with dementia, learning disabilities, mental health problems, brain injuries and other impairments affecting mental capacity.

The research looked at the range of best interests decisions being made and the prompts to this happening, such as changes in someone’s health or the need to protect someone from harm. It also found that one decision often requires others to be made and these may need to be managed quite differently.

Identifying that the person was unable to make a decision by assessing their capacity was a concern for all the professionals in this research, although most were following the Code of Practice. The research found a significant minority of best interests decisions being made for people who had either been shown to have capacity, could be supported to make decisions
with help, or who had been wrongly assessed as lacking capacity. There were particular concerns about the use of ineligible criteria for determining capacity in some dementia services. It concluded that more clarity about key issues such as ‘unwise’ decision-making and ‘insight’ might help address some of these problems. Similarly there was some confusion about when an authorisation for when the Deprivation of Liberty Safeguards (DoLS) should be sought.

The research showed that there are different ways of making best interests decisions and roles that have emerged to make the process work. While these do not breach the spirit of the MCA’s Code of Practice they are not currently reflected in the training and guidance that is available to health and social care workers. It found that generally the right people are involved in decision-making, although there was some confusion about the role that Independent Mental Capacity Advocates (IMCAs) played, but also identified good practice in involving people who lack capacity in the decision-making process. Successful outcomes flowed from most of the best interests decisions looked at, but there were delays in putting them into action in a small number of cases. Workers were also faced with dilemmas about balancing the autonomy of people who lack capacity with the need to ensure their safety and the wider needs of their families.

The report can be downloaded for free from: http://www.mentalhealth.org.uk/publications/bids-report/

Our other mental capacity work

Other recent mental capacity work by the Foundation has included the development of free, confidential online tools for health and social care practitioners to evaluate mental capacity work: Assessment of Mental Capacity Audit Tool (AMCAT) – www.amcat.org.uk. Developed by health and social care staff, AMCAT is an online tool that helps staff and others evaluate, reflect and learn about an assessment of mental capacity they have been involved in to improve the way they practice.

Best Interest Determination General Research and Evaluation Decisions – www.bestinterests.org.uk. BRIDGET is a simple online tool, similar to the AMCAT which allows health and social care staff to evaluate best interests decision that they have been involved with.

To find out more about how the Mental Health Foundation's mental capacity work including how it can help your organisation, please contact:

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