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HEATHER DILKS–HOPPER BA Hons

CAPACITY TO CONSENT TO HEALTHCARE IN ADULTS
WITH INTELLECTUAL DISABILITIES

Section A: Capacity to Consent to Healthcare Research and
Interventions in Adults with an Intellectual Disability: A Review of
the Theory and Evidence Base

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Consent to a Health Check in Adults with an Intellectual Disability

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A thesis submitted in partial fulfilment of the requirements of Canterbury
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SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed
(candidate)

Date

STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

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(supervisor)

Date

STATEMENT 2

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Summary of Major Research Project

Section A explores capacity to consent to healthcare in adults with an intellectual disability in a broad context. It examines the legal understanding of capacity to consent as defined by the Mental Capacity Act (2005), before going on to use decision-making theory as a framework for exploring the psychological understanding of capacity to consent. It then examines the empirical literature on what influences capacity to consent to healthcare interventions and research in people with an intellectual disability, highlighting what further research is needed.

Section B reports an empirical study, which follows up on some of the further research suggested by Section A. The study investigated the influence of verbal ability, decision-making opportunities and previous health experience, on capacity to consent to a health check, in adults with an intellectual disability, using both correlation and regression to explore the relationships between the variables. It also examined different decision-making abilities and the implications for assessing capacity to consent. Finally, the report draws conclusions on the findings and highlights areas for further research.

Section C provides a critical appraisal for the whole project, exploring what was learnt and what could have been improved on, as well as considering the implications for clinical practice and further research.

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Section A

Capacity to Consent to Healthcare Research and Interventions in Adults with an Intellectual Disability: A Review of the Theory and Evidence Base

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Abstract

This review examines the issues around capacity to consent to healthcare in adults with intellectual disabilities, including healthcare research and interventions. People with intellectual disabilities have unequal access to healthcare and poorer health outcomes. One of the contributing factors to this has been identified as poor understanding of capacity to consent amongst health professionals. This review therefore explores what the current understanding of capacity to consent is, from a legal and a psychological perspective. Decision-making theory helps us to understand how people make decisions and can therefore provide a useful framework for understanding capacity to consent. The review highlights the significant implications of this for people with intellectual disabilities – they are often required to be more rational than people without intellectual disabilities – and alternative theoretical models of assessing capacity to consent are discussed. The review then examines possible factors that might influence capacity to consent, based on decision-making theory. This reveals that considerable research is still required in the area, as few conclusions can be drawn. The implications of our current model of capacity to consent need to remain a matter for discussion and critique.

Introduction

Poor Healthcare

People with intellectual disabilities experience poorer healthcare and health outcomes than the general population. Van Schrojenstein Lantman-de Valk, Metsemakers, Haveman and Crebolder (2000) found adults with intellectual disabilities had over double the number of health problems compared to other people registered at the same GP practices. They experience increased primary conditions, such as epilepsy, mobility and sensory problems, as a direct result of their intellectual disability, but also increased secondary conditions, including obesity, fractures, constipation and gastro-oesophageal reflux disease, as a result of decreased mobility, increased medications and poorer healthcare (Van Schrojenstein Lantman-de Valk & Walsh, 2008).

In 2007 the Mencap report *Death by Indifference* highlighted extreme cases of poor healthcare for people with intellectual disabilities and concluded that a major contributing factor was that many healthcare professionals do not understand the law on capacity and consent and therefore people with an intellectual disability can be denied treatment.

Capacity to Consent

'Capacity to consent' is a legal construct (Dye, Hendy, Hare & Burton, 2004). The word consent indicates an individual agreeing to an act and its consequences, and is most often spoken about in relation to medical treatment or participating in

research. The word capacity refers to a person's ability to make the decision. Capacity "distinguishes the person capable of making a decision, whose choice we must therefore respect, from the person who requires someone else to make decisions" (Wong, Clare, Gunn & Holland, 1999).

The Importance of Capacity to Consent

Capacity to consent can be a significant barrier to people with intellectual disabilities gaining equal access to healthcare (Mencap, 2007; Goldsmith, Skirton & Webb, 2008). Clinicians' difficulties with understanding capacity to consent in people with intellectual disabilities raises two major issues: firstly, there is a potential for healthcare interventions to be conducted without the person's consent, even though they are able to consent. Even when done with the best intentions, this could constitute a civil or criminal offence of assault or battery (Wong et al., 1999). Alternatively, people with intellectual disabilities are denied healthcare interventions (Keywood, Forvargue & Flynn, 1999), either because health professionals fear infringing their human rights, or because capacity to consent is not properly assessed and challenging behaviour is interpreted as refusing treatment.

Keywood et al. (1999) found that people with intellectual disabilities were frequently not given accessible information about their health; their capacity to consent to medical treatment was not routinely assessed; and most health professionals were inviting care-givers to give 'proxy' consent, by signing consent forms. Carlson (2004) found only 44% of GPs were aware of existing professional and government

guidelines on consent. Hart (1999) found that the assessment of capacity varied markedly in the cases of 13 people with intellectual disabilities treated across seven hospitals: one person's attempt to withdraw their consent for an operation was ignored; one person, who attended the hospital independently, was not allowed to sign their consent form; a third person with seemingly lower ability, did sign her consent form. At the time of these studies it was widely accepted that a person should be presumed to have capacity unless proved otherwise and that 'proxy' consent had no validity in law (Keywood et al., 1999).

In the UK, a shift of values towards autonomy and independence for people with intellectual disabilities has brought with it the move from institutional to community care. As a result they rely more heavily on primary healthcare services to meet their needs (Bond, Kerr, Dunstan & Thapar, 1997), thus making it important that frontline healthcare professionals understand the legal and best practice guidance on capacity to consent.

Aim of the Review

This review examines the issues around capacity to consent to healthcare in adults with intellectual disabilities. It will particularly consider theory on decision-making and its implications for assessing capacity to consent, before examining the current evidence on what influences adults' with intellectual disabilities capacity to consent to healthcare. The search strategy is detailed in Appendix A1.

Understanding Capacity to Consent

Legal Understanding of Capacity to Consent

In 2007 the Mental Capacity Act (MCA; 2005) became law. It attempted to formalise the assessment of capacity and clarify the law on alternative decisions. Prior to this there were three different methods for assessing capacity (Wong et al., 1999): the outcome approach (judging capacity by the outcome of the decision); the status approach (judging capacity by the presence of a diagnosis e.g. intellectual disability); and the functional approach (capacity is judged by the extent to which a person's abilities meet the demands involved for that particular decision). However, case law and best practice guidance had generally rejected the first two methods (Wong et al., 1999; Department of Health, 2001).

The MCA has 5 core principles:

- A person must be assumed to have capacity unless it is proved otherwise.
- A person is not to be treated as unable to make a decision unless all practicable steps to help them do so have been unsuccessful.
- A person is not to be treated as unable to make a decision merely because they make an unwise decision.
- A decision made, under this Act, for a person who lacks capacity must be made in their best interests, in consultation with any relevant parties.

- Before the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a less invasive or restrictive manner.

The act put into law the requirement to do a functional assessment of capacity, rejecting both the outcome and status approach, and made it clear that no one person can consent to treatment on behalf of someone else. It also provided a framework for assessing a person's capacity to make a decision. It stated that a person must be able to understand the information relevant to the decision, retain that information long enough to make a decision, be able to weigh up the risks and benefits of the information, and communicate their decision.

Thus for the first time the MCA provided a clear legal framework about capacity to consent, which health professionals could follow.

Psychological Understanding of Capacity to Consent

Using Decision-Making Theory

Clarification of the law on capacity to consent is an important step in supporting the rights of people with intellectual disabilities to access equal healthcare. However, in order to understand what affects capacity to consent and how it might be maximised it is important to have a psychological understanding of capacity to consent.

Jenkinson (1993) argued that the literature on decision-making is an important part of understanding the processes involved in making decisions, in relation to capacity

to consent. Although decision-making theories focus on the general population, rather than adults with intellectual disabilities, it can still provide a theoretical context for understanding human decision-making, which can then be examined with regards to people with intellectual disabilities (Hickson & Khemka, 1999).

Normative Models

Early decision-making theory focused on normative models, which are based on the premise of rational choice and attempted to explain the decision procedures that people would use, in an ideal situation (Bell, Raiffa & Tversky, 1988). Broadly, they suggest people seek out all the necessary information, weigh up the advantages and disadvantages of each option, and then make a decision.

However, there is considerable evidence that people do not make decisions in this way (Carroll & Johnson, 1990). Our capacity to be rational is limited by our memory, attention and information-processing capacity (Anderson, 1990; Baddeley, 1986; Jenkinson, 1993; Newell & Simon, 1972). As a result we have to simplify decision-making situations to a manageable amount of information, by limiting the aspects we focus on and ignoring others. In order to cope with simplifying situations we often rely on shortcuts, based on habits and past choices (Camic, 1992), to help make the decision. In addition Tversky & Kahneman (1981) showed that framing the same decision in different ways can change the choice a person makes, which should not be the case if a person is fully considering the advantages and

disadvantages. Finally, the significant impact of social influences has been well-documented (Asch, 1951; Deutsch & Gerard, 1955).

Descriptive Models

Therefore, researchers tried to develop models that are a more accurate description of how we make decisions (Bell et al., 1988). Simon (1956) developed the idea of 'bounded rationality'. He described a process of "satisficing" whereby people set an aspiration level and then rationally attempt to find a solution to the problem that meets their aspiration level. Prospect theory (Kahneman & Tversky, 1979) proposed that people make decisions with regards to a reference point and the value of an outcome depends on the gains or losses in relation to that reference point. Regret theory (Bell, 1982; Loomes & Sugden, 1982) expanded on this, suggesting that the reference point is what might have happened if they had made a different choice. People therefore make decisions by trying to minimise the regret they might feel in choosing an outcome (Plous, 1993).

Critics argue these models only hold in situations when outcomes are considered on a single scale, such as risk of disease (Plous, 1993). However, when there are many criterion involved one has to make a "multi-attribute choice" (Einhorn & Hogarth, 1981), rather than an optimal decision. Svenson (1979) described two ways of doing this: compensatory and noncompensatory strategies. Compensatory strategies trade-off low values against high values, whilst noncompensatory strategies do not allow trade-offs and instead involve setting minimum criteria for different variables

(Plous, 1993). Decision-makers might use different strategies, depending on how complex or important the decision is, and how much information is available (Hickson & Khemka, 1999).

However, these models still do not explain why two people in the same situation might make different decisions (Hickson & Khemka, 1999). Janis and Mann's (1977) Conflict model proposed that in making a decision an individual feels conflict to accept or reject different alternatives. The individual's self-esteem and ability to handle stress will influence the coping style they use to deal with the psychological stress this conflict brings. Janis and Mann claimed a vigilant coping style was the most effective. This involves considering a range of options; considering the objectives to be met; weighing up the costs and benefits of all the options in relation to all the objectives; information searching for each alternative; reconsidering all the consequences; and planning for the chosen course of action and its consequences. In contrast, unconflicted adherence (ignoring the need to make a decision); defensive avoidance (procrastinating); and hypervigilance (making a rushed and panicked decision) are all maladaptive and more likely to lead to a poor decision (Hickson & Khemka, 1999).

Although this model focused on the process of decision-making, the vigilant coping style seems similar to normative decision models, which were rejected for being idealistic. Other authors have argued that people do not always apply a formal procedure to their decision-making (Einhorn & Hogarth, 1981; Evans, 1983; Kahneman & Tversky, 1979), as evidenced by the research on heuristics.

Heuristics are decision-making shortcuts, based on judgements, habits, past choice and moral values (Camic, 1992). Examples include: the anchoring heuristic (Tversky & Kahneman, 1974), whereby you use a piece of information you know, to estimate a piece of information you do not know; and the availability heuristic (Tversky & Kahneman, 1974) where decision-makers estimate the probability of an event occurring based on the information they can recall, rather than going out and researching all the facts.

Heuristics do not always lead to the same decision as rational decision-making might. For example, Tversky and Kahneman (1974) found the anchoring heuristic usually resulted in estimates too close to the anchor. However, Lichtenstein & Slovic (1971) concluded that heuristics may be an efficient method of reducing cognitive effort, whilst producing similar outcomes to optimal decision-making processes.

Emotions also influence our ability to make rational decisions. Loewenstein, Weber, Hsee and Welch (2001) argued that intense emotional reactions can override analytical appraisal of the situation. Slovic, Finucane, Peters and MacGregor (2004) demonstrated an affect heuristic, whereby we base a decision on our affective response to it. Etzioni (1988) suggested that the extent to which affective factors influenced our decision-making depended on the context. In addition, self-esteem, self-efficacy and how much we feel in control of the situation have all been proposed to affect whether we engage with decision-making (Janis & Mann, 1977; Ollendick, Greene, Francis & Baum, 1991; Hickson & Khemka, 1999), which will also have a significant effect on how rational our decision is.

Decision-Making Theory and Capacity to Consent

This brief overview of decision-making theory demonstrates that although there appears to be a consensus on what good decision-making ought to be (e.g. normative models, vigilant coping styles), our cognitive capacity, emotions and motivations all influence the extent to which we fully engage in this process. Janis and Mann (1977, p.15) concluded that the decision-maker,

“Does not behave in the manner of a rational calculator, [but is rather] a reluctant decision-maker, beset by conflicts, doubts and worry, struggling with incongruous longings, antipathies and loyalties, and seeking relief by procrastinating, rationalizing, or denying responsibility for his own choices.”

This psychological understanding of decision-making provides a basis for evaluating the literature on capacity to consent to healthcare, both theoretically in terms of how we assess it and empirically with regards to what influences it.

Assessing Capacity to Consent

Challenging the Current Model

The MCA guidance on assessing capacity is based on the principles of rational choice, despite the evidence that people frequently do not make rational decisions, but make more intuitive judgements based on heuristics or emotions (Dye et al., 2004; Reynolds & Nelson, 2007). Although it does provide a standardised

framework, Dye et al. argued that the MCA concept of capacity to consent is invalid, because it creates a two-tiered system in which people with intellectual disabilities are always required to be rational, whilst those without disabilities are not. Even for people without intellectual disabilities Lidz (2006) has argued for a model of informed consent that recognises that we do not make context-free decisions.

Thus the literature suggests a need to re-evaluate how we assess capacity to consent in people with intellectual disabilities. Dye et al. (2004) argued for a “recontextualisation” of the concept of capacity to consent, in order to address issues such as: few people with intellectual disabilities are deemed to have capacity to consent; not being able to consent may prevent people from partaking in medical research; our current assessments of capacity to consent are insufficient; and that not all elements of decision-making are equally important.

Inability to Participate in Research

The first two issues could result in people with intellectual disabilities having unequal access to healthcare. Participation in medical research can give people access to expertise unavailable outside a research setting (Charuvastra & Marder, 2006), which people with intellectual disabilities may be prevented from accessing if they are deemed unable to consent to the research. Furthermore, excluding them from studies means no research specific to their needs would ever be done.

Insufficient Assessment of Capacity to Consent

Dye, Hare and Hendy (2007) argued that current assessments of capacity are not sensitive enough. They report that 17 participants in their study, considered unable to consent using a standard assessment, all withdrew from the study, indicating an ability to give and withdraw consent. This raises questions about whether our standards for assessing capacity are too high.

Some effort has been made to investigate whether providing information in different formats might increase capacity to consent in people with intellectual disabilities, but without much success. Giving information in chunks to reduce the load on memory did not significantly improve capacity to consent (Wong, Clare, Holland, Watson & Gunn, 2000; Dye et al., 2007). Using photographs to give information about a medical procedure, to reduce verbal demand also failed to increase capacity to consent (Dye et al., 2007). However, Dunn, Stenfert-Kroese, Thomas, McGarry & Drew (2006) demonstrated that providing information about psychology services via video to people with intellectual disabilities significantly increased understanding about psychology services in all 19 participants, although there was no comparison with written or verbal information.

Cameron & Murphy (2007) argued that people with intellectual disabilities need to be given more time than other people to process the information they are given, but did not elaborate on how a clinician might judge this. Wong et al. (2000) looked at how people demonstrate their capacity to consent. They found that allowing people to identify statements they recognised or giving a non-verbal demonstration of the procedure, increased the number of people with intellectual disabilities who could

consent to a blood test. They concluded that assessments of capacity that rely on verbal expressive skills may be excluding people who are able to consent, but cannot express it verbally.

There is a lack of research on the impact of framing information differently in relation to capacity to consent, despite the evidence that framing affects how people make a decision (Tversky & Kahneman, 1981).

Elements of Decision-Making

Research has looked at which elements of decision-making people with intellectual disabilities find most difficult, raising the possibility of finding interventions to target these areas. Arscott, Dagnan and Stenfert-Kroese (1999) found that participants did better at understanding the problem, the alternative options and making a decision, but performed significantly lower on questions about legal rights and the consequences of choosing or refusing treatment. Morris, Niederbuhl and Mahr (1993) found similar results, but they also found that several people *without* intellectual disabilities struggled with the question about legal rights.

Wong et al. (2000) identified a significant trend for the best to least well understood questions: procedure>purpose>voluntariness>risks of procedure>risks of refusing. The authors suggested that generating risks seemed too complex and abstract for most participants with intellectual disabilities.

Cea and Fisher (2003) rated four standards of increasing difficulty: communicating a choice, understanding information, appreciation of the consequences and ability to

weigh up the consequences. They found no significant differences between participants with mild intellectual disabilities and no intellectual disabilities for communicating a choice, but as the standards became harder, the mild and moderate intellectual disabilities groups scored less well. They also found that more than 60% of the group *without* intellectual disabilities struggled with weighing up consequences.

Dye et al. (2007) found that all participants could make a choice about participating in research, but only 69.4% understood the impact of the choice. They also found that only 12.9% understood the nature of the study. This is in contrast to the healthcare intervention studies (Arscott et al., 1999; Morris et al., 1993; Wong et al., 2000) which found that understanding the nature of the procedure was one of the easier elements of the task. Fisher, Cea, Davidson and Fried (2006) also found that communicating a choice was the easiest element of decision-making, but understanding the purpose of the research and reasoning were the hardest categories. This suggests that understanding the reasons for doing healthcare research is harder for people with intellectual disabilities to understand, than having treatment.

Despite the varying results, all the studies show that understanding consequences and ability to reason are the hardest elements of decision-making, for people with and without intellectual disabilities. They also show that many people with intellectual disabilities, who might be deemed unable to consent because they cannot demonstrate these abilities, are often still able to understand the procedure and communicate a choice.

Possible Solutions

Some authors have proposed alternative methods of assessing capacity that are more in keeping with decision-making theory. Dye et al. (2004) proposed replacing dichotomous categorisation of capacity to consent with a matrix of decision-making which would include the influences of friends, family and previous experience. The model would assess the competency of the decision-making process, rather than the individual. They also argued that risk and capacity to consent need to be considered on a continuum, so that a very risky decision (e.g. having an operation) would require more 'informed' capacity than a low risk decision (e.g. having a blood test).

Fisher (2003) proposed a 'goodness-of-fit ethic', which conceptualises capacity to consent as a product of the relationship between the person and the consent context. Therefore assessing capacity would involve not just a consideration of the individual's understanding, but also ways in which the context could be manipulated to increase that understanding, placing an obligation on the assessor of capacity to consider both. The strength of this model is that it provides a platform for incorporating ideas on how information is presented and which elements of decision-making need to be considered. It also provides a framework for considering the unequal power dynamic between the clinician assessing capacity and the person with an intellectual disability (Lotan & Ells, 2010).

Both of these models are currently just propositions, but they fit better with decision-making theory. They would also allow a person to give consent to a less risky procedure, despite having difficulty with more complex elements of decision-making, as people without intellectual disabilities are able to do. However, they are

more complex than the MCA framework and would require more time from health professionals.

Reality of Assessing Capacity to Consent

Despite the criticisms of the rational assessment of capacity to consent, and the proposition of alternatives, the MCA remains law and is used in all recent research on capacity to consent to healthcare. This is important to consider when reviewing the empirical evidence of which factors affect capacity to consent to healthcare in adults with intellectual disabilities. The studies reviewed next all used questionnaires aimed at establishing the individual's understanding of the problem, the intervention, the consequences, their rights and options, and their ability to communicate their decision. Any person who did not provide a satisfactory answer to all these parts was deemed unable to consent. Further details of the studies reviewed below can be found in Appendix A2.

What Influences Capacity to Consent to Healthcare Interventions and Research?

Cognitive Ability

Decision-making theory highlighted the impact of limited cognitive capacity on rational decision-making, so we would expect that impaired cognitive abilities would impact capacity to consent.

Intellectual Ability (IQ)

Morris et al. (1993) assessed capacity to consent to three hypothetical healthcare vignettes. Whilst people without intellectual disabilities all had capacity to consent, six of fifteen people with mild intellectual disabilities and one of fifteen people with moderate intellectual disabilities had the capacity to consent, indicating an association between low IQ and lacking capacity to consent. However, the sample size was small and incomplete information was given on participants' IQ.

Cea and Fisher (2003) found that participants without intellectual disabilities did significantly better than participants with mild intellectual disabilities (IQ: 55-80), who did significantly better than participants with moderate intellectual disabilities (IQ: 36-54), for almost all elements of decision-making. However, the results are confounded by the use of different measures to assess IQ in the intellectual disability and control groups (Goldsmith et al., 2008). Fisher et al. (2006) found the same results when assessing consent to medical research.

Overall, the studies suggest that lower intellectual ability is associated with decreased capacity to consent. The limitation of the studies is that they are all based on hypothetical situations and only one study gave IQ scores.

Verbal Ability

Arcott et al. (1999) found a significant positive relationship between verbal ability and capacity to consent to healthcare vignettes (that were based on Morris et al. (1993)). Furthermore, verbal ability distinguished those who could consent, from

those who were unable to consent on all three vignettes. A small sample size prevented regression analyses being done.

Fisher et al. (2006) also found that verbal ability showed positive correlation with capacity to consent for the mild and moderate intellectual disabilities groups. However, capacity to consent in the moderate intellectual disabilities group also correlated with non-verbal reasoning, daily living skills and socialisation, suggesting an interaction between factors. Dye et al. (2007) and Arscott, Dagnan and Stenfert-Kroese (1998) both found a significant positive correlation between verbal ability and capacity to consent to research. Again most of these studies used hypothetical vignettes and regression analyses were not done.

Cameron and Murphy (2007) found that 40% of participants who were unable to consent to a research study only understood 1-2 information carrying words. In comparison, of those who could consent, 24/29 understood 3-4 information carrying words. However, no formal analysis was done to confirm the relationship or the influence of other variables.

Overall, the studies indicate a link between verbal ability and capacity to consent. However, Dye et al. (2007) found that reducing demand on receptive verbal ability did not improve capacity to consent. Although, Wong et al. (2000) found reducing demand on people's expressive verbal ability did increase capacity to consent. Thus although there is some relationship between lower verbal ability and decreased capacity to consent, it seems the relationship is not necessarily direct.

Memory

Arcott et al. (1999) found memory correlated significantly with all aspects of capacity to consent, except for understanding the nature of the problem. Memory scores also distinguished those who could consent from those who could not on two vignettes, but not the third. Dye et al. (2007) also found a significant positive correlation between memory and capacity to consent.

Again this conflicts with evidence that presenting information in chunks, rather than all in one go, did not improve capacity to consent (Wong et al., 2000; Dye et al., 2007). Dunn et al. (2006) did find that participants did better when shown a video about seeing a psychologist in chunks and asked relevant questions after each section, rather than being asked all the questions at the end, but the difference was not significant. The lack of significance may have been due to a small sample size.

Thus the relationship between memory and capacity to consent is less clear. It is possible that Wong et al. (2000) and Dye et al. (2007) did not reduce the demand on memory sufficiently to make a difference. However, their results may also indicate there are other factors involved.

Executive Functioning

There is a lack of research on the role of executive functioning in relation to capacity to consent to healthcare, despite some evidence that it interacts with adults' with intellectual disabilities decision-making ability in other areas e.g. finance (Wilner, Bailey, Parry & Dymond, 2010a; 2010b).

Emotions

There is no research about the role of emotions on capacity to consent to healthcare, despite decision-making theory highlighting its significant impact on rational decision-making (Loewenstein et al., 2001).

Decision-Making Opportunities

Jenkinson (1999) argued that a lack of choice or decision-making opportunities for people with intellectual disabilities was likely to lead to learned helplessness, whereby they perceive that nothing they do will make any difference to their lives, because they are not in control. Given that control is influential in being motivated to engage in a rational decision process (Ollendick et al., 1991) it seems likely that the amount of decision-making opportunities a person has, will affect their capacity to consent. However, it has not been investigated in relation to capacity to consent to healthcare.

Acquiescence

Acquiescence, defined as acceptance without protest (Goldsmith et al., 2008), is a concern with people with intellectual disabilities. Arscott et al. (1998) found that 42.5% of participants did not understand they could decline to participate in research. Arscott et al. (1999) showed that participants did not understand they could refuse medical treatment, or what the consequences were if they did. Morris

et al. (1993) reported that participants believed they would get treatment whether they agreed or not.

Fisher et al. (2006) found the majority of participants with mild intellectual disabilities understood they could refuse participation, compared to only half of those with moderate intellectual disabilities. Furthermore, few understood they could later withdraw their consent. Dunn et al. (2006) stated that initially only 10% of participants understood they could stop seeing a psychologist. Even after watching a video about seeing a psychologist, almost half the participants still did not understand their right to stop. However, Dye et al. (2007) reported that 17% of participants withdrew from their study, showing that some people with intellectual disabilities understand they can change their mind.

All these studies suggest that acquiescence is a significant problem for assessing capacity to consent and is something that researchers and clinicians need to be aware of. Further research into helping people with intellectual disabilities understand their right to refuse or withdraw from treatment is important.

Previous Experience

The use of heuristics in decision-making highlights the importance of previous experience. Cea and Fisher (2003) argued that understanding of factual information about a medical procedure would be improved if that person had had the procedure before.

There is little research on the effect of previous healthcare experience on capacity to consent. Morris et al. (1993) concluded that participants may have done better on the behavioural intervention vignette, compared with the medication and surgery vignettes, because they had more experience of behavioural interventions. However, Arscott et al. (1999) found that taking medication did not improve performance on the medication vignette, versus the behavioural or surgical vignettes. Fisher et al. (2006) found there was no association between the medical histories of participants and their capacity to consent.

However, Grisso and Appelbaum (1991) found that participants with a mental illness showed a better understanding of their condition than other medical conditions they had not experienced. Therefore there is a need to assess whether experience of a healthcare intervention influences capacity to consent to the same intervention, in people with intellectual disabilities.

Limitations of the Evidence

There are significant limitations to the evidence reported here. Firstly, different studies had different ways of recruiting participants and assessing their level of intellectual disability. Different measures were also used to assess cognitive abilities. As the level of intellectual disabilities was often not reported, other than in broad categories, it is difficult to know whether different findings could be due to different levels of abilities in the participants. Secondly very few factors were controlled for in participant samples, for example, residential status or gender. Thirdly, assessment of

capacity was done using a range of measures, which were all based on the concept of rational choice, but differed in their specific design. Finally, all the evidence comes from a small number of studies, so that conclusions are based on a small number of participant samples.

Summary of the Evidence

The studies described above demonstrate that our understanding of capacity to consent to healthcare for people with intellectual disabilities is far from clear. Intellectual ability emerged as a strong influence on capacity to consent, but the results for verbal ability and memory are less clear and the nature of the relationships requires further investigation. Many of the factors have insufficient evidence to draw a conclusion: executive function, emotions, decision-making opportunities and previous experience. Acquiescence emerged as a significant concern for those assessing capacity to consent and something health professionals and researchers need to consider.

Conclusions and Further Questions

This review highlights many areas for further research. The factors that decision-making theory suggests would influence capacity to consent almost all require further investigation. However, these factors need to be investigated not only in isolation, but also in relation to each other, which has not yet been done in this field. Exploring how the factors relate to each other might help to explain why

manipulating verbal and memory ability have not consistently improved capacity to consent, even though there appears to be a significant relationship between these factors and capacity to consent. The field also needs a broader number of studies to demonstrate that the findings are replicable across a variety of participant samples. Furthermore, in drawing conclusions from the evidence presented here, it is necessary to remember they are based on a rational model of capacity to consent, which we have seen does not accurately reflect how people make decisions.

It is important to extend the current research to find ways of improving capacity to consent to healthcare in people with intellectual disabilities. Attempts to manipulate the load on memory and verbal ability have not been successful. Instead it may be beneficial to focus on helping people with intellectual disabilities understand the more complex elements of capacity to consent, such as their legal rights and consequences of choice, which the evidence showed was the biggest barrier to people with intellectual disabilities demonstrating capacity to consent.

Finally, it is important to continue the debate about how to assess capacity to consent and whether the MCA creates a system which requires people with intellectual disabilities to be more rational than people without intellectual disabilities. A balance is needed between safeguarding vulnerable people who lack the ability to make decisions for themselves and ensuring that principles of self-determination for people with intellectual disabilities are upheld. Continuing research and discussion is needed to establish a fairer and more effective assessment of capacity to consent to healthcare.

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**EXPLORING THREE FACTORS INFLUENCING CAPACITY TO
CONSENT TO A HEALTH CHECK IN ADULTS WITH
INTELLECTUAL DISABILITIES**

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Abstract

Background: Capacity to consent has been identified as one of the significant barriers to healthcare faced by people with intellectual disabilities. In order to improve understanding, the literature has attempted to investigate factors that influence capacity to consent to healthcare.

Materials and Method: This study had 32 participants with learning disabilities, 22 carers and 3 nurse participants. It examined the correlations between verbal ability, decision-making opportunities and previous health experience, with capacity to consent to healthcare in people with learning disabilities, before exploring a regression model to show how the factors interacted.

Results: Previous health experience and verbal ability significantly positively correlated with capacity to consent, whilst the correlation with decision-making opportunities was almost significant. However, the regression model showed that only verbal ability was a significant predictor.

Conclusion: The study reveals the importance of looking at how factors that influence capacity to consent to healthcare interact with each other, rather than just acting individually. Further research is required to expand this model to include other variables.

Intoducton

Poor Healthcare

People with intellectual disabilities experience poorer healthcare and health outcomes than the general population. Van Schrojenstein Lantman-de Valk, Metsemakers, Haveman and Crebolder (2000) found that compared to other people registered at the same GP practices, people with an intellectual disability had more than double the number of health problems. They tend to experience increased primary healthcare conditions as a direct result of their intellectual disability (e.g. epilepsy, mobility and sensory problems) and increased secondary healthcare conditions (e.g. obesity, constipation) as a result of decreased mobility, increased medications and poorer healthcare (Van Schrojenstein Lantman-de Valk & Walsh, 2008).

Capacity to Consent

There is evidence that at times, people with intellectual disabilities have been denied healthcare interventions due to confusion about capacity to consent (Keywood, Forvargue & Flynn, 1999), either because health professionals fear infringing their human rights, or because capacity to consent is not properly assessed and challenging behaviour is interpreted as refusing treatment.

Confusion about capacity to consent can lead to clinicians failing to ask for consent, so that interventions are carried out without the capacitous person's consent, which could constitute an offence of assault or battery (Wong, Clare, Gunn & Holland, 1999). Alternatively, it can also lead to interventions not being carried out, for fear

of infringing people's human rights, as highlighted in the Mencap (2007) report *Death by Indifference*, which concluded that confusion about the law on capacity to consent amongst health professionals was a contributing factor in failing to tackle unequal access to healthcare for people with intellectual disabilities. Hence there is a significant need for a greater understanding about capacity to consent to healthcare in adults with intellectual disabilities.

Annual Health Checks

Research evidence has demonstrated that regular health screening identifies health problems that are often not reported by people with intellectual disabilities or their carers (Martin, Roy & Wells, 1997; Cooper et al., 2006), enabling improved healthcare. As a result Government good practice guidance indicates that commissioners need to provide for all people with intellectual disabilities to have annual health checks (Department of Health, 2008). In April 2008 the British Medical Association (BMA) and NHS Employers agreed that one of the new Directed Enhanced Services (DES) for GPs would be to provide an annual health check for all patients on the local authority intellectual disability registers.

It is therefore vital that healthcare professionals providing these health checks can assess people's with intellectual disabilities capacity to consent. The Mental Capacity Act (MCA; 2005) requires that each individual's capacity to consent is functionally assessed for each situation. This means decisions about capacity to consent can be complex and time-consuming, which can be challenging for primary healthcare

professionals who are encouraged to have short appointments (RCGP's information sheet No. 3, April 2004).

Understanding Capacity to Consent

In order to understand some of the issues related to capacity, recent literature has investigated variables that might influence a person's capacity to consent to healthcare (Goldsmith, Skirton & Webb, 2008). There is some evidence that decreased capacity to consent is associated with a lower IQ (Morris, Niederbuhl & Mahr, 1993; Cea & Fisher, 2003; Fisher, Cea, Davidson & Fried, 2006), decreased verbal ability (Arscott, Dagnan & Stenfert-Kroese, 1998; Arscott, Dagnan & Stenfert-Kroese, 1999; Wong, Clare, Holland, Watson & Gunn, 2000; Fisher et al., 2006; Cameron & Murphy, 2007) and impaired memory (Arscott et al. 1999; Dunn, Stenfert-Kroese & Drew, 2006; Dye, Hare & Hendy, 2007).

However, this research is still in the early stages. There are only a small number of studies conducted so far, so conclusions are based on a small number of participant samples. In addition, other factors that seem likely to influence capacity to consent to healthcare, have not yet been investigated. For example, there is no research into the influence of executive dysfunction, despite evidence that this affects capacity to make financial decisions (Dymond, Bailey, Willner & Parry, 2010; Wilner, Bailey, Parry & Dymond, 2010a; 2010b).

Furthermore, there is increasing evidence that where factors do influence capacity to consent in adults with intellectual disabilities, it is not necessarily a direct relationship. Despite the association between verbal ability and capacity to consent,

Dye et al. (2007) found that reducing the demand on verbal ability did not increase capacity to consent. Similarly, studies have found that reducing the demand on memory did not increase capacity to consent in adults with intellectual disabilities (Dye et al., 2007; Wong et al., 2000). Fisher et al. (2006) found that although capacity to consent positively correlated with verbal ability for people with moderate intellectual disabilities, it also positively correlated with non-verbal reasoning, abilities in daily living and socialisation, indicating there may not be a straight forward relationship.

Inter-relating Factors

In order to extend this area of research therefore it would be helpful to explore how the variables that affect capacity to consent interact with each other. For example, in Fisher et al.'s (2006) study it is possible that non-verbal reasoning, abilities in daily living and verbal ability interact with each other to influence capacity to consent. Suto, Clare, Holland & Watson (2005) have started to explore this idea in relation to capacity to make a financial decision. They explored the interaction between intellectual ability, decision-making opportunities and basic financial knowledge in contributing to financial decision-making ability. Having established individual relationships between the three variables and financial decision-making ability, they then used partial correlations, to show that the relationship between intellectual ability and financial decision-making ability was not direct, but was mediated by basic financial knowledge and everyday opportunities to make decisions, as shown in their model (re-drawn in Figure 1). They concluded that although intellectual ability

was important, in order to maximise capacity to make financial decisions a person needs access to basic financial skills and everyday decision-making opportunities.

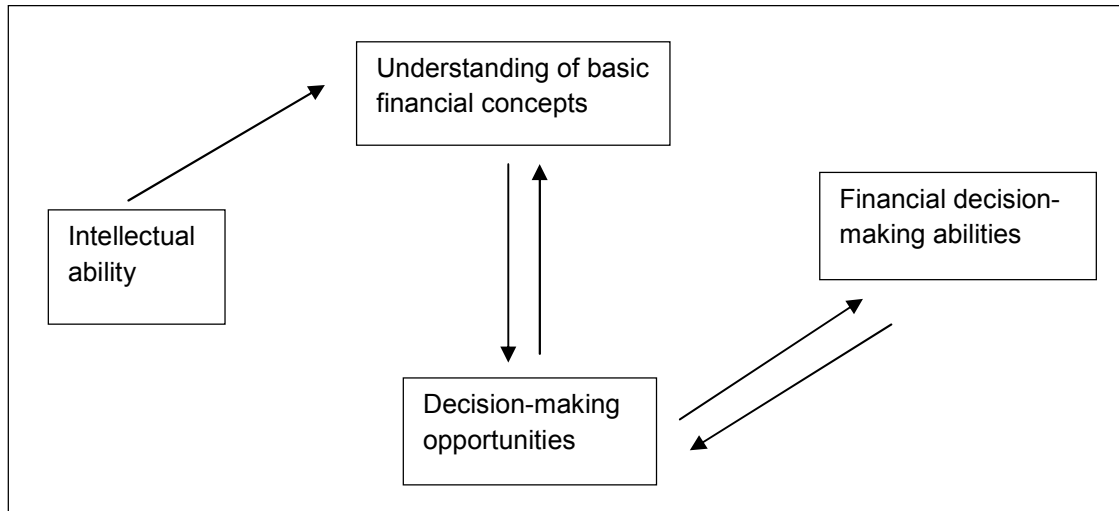


Figure 1. Suto et al. (2005) - Summary of the major direct relationships identified among the three measured factors affecting financial decision-making abilities among adults with intellectual disabilities.

In addition to providing a helpful theoretical understanding of some of the variables that relate to capacity to make financial decisions, their model also highlights ways in which capacity might be increased. It also provides an important illustration of why it is helpful to look and how the influencing variables interact with each other and not just their relationship with decision-making ability.

Decision-Making Abilities

In addition to exploring factors that influence capacity to consent, studies have attempted to identify those parts of the decision that people with intellectual disabilities find most difficult. To date the research has shown that understanding consequences and ability to reason are the hardest elements of decision-making, for

people with and without intellectual disabilities (Morris et al., 1993; Arscott et al., 1999; Wong et al., 2000; Cea & Fisher, 2003). Identifying the areas of capacity to consent that people with intellectual disabilities struggle most with could help identify possible areas for intervention.

Aims of this Research

This current study was a pilot study, aimed at investigating whether a similar model to Suto et al. (2005) can be applied to capacity to consent to healthcare, by exploring some of the factors that might affect capacity to consent to a health check. Health checks were chosen because they are a healthcare intervention that every adult with an intellectual disability should be receiving (Department of Health, 2008). They incorporate procedures such as being weighed, measuring blood pressure and having a blood test (BMA & NHS Employers, 2008), which are simple, but can also be invasive.

Three variables, similar to Suto et al. (2005), were chosen for exploration: verbal ability, decision-making opportunities and previous healthcare experience. Verbal ability was chosen because it is a key variable, which is linked with intellectual ability, but the research has shown a less clear relationship between capacity to consent to healthcare and verbal ability, compared to intellectual ability, suggesting further research might be helpful. In addition assessing verbal ability was likely to be quicker and more engaging for participants, thus reducing the burden on them and increasing the likelihood of their participation.

Decision-making opportunities were chosen because Suto et al. (2005) demonstrated a clear link with capacity to make a financial decision, but it has not yet been investigated in relation to capacity to make a healthcare decision. If a link was demonstrated it would also have practical implications for improving capacity to consent.

Finally, previous health experience was chosen because there is a current lack of evidence linking it to capacity to consent to healthcare, despite suggestions there might be a link (Morris et al., 1993; Arscott et al., 1999) and despite evidence that there is an association with capacity to consent to healthcare in people with a mental illness (Grisso & Appelbaum, 1991).

Hypotheses

It is hypothesised that there will be a positive relationship between verbal ability and capacity to consent to healthcare as shown in other research, described above. As well as influencing capacity to consent, it is hypothesised that increased verbal ability may also be associated with increased decision-making opportunities and previous healthcare experience. Those who have better verbal ability may appear more able and thus be allowed to make more decisions for themselves. Also, it may be that healthcare professionals are more likely to explain about the health procedures, if they believe the person can understand them.

It is hypothesised that knowledge of a health check, based on previous experience would also affect capacity to consent to a health check. Decision-making theory shows that people frequently use heuristics to make decisions (Lichtenstein & Slovic,

1971), based on previous experiences (Camic, 1992). If people have had a health check before, they might be more likely to know why certain procedures are helpful, but also the disadvantages (e.g. pain) of having them done (Cea & Fisher, 2003).

Finally, it is hypothesised that increased decision-making opportunities would affect capacity to consent to a health check. A lack of decision-making opportunities can lead to learned helplessness (Jenkinson, 1999), which in turn can lead to a lack of engagement with the decision-making process and therefore decreased ability to make decisions (Ollendick, Greene, Francis & Baum, 1991).

Therefore this study examines how verbal ability, decision-making opportunities and previous experience of a health check interact to influence capacity to consent to a health check in adults with an intellectual disability. In addition, it also aims to confirm and extend the findings on particular decision-making abilities in people with intellectual disabilities.

Materials and Methods

Ethical Considerations

Approval for the study was obtained from a national NHS research ethics committee, specialising in research with participants who are unable to consent, and from the relevant local NHS research and development committee (Appendix B and C). It was felt that most participants with intellectual disabilities would be able to consent to the research, but in order to ensure a broad range of participants who could and

could not consent to health checks, it was important not to exclude those who were unable to consent to the research. Consent was sought from every individual. Where it seemed the person could not consent, a research consultee was consulted (Appendix D and E), in line with the requirements of the MCA (2005). If it was then felt appropriate for the individual to participate in the research, their assent was also sought.

Participants

People with an Intellectual Disability

Forty-two adults with an intellectual disability were invited to participate. Of these, six declined. Opinions were sought from research consultees for two participants, one of whom took part and the other declined. A further three withdrew before starting data collection, leaving 32 participants in total. All participants, 20 male and 12 female, were on the local intellectual disability team register. Participants were included if they were English speaking, over 18 years old and had the expressive language ability to answer simple questions. People with a visual impairment or dementia were excluded. Nineteen participants lived in residential care homes, eight lived in supported living, two lived in Shared Lives adult placements, one was in an Assessment and Treatment unit, one lived with their partner and children and one lived with parents.

Carers

A carer was recruited for every participant with an intellectual disability, although some carers provided information on more than one participant, resulting in 22 carers in total. They were people who knew the participant well and could answer questions about their daily lives.

Nurses

Practice nurses were recruited through the local intellectual disability team, who had a register of all the local GP surgeries providing annual health checks for people with intellectual disabilities. All the nurses were sent a letter and information sheet (Appendix F and G) about the project which was followed up with phone calls and visits to their surgeries. Seven nurses agreed to take part. However, when followed up for further contact, only three responded. After several attempts to contact them without success, it was assumed the other four had withdrawn their participation from the study.

Design

This research used a correlational, cross-section design, in line with other research in the area. The study was quantitative and used both standardised and non-standardised measures.

Measures

Verbal Ability

Verbal ability was assessed using the British Picture Vocabulary Scale – 2nd Edition (BPVS; Dunn, Dunn, Whetton & Pintillie, 1982; Appendix H). It measures a person's receptive vocabulary and relates closely to verbal IQ. The measure has been shown to have good reliability and validity. Cronbach's Alpha was 0.93 with a split-half reliability of 0.86. The manual contains detailed information of the measure's strong positive correlation with other language tests, as well as its value in predicting cognitive ability. Although designed for children it has been widely used with adults with intellectual disabilities (e.g. Arscott et al., 1999; Howlin, Davies & Udwin, 1998; Dye et al., 2007).

Decision-Making Opportunities

In line with Suto et al. (2005), the Choice Questionnaire (CQ; Stancliffe & Parmenter, 1999; Appendix I) was used to assess decision-making opportunities. The original study showed it to have good reliability and validity. Internal consistency had a Cronbach's Alpha of 0.9 and inter-scorer agreement was 91.9%, whilst the test-retest reliability was 0.89. The questionnaire was also shown to have good concurrent validity (0.83) with a Quality of Life Empowerment scale. Construct validity was demonstrated by showing a significant difference between those living semi-independently compared with those living dependently. The measure can be self-report or completed by carers. For this study carers completed the questionnaire, to standardise administration across all participants, some of whom

would not have been able to complete it for themselves. In the original study no significant differences were found between participant and staff scores.

Previous Experience of Health Checks

A Health Experience Questionnaire (HEQ; Appendix J) was designed to assess how much previous experience of health checks participants could recall. It contained 11 questions asking about whether the person had experienced the different procedures in the health check. Participants could answer "yes", "no" or "don't know" for each procedure. "Yes" answers scored 1-point, and "no" or "don't know" scored 0-point, leading to a score out of 11.

The questionnaire used simple language and pictures to maximise understanding and a consultation was held with a local intellectual disability advocacy group to ensure its accessibility for people with intellectual disabilities. Content validity was achieved by basing the questionnaire on the Cardiff health check protocol (BMA & NHS Employers, 2008), which all health checks are based on. As a measure of reliability both the carer and the researcher scored the answer to each question, for 50% of the sample. Scores between them were compared and inter-rater reliability analysed.

Capacity to Consent

The assessment of capacity to consent to the health check (Appendix K) was similar to measures used in other capacity to consent studies (e.g. Morris et al., 1993), but

rather than presenting vignettes, information about the procedures in the health check was presented to the person using an information sheet with pictures and simple language (approved by members of a local intellectual disability advocacy group). A semi-structured questionnaire and scoring sheet (adapted from Suto et al., 2005) was then used to ask participants questions about the decision to be made. The researcher asked as many questions as were appropriate to give the individual maximum chance to demonstrate their knowledge. Appropriate answers could include information from the sheet or other individual responses.

Instead of presenting all the information at once, the assessment used 'Element Disclosure' (Wong et al., 2000), which involved breaking down the information into sections and asking questions after each part. Participants were also encouraged to use the information sheet when answering, to reduce the load on memory. There were four sections or subtests: measuring height and weight; checking ears, chest and blood pressure; urine and medication; and injections and blood tests.

The assessment was scored in two ways. Firstly, five decision-making abilities were rated for all four subtests. The abilities were: understanding what decision was being made and their right to say no (identification); understanding the advantages and disadvantages of the procedure (understanding); ability to reason, demonstrated by having an opinion on whether the procedure was good or bad (reasoning); understanding who would be affected by the decision (appreciation); and communicating the decision (communication). Each ability was scored 0 (no relevant information offered), 1 (partially relevant response), 2 (response indicating full understanding). This provided a total score out of ten for each subtest, giving a total

score out of 40 (across all the subtests). Secondly, a score was obtained for each decision-making ability across all subtests. This provided a score out of eight for each decision-making ability (across the four subtests).

Each assessment was rated by two people: the lead researcher and an Assistant Psychologist blind to their performance on other measures. Two assessments were used as a pilot for the raters to agree scoring criteria and inter-rater reliability was then analysed for the remainder of the sample.

Procedure

Initially people with an intellectual disability who attended the surgeries where the original seven nurses agreed to participate, were invited to take part. Later on other participants known to the intellectual disability team were also invited to participate. This amendment was approved by the NHS ethics committee (Appendix L). A member of the local intellectual disability team made contact through letters (Appendix M and N) and phone calls. The lead researcher then met all those who expressed an interest in the project to go through the information sheet and establish consent to take part. The information sheet and consent form were approved by a local intellectual disability advocacy group.

Following initial agreement a second appointment was arranged for data collection. At this appointment the researcher again confirmed that the person wished to take part and they signed a consent form (Appendix O). The BPVS, HEQ and Assessment of Capacity to Consent were then completed with the individual. The capacity assessment was also audio-recorded for the purpose of scoring inter-rater reliability

and this was agreed to on the consent form. Participants were given the option of their carer sitting in, which half the participants opted for. The appointments lasted approximately 45-60 minutes, although sometimes they were up to 90 minutes, with a break in the middle.

Carers were asked to complete the CQ and those who sat in on the assessment were also asked to rate the HEQ for inter-rater reliability purposes. This required carers to mark the HEQ according to the participant's response (not their opinion of what the response should be). This was to demonstrate that we were accurately recording responses and gave us a measure of inter-rater reliability which demonstrated that different people can use the measure to get the same information. All carers also signed a consent form (Appendix P).

Following data collection the nurses were contacted for a brief telephone conversation. They were asked about the capacity to consent of the participants in the study for whom they had conducted health checks and the criteria they used to establish whether an individual has the capacity to consent to the health check.

Following analysis of data, a summary of the results was sent to all participants, the relevant ethics committee and NHS research and development department (Appendix Q, R, S, U & V).

Statistical Analysis

All data analysis was done using SPSS Version 17 for Windows. Missing data were dealt with by excluding variables on an analysis-by-analysis basis.

Statistical Power

Power calculations conducted prior to starting the research, were based on previous studies using the CQ and the BPVS (Arscott et al., 1999; Suto et al., 2005), which had effect sizes ranging from $r = .55$ to $r = .58$. In order to detect a significant ($p < .05$) correlation between these measures and capacity to consent to healthcare, with adequate power ($> 80\%$), a sample size of 25 is suggested (Clark-Carter, 2010). To allow for the possibility of data not being normally distributed Clark-Carter (2010) suggests multiplying the sample size by 1.1, indicating 28 participants.

Regression analyses have not been done in this field of research. However, in order to obtain a large effect size, $R^2 = .26$, a sample size of 40 is suggested (power $> 80\%$) to detect a significant regression (Clark-Carter, 2010). The potential impact of not having a large enough sample size for regression is reflected on in the Discussion.

Results

The distribution of the data was checked for normality (Appendix W). The capacity assessment, CQ and BPVS scores were all normally distributed. Correlations for these variables were conducted using Pearson's correlation coefficients. Scores for the HEQ were negatively skewed. Scores for decision-making abilities and subtests of the capacity assessment were also found to be non-normally distributed. Therefore, all correlations associated with these variables were conducted using a non-parametric test – Kendall's Tau. This test was used because it can be more accurate for smaller sample sizes (Field, 2009). A non-parametric ANOVA,

Friedman's test, was used for comparing scores on decision-making abilities and capacity assessment subtests.

Inter-rater Reliability

Inter-rater reliability was calculated for the Assessment of Capacity to Consent using two-way random single measure intra-class correlation (ICC; Shrout & Fleiss, 1979). The ICC for capacity to consent subtests 1-4 were 0.93, 0.92, 0.95 and 0.92 respectively, indicating very good reliability. Inter-rater reliability for the HEQ was calculated using Cohen's Kappa coefficient = .66, $p < .001$, indicating substantial agreement (Landis & Koch, 1977).

Dependent Variables

The results of the HEQ, CQ and BPVS are shown in Table 1.

Table 1

Characteristics of the Three Dependent Variables

Measure	Mean (SD)	Possible Range	Actual Range
Health Experience Questionnaire	9.31 (1.71)	0-11	5-11
Choice Questionnaire	61.17 (6.73)	26-78	49-73
British Picture Vocabulary Scale	73.1 (24.48)	0-168	25-123

Health Experience Questionnaire

The mean score for the HEQ indicated a high level of previous healthcare experience on average. The range of scores showed that everyone could recall some previous experience of the procedures in the health check.

Choice Questionnaire

One participant did not have a carer to complete the CQ and one participant was removed as an outlier on this measure. His score was more than two standard deviations below the mean and clinically it was felt that his very restrictive residential placement was inappropriate, given his level of ability. Hence data was included for 30 participants. The mean score indicated a reasonable level of choice on average.

British Picture Vocabulary Scale

One participant was unable to complete this measure due to an eye infection that developed before it could be completed, so data was analysed for 31 participants. The mean score is equivalent to the expected verbal ability of a seven year old. There was a large range of scores, indicating a range in ability from that expected of a two year old, up to that of a fourteen year old.

Capacity to Consent Assessment

The characteristics of the capacity assessment can be seen in Table 2. These figures show a wide range of scores, but demonstrate that some participants were able to

score the maximum points. In addition no participants scored zero on any of the subtests showing that everyone was able to demonstrate some decision-making ability. The Friedman test revealed there were no significant differences between the four subtests in the assessment: $\chi^2 (3, N=32) = 5.41, p = .14$.

Table 2

Characteristics of the Subtests and Total Score for Capacity to Consent Assessment

Subtest	Median	Range	Possible Range	No. of Participants Gaining Maximum Score
1. Health and Weight (n=32)	7.00	3-10	0-10	3
2. Ears, Blood Pressure and Chest (n=32)	7.00	4-10	0-10	2
3. Urine and Medication (n=32)	7.00	2-10	0-10	3
4. Injections and Blood Test (n=32)	7.00	3-10	0-10	4
Overall Total (n=32)	29	14-40	0-40	1

Relationships between Variables

Predictor Variables

As predicted BPVS scores showed significant positive correlation with HEQ ($\tau = .25$, p (one-tailed) = .04) and CQ scores ($r = .35$, p (one-tailed) = .03). The positive correlation between CQ scores and HEQ scores ($\tau = .20$, p (one-tailed) = .07) was almost significant.

These results show that increased verbal ability is associated with increased recall of previous healthcare experience and increased decision-making opportunities. The results also suggest that there is a relationship between increased decision-making opportunities and increased health experience, but the relationship is not quite significant.

Relationship with Capacity to Consent

HEQ scores ($\tau = .31$, p (one-tailed) = .01) and BPVS scores ($r = .61$, p (one-tailed) <.001) both showed significant positive correlation with total capacity to consent scores. However, whilst there was a positive correlation between CQ scores and capacity to consent ($r = .29$, p (one-tailed) = .06), it just failed to meet the significance level of $p < .05$.

These results demonstrate that increased verbal ability and previous experience of health checks are associated with increased capacity to consent to a health check. Decision-making opportunities did not show a strong enough relationship with

capacity to consent to be significant, but there was a trend to suggest that increased decision-making opportunities may be associated with increased capacity to consent.

Model of Regression

A regression model was then used to establish whether any of the variables could predict capacity to consent. Inspection of the data to ensure it met the assumptions of linearity, homoscedasticity and normally distributed errors required for a regression model (Field, 2009) are detailed in Appendix X. The correlations between the predictor variables were not large enough to cause a concern. The Variance Inflation Factor (VIF) and tolerance variables were acceptable (VIF = 1.15; Tolerance = .87) indicating the model is not biased and multicollinearity is not a problem (Field, 2009). The Durbin-Watson test was used to check for independence of errors. A value of 2.04 suggested there were no problems (Field, 2009).

The Enter method was used due to the small sample size (Brace, Kemp & Snelgar, 2006) and BPVS and HEQ scores were entered as independent variables. CQ scores were not included as they had not shown a significant correlation with capacity to consent. This produced a significant model ($F(2,28) = 9.34, p < .01$) which explained 40% of the variance ($R^2 = .40$). The information for the predictor variables is shown in Table 3.

Table 3

Unstandardised and Standardised Regression Coefficients for the Predictor Variables in the Regression Model

Variable	<i>B</i>	<i>SE B</i>	β
Previous Health Experience	0.76	0.62	.19
Verbal Ability	0.15	0.04	.54*

* $p < .01$.

These results show that only verbal ability was a significant predictor of capacity to consent. Once verbal ability was controlled for, previous health experience was not a useful predictor.

Capacity to Consent

The MCA (2005) requires that at some point a decision is made about whether a person has capacity or not. A strict criterion to determine this, in line with the MCA guidance, would be gaining the maximum score of 40. Capacity to consent could also be based purely on the clinical judgement of the interviewer. Table 4 shows the number of participants who would achieve capacity to consent, according to the different criteria. It also shows the number of people who scored 50% and 75% on the assessment.

Table 4

Number of Participants who had Capacity to Consent Dependent on Cut-off Point

Criterion	No. of Participants with Capacity to Consent
Maximum score of 40	1
Scoring 28 out of 40 (75%)	21
Scoring 20 out of 40 (50%)	28
Clinical Judgement	20

Decision-Making Abilities

The characteristics for each decision-making ability, across all subtests in the capacity assessment, are shown in Table 5.

Table 5

Characteristics for each Decision-Making Ability across all Capacity Assessment Subtests

Decision-Making Ability	Median	Range	Possible Range	No. of Participants Gaining Maximum Score
Identification (n=32)	5.50	4-8	0-8	11
Understanding (n=32)	4.00	0-8	0-8	3
Reasoning (n=32)	4.00	0-8	0-8	3
Appreciation (n=32)	8.00	0-8	0-8	19
Communication (n=32)	8.00	5-8	0-8	26

Patterns of Decision-Making

The numbers in the table suggest that some decision-making abilities were easier than others. The median scores indicate that appreciation and communication were the easiest decision-making abilities, with the range indicating that people scored better for communication. Understanding and reasoning seemed to be the hardest decision-making abilities.

The Friedman test revealed there were significant differences between the decision-making abilities: $\chi^2 (4, N=32) = 66.28, p < .001$. Post hoc analyses using Wilcoxon-signed rank tests are shown in Table 6. A Bonferroni correction was used to reduce the risk of Type 1 errors. The results show that communication, identification and appreciation were all significantly easier than understanding and reasoning. Communication was also significantly easier than identification.

Table 6

Results of Friedman's Test Post Hoc Analysis for Comparing Decision-Making Abilities

Comparison	Z	Effect size (<i>r</i>)
Understanding – Identification	-3.28*	– .26
Reasoning – Identification	-3.78*	– .30
Identification – Appreciation	-1.54	– .12
Identification – Communication	-3.76*	– .30
Understanding – Reasoning	-0.76	– .06
Understanding – Appreciation	-4.20*	– .33
Understanding – Communication	-4.72*	– .37
Reasoning – Appreciation	-4.09*	– .32
Reasoning – Communication	-4.74*	– .37
Appreciation - Communication	-2.07	– .16

* $p < .005$ *Relationships between Predictor Variables and Decision-Making Abilities*

Further correlation analyses, using Kendall's Tau, were done to explore which particular decision-making abilities, the three predictor variables correlated with. The results of the correlation analyses are shown in Table 7. A Bonferroni correction was not applied to take into account the number of correlations, because these were exploratory analyses.

Table 7

Correlations between the Three Predictor Variables and Decision-Making Abilities

	HEQ Score	CQ Score	BPVS Score
Identification	.27*	.19	.11
Understanding	.34**	.31*	.49**
Reasoning	.18	.16	.52**
Appreciation	.18	.13	.28*
Communication	.02	.06	.26*

* $p < .05$. ** $p < .01$.

These results show that increased previous health experience is related to increased understanding that you have a right to say no and understanding of advantages and disadvantages. Having more decision-making opportunities is associated with an increase in understanding of the advantages and disadvantages of the health check. Finally, better verbal ability is associated with an increase in understanding the advantages and disadvantages of the health check, ability to reason, appreciating who is impacted by the decision and communicating the decision.

Feedback from Nurses

Feedback from nurses was limited due to the small number of nurses participating and is therefore not suitable for thorough statistical or qualitative analysis. Information was gathered on six participants, all of whom nurses stated were able to consent. Capacity assessment scores for these participants were 17, 18, 22, 23, 31

and 33. Although a very small sample, the scores indicate that nurses were viewing some people as able to consent, despite scoring less than 50% on the capacity to consent assessment.

Simple thematic analysis of the nurse feedback identified four main criteria the nurses looked for in judging capacity to consent:

- Coming to appointments on their own
- Being able to answer questions
- Agreeing to the procedure
- Being able to have some sort of conversation

All three nurses said they had never had anyone refuse a procedure as part of a health check.

Discussion

Predictor Variables and Capacity to Consent

In support of our hypotheses the results found that previous health experience and verbal ability were both associated with capacity to consent to a health check. The findings show that verbal ability has a strong relationship with capacity to consent, as demonstrated by a large effect size, and the fact the relationship was not reduced by the other variables. Thus the findings that reducing demand on verbal ability did not improve capacity to consent (Dye et al., 2007) are unlikely to be due to a lack of association between verbal ability and capacity to consent. Instead it may be that

they did not reduce the demand on verbal ability significantly enough to make a difference.

The link between previous health experience and capacity to consent is a new finding in the literature on capacity to consent to healthcare, in people with intellectual disabilities. Fisher et al. (2006) found no link between medical histories and capacity to consent. However, as Cea & Fisher (2003) recommend, this study examined the link between previous experience of, and capacity to consent to, the same specific procedure – having a health check. Therefore, evidence of a link between the two supports the view that capacity to consent is situation and context specific.

This association is important to explore further, because it suggests that each time a person attends for a health check they will have increased capacity to consent. Therefore healthcare professionals need to be wary of assuming that if someone was unable to consent last time, they also cannot consent the next time.

Contrary to our predictions, the association between decision-making opportunities and capacity to consent was not quite significant. The number of participants for the study was based on large effect sizes as demonstrated by Suto et al. (2005), but the effect size for the correlation between decision-making opportunities and capacity to consent was medium (Cohen, 1988), which suggests a larger participant sample may be needed to show if the result is significant or not.

Relationship between Predictor Variables

As hypothesised verbal ability showed a significant association with decision-making opportunities and previous health experience. The link between verbal ability and previous experience suggests that participants with a higher verbal ability are more likely to go to the doctors regularly, possibly because they are more able to report health problems. Although, the finding may also be influenced by the fact the HEQ required verbal responses, even though it was designed to have a very low demand on verbal ability. This requires further investigation. The same argument does not explain the link between decision-making opportunities and verbal ability, because the CQ was completed by staff. Therefore the finding lends support to the hypothesis that those with greater verbal ability are given more opportunity to make their own decisions.

Model of Capacity to Consent

The aim of this study was to see whether a model could be created to show how the factors interrelated to influence capacity to consent. Figure 2 shows a model of the results of the correlation.

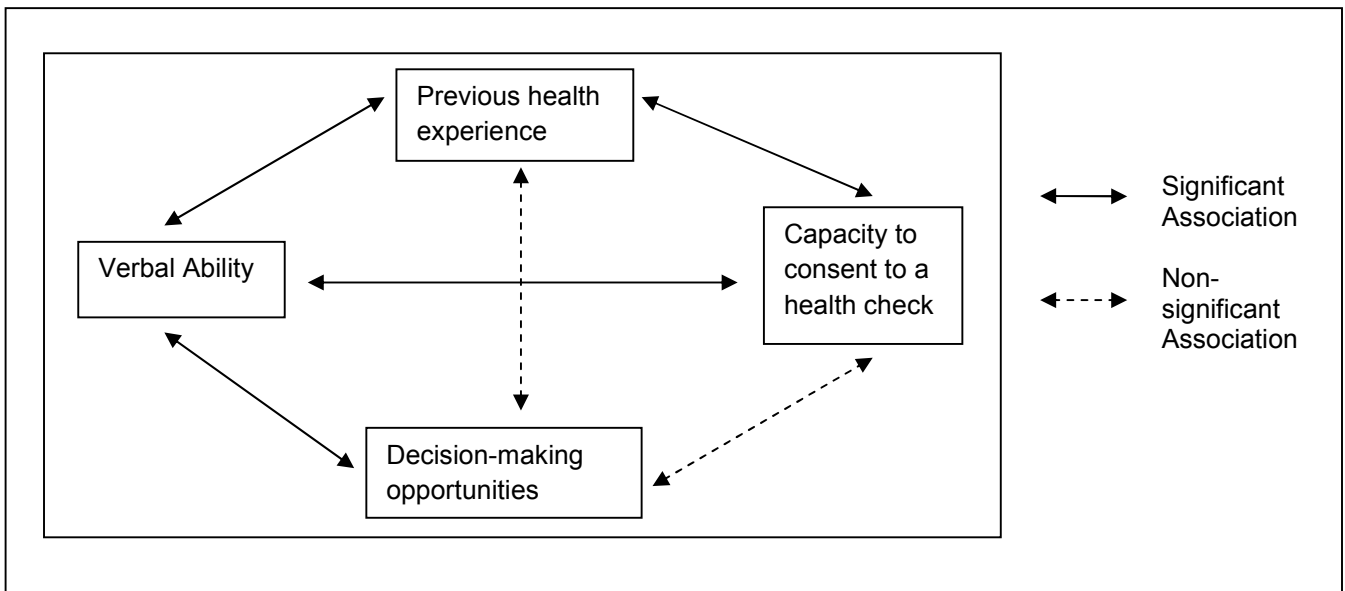


Figure 2. Correlational model of the relationships between the three predictor variables, verbal ability, previous health experience and decision-making opportunities and the dependent variable capacity to consent.

However, the correlation model does not show the direction of the associations or the influencing strength of each of the predictor variables. The model of regression looks quite different (Figure 3).

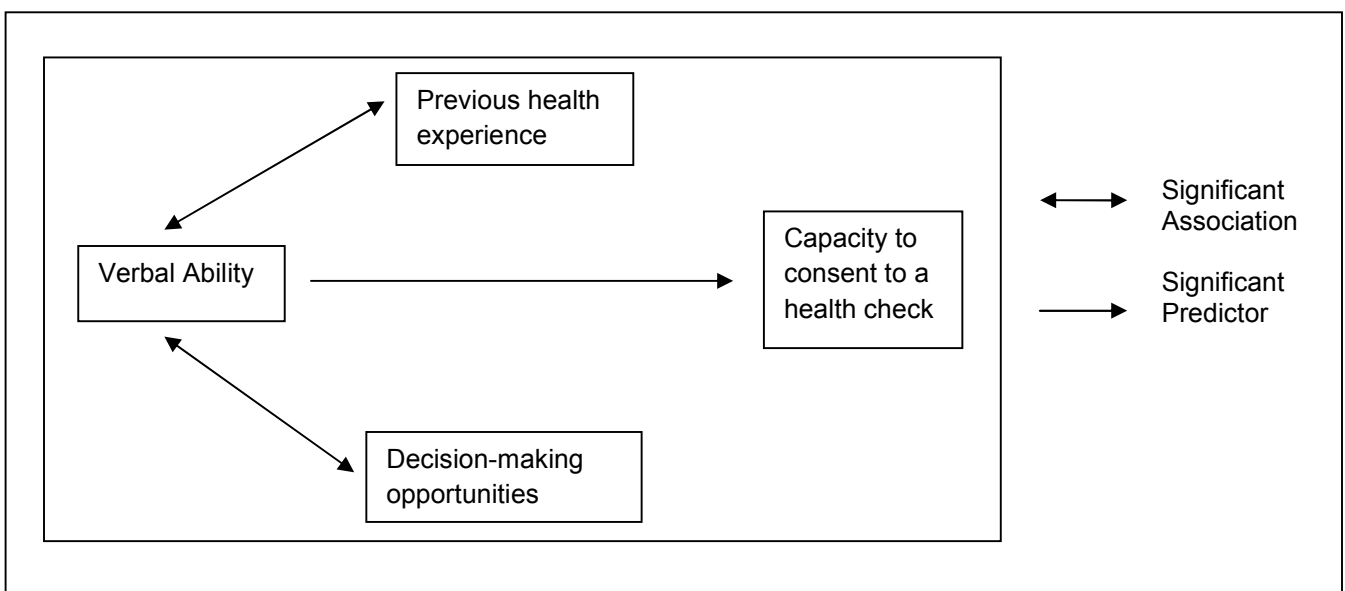


Figure 3. Regression model of the relationships between the three predictor variables, verbal ability, previous health experience and decision-making opportunities and the dependent variable capacity to consent.

This model showed that verbal ability was the only useful predictor of capacity to consent, which highlights the importance of not making assumptions from correlations. The large effect size indicates that there were enough participants in the study for a significant regression model, however greater participant numbers are required to fully explore the impact of previous health experience and decision-making opportunities.

Decision-Making Abilities

The results showed that understanding advantages and disadvantages and ability to reason were the hardest elements of decision-making, in line with other research (Arscott et al., 1999; Morris et al., 1993; Wong et al., 2000; Cea & Fisher, 2003). Communicating a choice seemed to be the easiest (Fisher et al., 2006), as only six participants failed to get the maximum score. This evidence helps identify potential areas of intervention, to improve capacity to consent to healthcare. Difficulties in understanding the consequences of a decision suggest we need to find better ways to communicate this information to people with intellectual disabilities. Suggestions include providing more visual information, giving people time to process it, repeating information at time intervals or where possible providing physical demonstrations. Further research is needed to explore these possibilities.

Acquiescence

Although the results suggested that understanding their right to say no was one of the easier decision-making abilities, less than 50% gained full marks for this,

suggesting more than half of participants felt pressured or unable to say no at some point. Similar findings have been reported in other studies (Morris et al., 1993; Arscott et al., 1999; Fisher et al., 2006). Notably, the nurses also reported that no person with an intellectual disability had ever refused a procedure. It is therefore important that health professionals are aware of the pressure a person might feel to agree and that increased attempts are made to help people with intellectual disabilities understand they have a right to choose.

Assessing Capacity to Consent

There is some debate in the literature, promoted by Dye, Hendy, Hare and Burton (2004) that the method of assessing capacity as required by the MCA (2005) is not well-matched to theory, requiring people with intellectual disabilities to be more rational than people without intellectual disabilities. Only one participant in this study had the capacity to consent, if achieving the maximum score is the criterion for capacity. However, participants were often able to understand the decision to be made, who it would impact and communicate their decision, but may not have fully understood all the consequences or showed entirely rational reasoning. Relaxing the cut-off point to 75% (i.e. scoring 7 out of 10 on average for each subtest) to allow some flexibility for these participants meant that 21 of the participants could consent, which is a considerable difference. Relaxing the cut-off further to 50%, meant 28 participants could consent.

It is difficult to establish where an appropriate cut-off point would be, if we attempt to allow some flexibility and hence do not use the maximum score. However, Grisso

and Appelbaum (1998) argued that measures of capacity should only provide a framework to help the clinician make a clinical judgement and it is interesting to note that a cut-off of 75% is most closely aligned with the clinical judgement of the interviewer in this study. Studies have also shown that people without intellectual disabilities have struggled with understanding consequences and reasoning ability (Morris et al., 1993; Cea & Fisher, 2003) and yet their capacity to consent is unlikely to be questioned. Hence these results lend weight to the argument for the "recontextualisation" (Dye et al. (2004) of capacity to consent for people with intellectual disabilities.

Link between Predictor Variables and Decision-Making Abilities

Results showed that previous health experience was associated with an increased understanding of the advantages and disadvantages of health checks and the right to say no. This fits with Cea & Fisher's (2003) argument that understanding of factual information about a medical procedure would be improved if that person had had the procedure before. For example it may be difficult to imagine that being weighed could be embarrassing, or that providing a urine sample could be "disgusting" unless they have done it before.

Verbal ability was also linked to understanding advantages and disadvantages, as well as ability to reason, understanding who the decision impacts and communication. This could be because those with better verbal ability were more able to explain their reasoning and understanding than those with lesser verbal abilities.

Decision-making opportunities were linked to understanding advantages and disadvantages. This could be because as people make more decisions they become more aware that each choice has advantages and disadvantages. However, the relationship may go the other way and it may be that participants with a greater understanding of the advantages and disadvantages of a decision, are more likely to be allowed to make their own decisions. Further research is needed to establish the direction of the relationship.

Feedback from Nurses

Feedback from nurses was very limited. However, their comments indicated that they relied significantly on verbal communication from participants, which matches the finding that verbal ability is a significant predictor of capacity to consent. Notably however none of the nurses reported following MCA criteria to assess capacity, raising the question of whether the MCA is being followed by health professionals. Taking someone's agreement as evidence of capacity has significant limitations, because of difficulties with acquiescence or a lack of understanding and this may possibly explain why nurses judged some participants to have capacity to consent, even though they actually had low scores on the capacity to consent assessment. It could also be that being in the doctor's surgery provided more clues about the situation, increasing participants understanding and therefore their ability to consent. Further research is required into how nurses assess capacity to consent.

Strengths and Limitations

A significant strength of this study was that assessment of capacity to consent was based on a real life situation, instead of a hypothetical vignette. All the participants had received health checks within the last year, meaning no participants had to imagine an unknown event, as is the case in many other studies on capacity to consent to healthcare (Murphy & Clare, 2003). In addition using a regression model to examine the direction of the relationships between variables, showed the importance of extending the research beyond simply finding associations between individual variables and capacity to consent.

One of the limitations of this study is the small sample size, which reduces the power of the statistics and may explain some of the non-significant results, as discussed above. However, the sample size was similar to other published studies (Arscott et al., 1999; Suto et al. 2005). In addition, this study was always meant to be a pilot study, with the idea that it could be expanded and developed in further research.

A further limitation of the study was not compiling the age of the participants. This limits the comparisons that can be made with participant samples in other studies. It also could have been helpful to look at the correlation between age and previous health experience, to see whether it mediated the relationship between previous health experience and capacity to consent.

It was a shame that the CQ was completed by carers rather than participants. Although Stancliffe & Parmenter (1991) found little difference between staff and self-report scores, it is still possible that using self-report may have produced

different results in this study. However, asking participants to complete the measure would have meant only including participants able enough to do so and excluded people with more severe difficulties.

The HEQ was a newly designed measure for this study and only a small amount of data could be collected on its reliability and validity. The HEQ did rely on some verbal ability, which may have influenced the findings, but it was important to use a measure that participants answer themselves, because a carer saying a person has had a procedure before is not the same as the person recalling it themselves. It would also have been helpful to pilot the measure first before using it.

Finally, the small number of nurse participants significantly limited the value of their feedback. Although many nurses were interested in taking part, finding the time to do so was a major challenge for all of them.

Further Research

Further research is now required to replicate this study with a larger population and to add variables to the model as our knowledge increases. Decision-making theory provides a helpful starting point for considering which variables are worth investigating. Research can then explore how these variables might be manipulated to improve capacity to consent. Identification of the weakest parts of the decision-making process also highlights possible areas of intervention, which require further investigation. The research also contributes to the debate on the best way of

assessing capacity to consent in people with intellectual disabilities and it is hoped research and discussion in this area continue.

Conclusions

This study found that verbal ability and previous health experience are associated with capacity to consent to a health check, whilst decision-making opportunities are not quite significantly related. The model of regression demonstrated the importance of exploring how these variables interact with each other and showed that only verbal ability significantly predicted capacity. The model now requires replicating in a larger sample and needs to be developed to include other variables. Further research is also needed into different decision-making abilities, with the aim of suggesting specific targets for intervention to help improve capacity to consent to healthcare in adults with intellectual disabilities. Finding ways to improve the decision-making ability of people with intellectual disabilities would empower them to have more say in their own healthcare, which is important for quality of life (Wehmeyer, 2001) and may well be important for health outcomes.

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CRITICAL APPRAISAL OF MAJOR RESEARCH PROJECT

Word Count: 1932

**Whatesach killsha□e vuleaned and whatesach abilitesha□e vu
de□eloped fom undetaking hisprojectand whatdo vubink vuneed to
lean fbe?**

Completing my MRP has taught me a lot about organising a research project. Having not conducted independent research before, there were practical elements of it, particularly writing information sheets, which I have learned far more about since doing the project. For example, with hindsight I feel my information sheets for carers and nurses could have been improved to be more accessible.

I feel this project particularly engaged and developed my skills in recruitment. Recruiting nurses in GP practices who have very busy schedules was a challenge and it became clear quite quickly that sending out letters to them was not enough. Hence, I had to be more proactive and visit nurses in person. I had to learn the delicate balance between being active and encouraging enough to engage people in the project, whilst ensuring people did not feel pressurised to take part. Recruiting participants with intellectual disabilities was also a delicate balance between encouragement and pressure, particularly in addition to assessing capacity to consent and bearing in mind problems with acquiescence in this population (Finlay & Lyons, 2002). I often found that people with intellectual disabilities were keen to take part and I had to ensure they understood they were agreeing to the research and not just to me visiting them again.

Writing a research proposal and applying for ethics approval was something I had not done before and I feel I developed skills in working out how best to present my project in a way that was accessible for everyone. There is a certain skill in completing an NHS

ethics form in such a way to demonstrate you have considered all the issues, particularly as my project potentially involved those unable to consent for themselves. However, I feel I achieved this well, as there were few amendments from the ethics committee and I feel much better prepared for completing it again for any further research.

I struggled initially to frame my research within the context of psychological theory. I had many ideas about practice-based research but found it difficult to link it meaningfully with psychological theory. However, having identified decision-making theory as a possible basis for my research, I found it really interesting to link the findings from exploring the theory with the current ways of assessing capacity and also the empirical literature. I enjoyed engaging with the debate about how to assess capacity to consent without providing double standards for people with and without intellectual disabilities, which only came through exploring the theory as much as the empirical literature. Completing Part A also developed my skills in doing a broad literature review. In comparison with the critical reviews there was more scope for considering tangents and broader perspectives, which I feel is a valuable research skill.

My knowledge of quantitative statistics has increased significantly by doing this project, as the statistics you are taught at undergraduate level are considerably below what is required of a doctorate thesis. However, by doing a quantitative project I did not have the opportunity to explore some of the qualitative methods we have been taught, which I would like to do in further research.

The project also taught me a lot about being adaptable; being able to problem solve when challenges arise and being flexible with time and logistics to make sure as many people can participate as possible. For example, meeting participants outside of hours at weekends or bank holidays; breaking down data collection into two appointments; or needing to go back to the ethics committee for a minor amendment to increase the pool of potential participants.

If you were able to do this project again, what would you do differently and why?

One of the major limitations of the project was not recruiting enough nurses. I had intended to get a nurse's perspective on capacity to consent for every participant, but in the end this was not possible. There were several practice nurses I approached who were interested in the project but did not have the time to take part. I did my best to make the time burden on nurses as minimal as possible, but on reflection I feel it would have been better to recruit GP surgeries as a whole, because their support would have allowed nurses to take time out from their daily schedule to participate.

In addition recruiting participants with intellectual disabilities was also a challenge. Ethics rules stated that my supervisor had to make initial contact with each participant because they were recruited through the intellectual disability team, which she was a part of. This was extremely time-consuming for my very busy supervisor and made recruitment a challenge. In addition, staff from residential homes were often cautious about allowing me to meet people. Ideally I would have recruited participants directly

through the GP surgeries, but this would have involved even greater nurse involvement, which would not have been possible. An alternative may have been to recruit participants through the organisations that run residential homes or provide support workers to those living independently. This would have allowed me to recruit participants myself, rather than having to rely on my supervisor. It also may have helped me to develop better relationships with staff carers, which could have aided recruitment. However, it would have meant excluding people who lived with families.

It could be argued that one limitation of the project was the fact we did not assess the cognitive ability of participants. Instead we used 'being on the intellectual disability team register' as an inclusion criterion. I think assessing cognitive ability would have been helpful, however, it is time consuming for participants and increases the burden of the research on them, which was a significant reason for not doing it. It may have been possible to get some data from the intellectual disability team for certain participants, however it is unlikely all of them would have had a cognitive assessment.

The project could have benefited from improving the validity and reliability of the Health Experience Questionnaire. It would have been useful to pilot it first and to better understand how much verbal ability it required to complete. It may have helped to liaise with a speech and language therapist when developing it. It would have been helpful to pilot the Assessment of Capacity measure as well. However, both measures were consulted on and approved by members of the local intellectual disability advocacy group.

Finally I would like to have had the time to do this research with more participants in order to improve the number of findings that were significant. Suto, Clare, Holland and

Watson (2005) found a significant link between decision-making opportunities and capacity to make a financial decision, with a reasonable effect size and it would have been nice to show a similar link with capacity to consent to healthcare. Particularly, because it would highlight another possible area of intervention for improving capacity to consent.

As a consequence of doing this study, would you do anything differently in regard to making clinical recommendations or changing clinical practice, and why?

Conducting this MRP has challenged my views on capacity to consent. Previously I had not thought to question the requirement for people with intellectual disabilities to demonstrate rationality in their decision-making, however writing Part A has given me a better understanding of all the issues involved in assessing capacity which I think will be significant for my clinical work. Whilst the Mental Capacity Act (2005) makes rationality a legal requirement in assessing capacity, I think there is flexibility within that to consider the arguments put forward about considering capacity within the context of risk (Dye, Hendy, Hare & Burton, 2004) and Fisher's (2003) argument that we need to be aware of our responsibility to match the environment and context to the capacity of the individual.

As well as being aware of this in my own clinical practice I think it has implications for carers of people with intellectual disabilities who regularly have to make judgements on whether a person can make a decision for themselves or whether someone needs to

make it for them. These can be simple decisions such as choosing to meet with someone about research. Whilst recruiting for the project I often found care staff were very anxious about allowing the person to meet with me, even when the person had expressed an interest in doing so. Encouraging staff to consider the risk of the decision, e.g. I only wanted to speak with the person, and how the context can be altered to reduce the risk, e.g. providing the person with maximum information about my visit and sitting in on the appointment, demonstrate ways in which people with intellectual disabilities might be enabled to make their own decisions, which is important for quality of life (Wehmeyer, 2001).

The research also highlighted the need for close links between the intellectual disability team and carers who support people with intellectual disabilities. Although initially carers were wary about the people they support participating in research, many of them were also very interested in the project and I had feedback from several staff that they thought the project was worthwhile. Engaging them in the project was as important as engaging the person with an intellectual disability, because they often influence the person's decision to take part, both emotionally in the same way we seek guidance from important people in our lives, and practically by aiding the person to be available for the appointment. The same is likely to be true when offering people with an intellectual disability the chance to engage in groups or psychological therapy.

If you were to undertake further research in this area what would that research project seek to answer and how would you go about doing it?

I think there is a great need to continue to conduct research with people with intellectual disabilities, particularly those with a lower level of ability. As highlighted in Part A, people can miss out if they are not given the opportunity to participate in research (Charuvastra & Marder, 2006) and it can mean that the research done is not specific to their needs. Giving people with intellectual disabilities a chance to participate in research enables them to have a voice.

There are many project ideas following on from this research, particularly with a view to developing a model of capacity to consent to healthcare in people with intellectual disabilities. However, I would be most interested in finding ways to improve capacity to consent. My research highlighted the difficulty that participants had with understanding the consequences advantages and disadvantages of health checks. Therefore I would look to do a pre- and post- analysis of capacity to consent, with an intervention aimed at increasing understanding of advantages and disadvantages. The intervention could include presenting pictures about the procedures, videos of the procedures being done and use of objects of reference. If we could demonstrate that capacity to consent could be improved in this way, it would be an important step in empowering people with intellectual disabilities to make their own healthcare decisions. A similar study was done by Louise Ferguson and Glynis Murphy in the area of decision-making with respect to medication for people with intellectual disabilities (soon to be submitted to the Journal of Applied Research in Intellectual Disabilities).

This project would need to involve greater input from carers who have the expertise in engaging the individual and the way they best understand information. Furthermore the intervention may need to be more than a one-off session and ideally would be something carers could repeat with the person to enable them maximum opportunity to learn and process. In doing this type of project I could draw a lot on the lessons learned from the current study about recruitment and information sheets.

An alternative intervention for improving capacity to consent might include increasing the decision-making opportunities participants have, particularly to reduce learned helplessness (Jenkinson, 1999), which could be investigated in a similar pre- and post-analysis design.

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SECTION D

APPENDICES A-Z

Appendix A1

An electronic literature search was conducted in July 2010 using the PsycInfo and Medline databases. Search terms used fell into four broad categories covering the topics of capacity to consent, healthcare and research, learning disability and decision-making. Searches were limited to publications between 1990-2010 and published in the English language. Combinations of these categories were then used to find relevant literature. Table 1 below shows the search terms used for each category. From this search, articles that described an empirical investigation on capacity to consent to healthcare, or explored the theoretical concepts of capacity to consent, for people with learning disabilities were collated. They were then searched for further references. This led to identifying 12 key studies, 9 of which contained an empirical investigation. The library at Canterbury Christ Church University was also searched for books on decision-making.

Category	Search Terms	Number of Results
Capacity to consent	Informed consent, capacity to consent, mental capacity, competence, consent to treat*, consent to exam*, consent to research, informed choice, consent	50,640
Healthcare and research	Health, healthcare, health research, treatment	1,277,248

Learning disability	Learning disability*, intellectual disability*, intellectual impairment, mental handicap, mental deficiency, mental retardation, developmental disability*, learning difficult*	84,593
Decision-making	Decision making, choice, decision*	340,378
Combined Terms for Learning Disability and Capacity to Consent		803
Combined Terms for Healthcare, Learning Disability and Capacity to consent		158
Combined Terms for Decision-making and Learning Disability		3701

Author	Influencing Variables Considered	Assessment of Capacity	Number of Participants	Level of Learning Disability	Other Participant Characteristics
Arscott, Dagnan & Stenfert Kroese (1998)	Verbal Ability	Read through information passage on study twice and then asked five questions about the study	40 participants	No details given	22 men, 18 women Mean age: 40.6 years 65% lived in family homes, 25% community homes, 7.5% lived alone, 2.5% in hospital accommodation
Arscott, Dagnan & Stenfert Kroese (1999)	Verbal Ability Memory Ability	Ability to Consent Questionnaire Based on hypothetical vignettes Adapted from Morris et al. (1993)	40 participants	No details given	22 men, 18 women Mean age: 40.63 years 65% lived in family homes, 25% community homes, 7.5% lived alone, 2.5% in hospital accommodation
Cameron & Murphy (2007)	Verbal Ability	Process of the research explained verbally and using pictures, then person asked to consent or not	48 participants	No details given Divided into four groups according to verbal ability	No further details given

Author	Influencing Variables Considered	Assessment of Capacity	Number of Participants	Level of Learning Disability	Other Participant Characteristics
Cea & Fisher (2003)	Intellectual Ability	Assessment of Consent Capacity – Treatment Based on hypothetical vignettes	90 participants	No mental retardation (IQ: 80-117) Mild mental retardation (IQ: 55-80) Moderate mental retardation (IQ: 36-54)	54% Caucasian, 29% African-American, 7% Hispanic, 3% Asian, 7% Other. Mean Age for each IQ group were 30 years, 43.4 years and 40.6 years respectively
Dunn, Stenfert Kroese, Thomas, McGarry & Drew (2006)	Indirectly looked at Memory Ability	Video information followed by a 10-question comprehension test	19 participants	Mild – moderate learning disability No IQ details given	11 male, 8 female Age range: 22-63 years
Dye, Hare & Hendy (2007)	Verbal Ability Memory Ability Non-reasoning Ability	Ability to Consent Questionnaire Adapted by Arscott et al. (1998, 1999)	85 participants	Mild – moderate learning disability No IQ details	43 Female, 42 Male Age Range: 20-65 years 77.6% lived with family 22.4% lived in residential homes

Author	Influencing Variables Considered	Assessment of Capacity	Number of Participants	Level of Learning Disability	Other Participant Characteristics
Fisher, Cea, Davidson & Fried (2006)	Intellectual Ability Adaptive Behaviour	Assessment of Consent Capacity – Randomised Clinical Trials Based on hypothetical vignettes	150 participants	No mental retardation (Mean IQ: 106) Mild mental retardation (Mean IQ: 60.3) Moderate mental retardation (Mean IQ: 48)	54% Female 70% Caucasian Mean Age for each IQ group were 19.5 years, 43.8 years and 41.2 years respectively
Morris, Niederbuhl & Mahr (1993)	Intellectual Ability	Three hypothetical vignettes on surgery, psychotropic medication and restrictive behavioural intervention	45 participants	Without Mental Retardation Mild Mental Retardation Moderate Mental Retardation (No IQ details)	Moderate expressive language abilities Willingness to be interviewed
Wong, Clare, Holland, Watson & Gunn (2000)	Diagnosis Indirectly looked at Verbal Ability and Memory Ability	Information sheet and semi-structured interview with four conditions: Uninterrupted disclosure, Element Disclosure, Recognition and non-verbal demonstration	20 participants with a learning disability 42 participants with another 'mental disability' 20 comparison participants	Mean verbal IQ = 60.2	English Speaking and had some expressive language Mean age: 36.8 years 70% male

Appendix B

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Appendix C

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Appendix D



Salomons Campus at Tunbridge Wells

Dear

My name is Heather Dilks-Hopper and I am a Trainee Clinical Psychologist at Canterbury Christ Church University. I am carrying out a research project with the Community Learning Disability Team. I am writing to you regarding _____ and their potential participation in this research project. They have agreed for me to contact you about it. We would be very grateful if you could act as a Research Consultee on this person's behalf.

I am enclosing the information sheet about the research project and your role as a Research Consultee, as well as an assent form for you to complete and return to me.

Please return the form to:
Professor Glynis Murphy
(CLDT Address)

I am very happy to discuss the matter further with you and my details are provided in the information sheet.

Yours sincerely,

Heather Dilks-Hopper
Trainee Clinical Psychologist

Department of Applied Psychology
Faculty of Social and Applied Sciences

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Professor Michael Wright, Vice Chancellor and Principal

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Information Sheet for Research Consultees

You have been invited to act as a Research Consultee for _____. The purpose of your role is to help us decide whether it is suitable for them to take part in our research project. They have been assessed and the researchers have decided that this person is not able to consent themselves to taking part and this is why we need your help.

You have been asked because you are not paid to care for this person and you have no connection with the research project. This means you are more likely to come to a fair decision about whether it is right for this person to take part. Most likely you are also someone who knows this person well and so will know what their wishes and feelings about it might be.

This project is about consent to having a health check. We are going to look at three factors that may affect consent: the person's verbal ability, how much opportunity they have to make decisions about their life, and how much experience they have had of health checks. We want to find out if any of these factors make it more or less likely that they are able to consent.

The project involves the participant answering a questionnaire and naming some pictures, with the researcher Heather Dilks-Hopper. Then it will involve going through some information about health checks and answering questions about the advantages and disadvantages of it, in order for the researcher to decide whether they are able to consent to a health check. This bit of the research will be audio-recorded so that one other person can listen to it, to see whether they agree with the researcher's view. The other person listening to it will either be the researcher's supervisor or another member of the person's community learning disability team. Once it has been listened to by the other person the recording will be deleted.

The researcher will also complete a questionnaire with their carer and conduct a short interview with the nurse who carried out the health check to ask if the nurse thought the participant had the ability to consent and why, as well as to check which procedures took place in the health check.

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If at any point the participant becomes distressed by the procedure or objects to taking part, they are free to stop the process. They will not be forced to take part. The main advantage of the person taking part is that they are helping us to collect useful information about what helps a person to be able to consent to a health check. The main disadvantage to the person is spending the time doing the tasks, although they have been designed to be as short and interesting as possible (they should only take 1.5 hours per person).

All data will be anonymised and stored securely. Feedback to all participants will be anonymised. The participants will not be identifiable in any publications of the findings. The study has been approved by the NHS Research Ethics Committee.

The research will be carried out by myself, a Trainee Clinical Psychologist, and my supervisor, a Consultant Clinical Psychologist, in association with the Community Learning Disability Team (**** NHS Foundation Trust). Should you wish to have a further discussion about the study or require any more information, please contact me at hld1@canterbury.ac.uk or ring me on 01892 50 7673 (Please note this is a 24hr answer phone for several studies. You will need to leave a message saying you are calling for me and I will get back you).

We would like to ask your advice on whether you think this person should take part in the project. We would also like to know what you think this person's wishes and feelings about taking part in the project would be if they were able to consent. I am enclosing an assent form for you to sign and return to me.

Heather Dilks-Hopper
Trainee Clinical Psychologist

Professor Glynis Murphy
Consultant Clinical Psychologist

Assent Form for Research Consultees

Name of Participant: _____

1. What do you think the person's wishes and feelings would be about taking part in this project?

2. What is your view on the person taking part in this project?

3. In your opinion do you think the person should take part in this project?

Yes

No

Signed:

Print Name:

Date:

Dear

My name is Heather and I am training to be a Clinical Psychologist at Canterbury Christ Church University. I am also working with Professor Glynis Murphy in the Community Learning Disability Team and we are doing some research together. M* * B* * from * * * CLDT has given me your name.

I would like to invite you to meet with me and discuss whether you would like to take part in my research project. The project is about people with a learning disability's capacity to consent to having a health check. I am attaching the information sheet and the consent form for you to read. If you would like to take part please could you return the consent form to:

Professor Glynis Murphy
(CLDT address)

If you have any questions you would like to ask me before agreeing to take part you can contact me at hld1@canterbury.ac.uk or **01892 50 7673** (please state who you are calling for, and leave your name and number and I will get back to you).

If we have not heard from you within two weeks of sending this letter, Glynis Murphy will call you, to check whether you are interested, but have not got round to replying. If you say at this phone call you do not wish to take part, you will not be contacted again.

Yours Sincerely,

Heather Dilks-Hopper
Trainee Clinical Psychologist

Department of Applied Psychology
Faculty of Social and Applied Sciences

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Professor Michael Wright, Vice Chancellor and Principal

Research Project about Informed Consent to Healthcare in Adults with Learning Disabilities

I would like to invite you to take part in my research study. Please take the time to read the following information carefully and ask me if there is anything that is not clear or if you would like more information.

In 2005 the Mental Capacity Act was passed giving guidelines on assessing people with a learning disability's capacity to consent to healthcare assessment and treatment. The main aim of this study is to look at 3 variables that might affect someone's capacity to consent to an annual health check.

- These variables are: their verbal ability, their previous experience of having a health check and how many opportunities they have to make decisions.
- Researchers will need to check whether the person with a learning disability has the capacity to consent to their health check, so they can see how the other variables affect it. They will also ask for your opinion on whether the person has the capacity to consent, as there may be factors at the time of the health check that mean your decision would be different to ours.

You have been invited to participate because you are currently involved in the project of rolling out annual health checks for this population.

What it will involve:

- Following the health check I will conduct a short telephone interview with you to find out whether you think the person had the capacity to consent to the health check and what led you to this decision. I will also ask exactly what procedures happened in the health check e.g. blood test, vaccinations, but will not require any details about that person's health. This interview should take no more than 5-10 minutes.

Taking part in the study is entirely voluntary. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You are free to withdraw from the study at any time and without giving a reason.

All data will be anonymous and confidential, and will be stored securely. Feedback to all participants will be anonymised. You will not be identifiable in any publications of the findings. The study has been approved by the NHS Research Ethics Committee. We will feed back the findings of the research to you and the other groups of participants. We also aim to publish the findings in 2012.

The research will be conducted by myself, a Trainee Clinical Psychologist in fulfilment of my clinical doctorate, and my supervisor, a Consultant Clinical Psychologist, in association with the Community Learning Disability Team (**** NHS Foundation Trust). Should you wish to have a further discussion about the study or require any more information, please contact me at hld1@canterbury.ac.uk or ring me on **01892 50 7673** (Please note this is a 24hr answer phone for several studies. You will need to leave a message saying who you are calling for and I will get back you).

Nurse Consent Form
Version 2 – 27/6/10



Thank you for taking part in the study

Heather Dilks-Hopper
Trainee Clinical Psychologist

Professor Glynis Murphy
Consultant Clinical Psychologist

Participant Number:

CONSENT FORM

Research Project about Informed Consent to Healthcare in Adults with Learning Disabilities

Researcher: Heather Dilks-Hopper

1. I confirm that I have read and understand the information sheet dated..... for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.
3. I understand that the results may be published but that they are completely anonymised and I cannot be identified from them.
4. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

Appendix H

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Appendix I

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Appendix J

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Appendix K

MEASURE OF CAPACITY TO CONSENT TO AN ANNUAL HEALTH CHECK

Part of Decision-making	Score	Rating
Identification (A)	0	Doesn't recognise there is a choice
	1	Aware that you can choose, but believes there might be negative implications of saying no or indicates feeling pressured to say yes.
	2	Understands they are free to say yes or no
Understanding (B)	0	No relevant information offered
	1	Partial identification of advantages and problems: i.e. can only identify advantages or disadvantages, or only identifies advantages for saying yes and disadvantages of saying no.
	2	Identification of advantages and disadvantages for both choices
Reasoning (C)	0	No relevant information offered
	1	Opinion on decision outcome offered, but with an insufficient explanation of why
	2	Opinion on decision outcome offered, with a sufficient explanation of why
Appreciation (D)	0	No relevant information offered, or doesn't recognise decision will affect them or thinks that the decision will affect only people who are actually unaffected
	1	Aware that the decision will affect them, but also thinks the decision will affect people who are actually unaffected
	2	Aware that the decision will affect them (and possibly others who are also affected)
Communication (E)	0	Unable to communicate anything
	1	Ambiguous communication
	2	Able to communicate a decision

Semi-structure interview designed to test the individual's understanding of the decision being made. Further probing questions may be used if it is not clear from their answers what their understanding is, as it is necessary to give them the maximum opportunity to demonstrate their understanding.

PatA

Can you tell me what choice has to be made here?

(Who has to make a choice? What choice do you have to make?)

Do you have to have it done? Are you allowed to say no?

PatB

What is good about doing x ? (What would be good about doing x)

What is bad about doing x ?

What would happen if you didn't do x ?

PatC

What do you think you should do?

Is it good to have it done?

Why do you think its good/bad to have it done?

PatD

Who does it affect if you say yes or no?

Will it affect anyone else? Does anyone else mind?

PatE

What would you choose to do?

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Appendix L

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Dear

My name is Heather and I am working with Professor Glynis Murphy in the [REDACTED] Community Learning Disability Team.

I don't have your name. [REDACTED] Learning Disability Team is sending this letter out for me.



Would you like to meet me to have a chat about my project?

The project is about what helps people with a learning difficulty to make a decision about seeing the doctor or the nurse. You might want to take part.

I would like to talk to your carer as well.

If you would like to talk to me, you can ring Glynis.

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Faculty of Social and Applied Sciences

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Professor Michael Wright, Vice Chancellor and Principal

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Registered Charity No: 1098136



If you don't call her, Glynis might call you to see if you want to meet me. You can say **YES** or **NO**.

Yours Sincerely,

Heather Dilks-Hopper
Trainee Clinical Psychologist

Dear

My name is Heather and I am a Trainee Clinical Psychologist from Canterbury Christ Church University. I am doing some research with Professor Glynis Murphy in the [REDACTED] Community Learning Disability Team. I do not have your personal details. This letter is being sent out by [REDACTED] CLDT and I will only be given your details if you agree to meet with me.

I would like to invite you and the person you care for _____ to meet with me to discuss my research project and see if you would like to take part. The project is about what helps someone with a learning disability to be able to make a decision about their health care.

If you agree to meet with me to discuss the project, that doesn't mean you have to agree to take part in the project. When we meet I would go through all the information about the project and you could decide whether or not to take part. Please note I am looking for carers and the person with a learning disability to participate together.

If you are interested in meeting with me, please could you ring Glynis Murphy. Her number is [REDACTED].

If we have not heard from you within two weeks of sending this letter, Glynis Murphy will call you, to check whether you are interested, but have not got round to replying. If you say at this phone call you do not wish to take part, you will not be contacted again.

Yours Sincerely,

Heather Dilks-Hopper
Trainee Clinical Psychologist

Going for a Health Check

Information Sheet



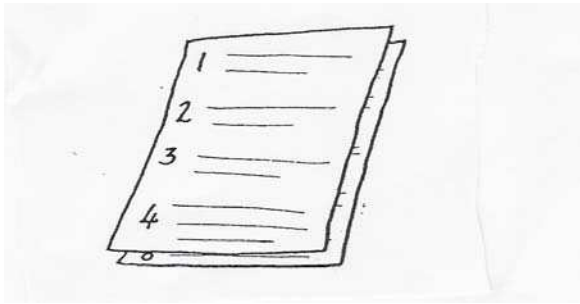
We are trying to find out **what helps** people with a learning difficulty to **decide** to have their **health check**.



You can say **NO** to taking part in this project.



Or you can say **STOP** at any time.



We would like to ask you some **questions** about going to see the nurse for your health check and **about the decisions** you make.

Picture removed for electronic copy

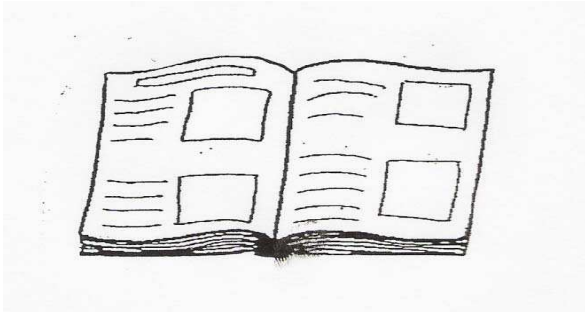
We would like to ask you to **name** some **pictures** for us.



We would like to **record** some of your **answers** on a **tape**.



Everything will be kept **private**. We won't tell anyone your name.



The information may be published in a **professional journal**. This is a **magazine** for people who work with learning difficulties to read.



If you want any **more information** about this project you can **ring me** on **01892 507673**.

If you call me you will need to leave a message saying my name and what your name and telephone number is. Then I can call you back.

Name

Heather Dilks-Hopper

Glynis Murphy

Job Title

Trainee Clinical Psychologist

Consultant Clinical Psychologist

Going for a Health Check

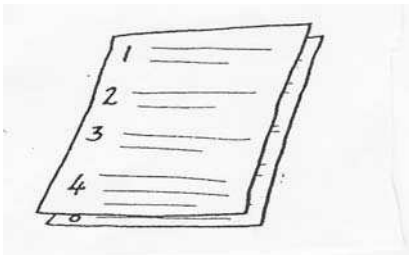
Consent Form

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I have **seen** the **information sheet** about this project and **talked about** it with **Heather Dilks-Hopper**.

Picture removed for electronic copy

I understand that I will **answer** some **questions** with Heather and **name** some **pictures**.



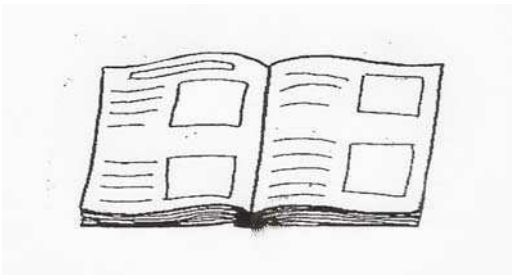
I understand that some of **these questions** will be **recorded on tape**.



I understand that anything I say will be **private and confidential**.



I understand that I can **stop** if I want to.



I understand that the **information** may be **published** in a **professional journal**.



I would like to take part in this project.

I agree to answer some questions with Heather and name some pictures:

YES

NO

I agree to have some of my answers recorded:

YES

NO

Thank You for Helping Me with my Project!

Your name

Date

Signature

Name of researcher

Date

Signature

1 copy for you / 1 copy for Heather Dilks-Hopper

Research Project about Informed Consent to Healthcare in Adults with Learning Disabilities

I would like to invite you to take part in my research study. Please take the time to read the following information carefully and ask me if there is anything that is not clear or if you would like more information.

In 2005 the Mental Capacity Act was passed giving guidelines on assessing people with a learning disability's capacity to consent to healthcare assessment and treatment. The main aim of this study is to look at 3 variables that might affect someone's capacity to consent to an annual health check.

- These variables are: their verbal ability, their previous experience of having a health check and how many opportunities they have to make decisions.
- Researchers will need to check whether the person with a learning disability has the capacity to consent to their health check, so they can see how the other variables affect it.

You have been invited to participate as the carer of the selected person with a learning disability.

What it will involve:

- I will visit the person you care for, to ask them to consent to the research
- I will then visit them again to go through some questionnaires with them. I will need to ask you some questions. I will also need you to help me score one of the questionnaires. It is easy to do and I will show you how to.
- I will also record the responses to one of the questionnaires that the person you care for completes. This will be listened to by a 2nd person from the research team to make sure they agree with my scoring of the questionnaire. After it has been listened to by this person it will be destroyed. It will **not** involve recording your responses.
- After their health check I will interview the nurse who conducted it and ask them what procedures took place in the health check and whether they thought the person you care for was able to consent to the health check. I will not be asking for details about that person's health.

If at any stage during the process the person you care for should disclose anything that shows themselves or anyone else to be at risk, this information will be passed to my supervisor Glis Murphy. She will make a decision about whether it is necessary to pass on this information to other professionals, for example a social worker or the practice nurse, depending on what has been disclosed.

Taking part in the study is entirely voluntary. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You are free to withdraw from the study at any time and without giving a reason.

All data will be anonymous and confidential, and will be stored securely. Feedback to all participants will be anonymised. You will not be identifiable in any publications of the findings. The study has been approved by the NHS Research Ethics Committee.

Appendix P



Salomons Campus at Tunbridge Wells

We will feed back the findings of the research to you and the other groups of participants. We also aim to publish the findings in 2012.

The research will be conducted by myself, a Trainee Clinical Psychologist in fulfilment of my clinical doctorate, and my supervisor, a Consultant Clinical Psychologist, in association with the [REDACTED] Community Learning Disability Team ([REDACTED] NHS Foundation Trust). Should you wish to have a further discussion about the study or require any more information, please contact me at hld1@canterbury.ac.uk or ring me on **01892 50 7673** (Please note this is a 24hr answer phone for several studies. You will need to leave a message saying who you are calling for and I will get back you).

Thank you for taking part in the study

Heather Dilks-Hopper
Trainee Clinical Psychologist

Professor Glynis Murphy
Consultant Clinical Psychologist

Participant Number:

CONSENT FORM

Research Project about Informed Consent to Healthcare in Adults with Learning Disabilities

Researcher: Heather Dilks-Hopper

- 1. I confirm that I have read and understand the information sheet dated..... for the above study and have had the opportunity to ask questions.

- 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.

- 3. I understand that the results may be published but that they are completely anonymised and I cannot be identified from them.

- 4. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

4th July 2010

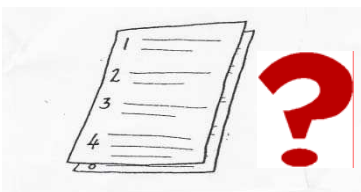
Dear

Picture
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electronic copy

Thank you for meeting me and helping me with my project.

Picture
removed for
electronic copy

I asked you to name some pictures and answer some questions



I found out that **most people know quite a lot**



about health checks and were good at answering the questions.



I found out that if you **understand more words**, you will find it **easier to understand about health checks**.

YES

NO

I found out it is **easier to tell people yes or no**.



It is **harder to understand everything about health checks**.

This information **helps us to know more** about how to help **you** understand about having a health check.

If you want **more information** about **health checks** you can ask your **doctor** or your **nurse**.

THANK YOU!

30th June 2011

Dear

Thank you for taking part in my research project about capacity to consent to health checks. I was grateful for your time spent supporting the person you care for to take part in the project and also for your time in completing questionnaires.

I met with 32 adults with a learning disability, including the people you support. I measured how much language they can understand, how much they remember about having health checks and how many opportunities they have to make decisions. I then assessed whether they were able to consent to a health check or not.

My results showed that the more language a person with a learning disability understands the more likely it is that they will be able to consent to a health check. It is important to remember though that there are other factors involved so you can't decide if a person is able to consent *just* based on how much language they understand.

There was also a link between previous experience of a health check and understanding more about health checks. This needs more investigation but it suggests there is a possibility that each time a person comes for a health check, they are more likely to be able to consent.

The results also showed which parts of making a decision seem to be easier for people with a learning disability. Most people found understanding the advantages and disadvantages of a health check, and deciding whether a health check is a good idea the hardest parts of the decision. Most people found knowing they were allowed to say no and communicating their choice the easiest parts of the decision.

Feedback from a small number of nurses showed that the main criteria used for assessing whether someone has the capacity to consent to the health check are: coming to appointments on their own; being able to answer questions; being able to have some sort of conversation; and agreeing to the procedure. None of the nurses commented specifically that they followed Mental Capacity Act criteria.

We got feedback from nurses about six of the participants, which showed that the nurse's judgment of capacity to consent did not always match our judgement. This could be because when the person is in the GP surgery it provides more clues to them and they have a better understanding of what is being talked about. Or it could be that they do not understand as much as it appears but are just trying to be helpful.

These findings help us to understand how we might be able to help people with a learning disability become more able to consent to healthcare procedures such as a health check. This is important in helping people with a learning disability to have control over their own lives and to be able to make their own decisions.

Thank you again for taking part in the project.

Yours sincerely,

Heather Dilks-Hopper

Trainee Clinical Psychologist

Professor Glynis Murphy

Consultant Clinical Psychologist

Department of Applied Psychology
Faculty of Social and Applied Sciences

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www.canterbury.ac.uk

Professor Michael Wright, Vice Chancellor and Principal

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A Company limited by guarantee
Registered Charity No: 1098136

30th June 2011

Dear

Thank you for taking part in my research project about capacity to consent to health checks. I was grateful for your time spent talking to me on the phone.

I met with 32 adults with a learning disability. I measured how much language they can understand, how much they remember about having health checks and how many opportunities they have to make decisions. I then assessed whether they were able to consent to a health check or not.

My results showed that the more language a person with a learning disability understands the more likely it is that they will be able to consent to a health check. It is important to remember though that there are other factors involved so you can't decide if a person is able to consent *just* based on how much language they understand.

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Thank you again for taking part in the project.

Yours sincerely,

Heather Dilks-Hopper

Trainee Clinical Psychologist

Professor Glynis Murphy

Consultant Clinical Psychologist

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Registered Charity No: 1098136

30th June 2011

Dear

Thank you for initially agreeing to take part in my research project about capacity to consent to health checks. Unfortunately I have now made several attempts to contact you without success, and have therefore assumed that you no longer wished to participate in the study. The project has now finished and in case you are interested, I include below a summary of the research findings.

I met with 32 adults with a learning disability. I measured how much language they can understand, how much they remember about having health checks and how many opportunities they have to make decisions. I then assessed whether they were able to consent to a health check or not.

My results showed that the more language a person with a learning disability understands the more likely it is that they will be able to consent to a health check. It is important to remember though that there are other factors involved so you can't decide if a person is able to consent *just* based on how much language they understand.

There was also a link between previous experience of a health check and understanding more about health checks. This needs more investigation but it suggests there is a possibility that each time a person comes for a health check, they are more likely to be able to consent.

The results also showed which parts of making a decision seem to be easier for people with a learning disability. Most people found understanding the advantages and disadvantages of a health check, and deciding whether a health check is a good idea the hardest parts of the decision. Most people found knowing they were allowed to say no and communicating their choice the easiest parts of the decision.

Feedback from a small number of nurses showed that the main criteria used for assessing whether someone has the capacity to consent to the health check are: coming to appointments on their own; being able to answer questions; being able to have some sort of conversation; and agreeing to the procedure. None of the nurses commented specifically that they followed Mental Capacity Act criteria.

We got feedback from nurses about six of the participants, which showed that the nurse's judgment of capacity to consent did not always match our judgement. This could be because when the person is in the GP surgery it provides more clues to them and they have a better understanding of what is being talked about. Or it could be that they do not understand as much as it appears but are just trying to be helpful.

These findings help us to understand how we might be able to help people with a learning disability become more able to consent to healthcare procedures such as a health check. This is important in helping people with a learning disability to have control over their own lives and to be able to make their own decisions.

Yours sincerely,

Heather Dilks-Hopper

Trainee Clinical Psychologist

Professor Glynis Murphy

Consultant Clinical Psychologist

Department of Applied Psychology
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Appendix U



Reverend Dr Joyce Smith
Chair
East London REC 3
Board Room A
2nd Floor
Becket House
2/14 Ilford Hill
Ilford
Essex
IG1 2QX

4th July 2011

Dear Reverend Dr Joyce Smith,

**Re: REC reference application 10/H0701/70. Informed consent to healthcare:
What influences someone's capacity to decide?**

Thank you for approving the above research project on 8th July 2010. Data collection for the project is now complete and I am enclosing a Declaration of End of Study form in this letter, as well as a summary of the research and its findings.

Please do not hesitate to contact me if you require further information.

Yours sincerely

Heather Dilks -Hopper
Trainee Clinical Psychologist
hld1@canterbury.ac.uk

Department of Applied Psychology
Faculty of Social and Applied Sciences

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DECLARATION OF THE END OF A STUDY

(For all ~~trials~~ except clinical trials of investigational medicinal products)

To be completed in typescript by the Chief Investigator and submitted to the Research Ethics Committee that gave a favourable opinion of the research ("the main REC") within 90 days of the conclusion of the study or within 15 days of early termination. For questions with Yes/No options please indicate answer in bold type.

1. Details of Chief Investigator

Name:	Heather Dilks -Hopper
Address:	Department of Applied Psychology Salomons Estate, Broomhill Road, Southborough, Kent TN3 0TG
Telephone:	07931363617
Email:	hld1@canterbury.ac.uk
Fax	

2. Details of study

Title of study	Informed consent to healthcare: What influences someone's capacity to decide?
Research sponsor:	Canterbury Christ Church University
Name of main REC:	East London REC 3
Main REC reference number:	10/H0701/70

3. Study duration

Date commenced:	1/9/2010
Date ended:	15/5/2011
Did this study terminate prematurely?	Yes / No

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Faculty of Social and Applied Sciences

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	<i>If yes please complete sections 4, 5 & 6, if no please go direct to section 7.</i>
--	---

4. Circumstances of early termination

What is the justification for early termination?	
--	--

5. Temporary halt

Is this a temporary halt to the study?	Yes / No
If yes, what is the justification for temporarily halting the study? When do you expect the study to recommence?	<i>e.g. Safety, difficulties recruiting participants, trial has not commenced, other reasons.</i>

6. Potential implications for research participants

Are there any potential implications for research participants as a result of terminating/halting the study prematurely? Please describe the steps taken to address them.	
---	--

7. Final report on the research

Is a summary of the final report on the research enclosed in this form?	Yes / No
	<i>If no, please forward within 12 months of the end of the study.</i>

8. Declaration

Signature of Chief Investigator:	
Print name:	Heather Dilks-Hopper
Date of submission:	15/7/2011

Informed consent to healthcare: What influences someone's capacity to decide?

REC Ref: 10/H0701/70

Heather Dilks-Hopper, Trainee Clinical Psychologist, Canterbury Christ Church University

Supervised by: Professor Glynis Murphy and Ms Celia Heneage

Introduction

People with learning disabilities experience poorer healthcare and health outcomes than the general population (Van Schrojenstein Lantman-de Valk & Walsh, 2008) and capacity to consent has been identified as one of the significant barriers to healthcare faced by people with learning disabilities (Keywood, Forvargue & Flynn, 1999; Mencap, 2007). In order to improve understanding of capacity to consent, the literature has attempted to investigate factors that influence capacity to consent to healthcare.

This study examined how verbal ability, decision-making opportunities and previous experience of a health check interact to influence capacity to consent to a health check in adults with a learning disability. It explored the relationships between the variables using correlations, but then used a regression model to identify useful predictors, attempting to create a similar model to that identified by Suto et al. (2005) in financial decision-making. In addition, it also explored particular decision-making abilities in people with learning disabilities.

Method

Thirty-two adults with learning disabilities were recruited through local learning disability teams. Twenty-two carers also participated and three practice nurses from local GP surgeries. Measures used were the Choice Questionnaire (Stancliffe & Parmenter, 1999);

British Picture Vocabulary Scale – 2nd edition (Dunn et al., 1982); a newly designed Health Experience Questionnaire; and an assessment of capacity to consent, similar to that of Suto et al. (2005).

Findings

Model of Capacity to Consent

As predicted, verbal ability and previous health experience showed significant positive correlation with capacity to consent to a health check. However, the correlation with decision-making opportunities was not quite significant. In addition previous health experience and decision-making opportunities both showed significant positive correlation with verbal ability, but not with each other.

Importantly though the model of regression showed that only verbal ability was a useful predictor, which highlights the importance of not drawing too many assumptions from correlation.

Elements of Decision-Making

The results also showed that understanding advantages and disadvantages and ability to reason were the hardest elements of decision-making. Communicating a choice and understanding the right to say no seemed to be the easiest. This evidence helps identify potential areas of intervention, to improve capacity to consent to healthcare. Difficulties in understanding the consequences of a decision suggest we need to find better ways to communicate this information to people with learning disabilities.

In addition, although the results suggested that understanding their right to say no was one of the easier decision-making abilities, less than 50% gained full marks for this, suggesting more than half of participants felt pressured or unable to say no at some

point. It is therefore important that health professionals are aware of the pressure a person might feel to agree and that increased attempts are made to help people with learning disabilities understand they have a right to choose.

Assessing Capacity to Consent

Using strict Mental Capacity Act (2005) standards, only one person in this study had the capacity to consent. However, participants were often able to understand the decision to be made, who it would impact and communicate their decision, but may not have fully understood all the consequences or showed entirely rational reasoning. Relaxing the cut-off point to scoring 75% on the assessment of capacity, to allow some flexibility for these participants, meant that 66% of the participants could consent. Most interestingly this criterion produced similar numbers of people with capacity, as the criterion of clinical judgement.

Link between Predictor Variables and the elements of Decision-Making Abilities

Results showed that previous health experience was associated with an increased understanding of the advantages and disadvantages of health checks and the right to say no. This fits with Cea & Fisher's (2003) argument that understanding of factual information about a medical procedure would be improved if that person had had the procedure before.

Verbal ability was also linked to understanding advantages and disadvantages, as well as ability to reason, understand who the decision impacts and communication. This

could be because those with better verbal ability were more able to explain their reasoning and understanding than those with lesser verbal abilities.

Decision-making opportunities were linked to understanding advantages and disadvantages. It is not clear whether this is because as people make more decisions they become more aware that each choice has advantages and disadvantages, or whether participants with a greater understanding of the advantages and disadvantages of a decision, are more likely to be allowed to make their own decisions.

Feedback from Nurses

Feedback from nurses was very limited. However, their comments indicated that they relied significantly on four main criteria to assess capacity to consent: coming to appointments on their own; being able to answer questions; being able to have some sort of conversation; and agreeing to the procedure. None of them reported using the criteria set out by the Mental Capacity Act (2005).

Conclusions and Further Research

The study reveals the importance of looking at how factors that influence capacity to consent to healthcare interact with each other, rather than just acting individually. Further research is required to expand this model to include other variables and to replicate it in a larger participant sample, because this was just a pilot study. Further research is also needed into different decision-making abilities, with the aim of suggesting specific targets for intervention to help improve capacity to consent to healthcare in adults with learning disabilities.

Dissemination

I plan to publish the findings in the Journal of Applied Research in Intellectual Disabilities. All participants received feedback of the findings.

References

Cea, C.D. & Fisher, C.B. (2003). Health care decision-making by adults with mental retardation. *Mental Retardation*, 41, 78-87.

Dunn, L. M., Whetton, C. & Pintillie, D. (1982). *British Picture Vocabulary Scale – 2nd Edition*. London: NFER-Nelson.

Keywood, K., Fovargue, S. & Flynn, M. (1999). *Best Practice? Health care decision-making by, with and for adults with learning disabilities*. Manchester: National Development Team.

Mencap (2007). *Death by indifference*. London: Mencap.

Mental Capacity Act. (2005). Retrieved 9 June, 2011 from:
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Standliffe, R. J. & Parmenter, T. R. (1999). The choice questionnaire: A scale to assess choices exercised by adults with intellectual disability. *Journal of Intellectual and Developmental Disability*, 24, 107-132.

Suto, W. M. I., Clare, I. C. H., Holland, A. J. & Watson, P. C. (2005). The relationships among three factors affecting the financial decision-making abilities of adults with mild intellectual disabilities. *Journal of Intellectual Disability Research*, 49, 210-217.

Van Schrojenstein Lantman-de Valk, H. M. J. & Walsh, P. N. (2008). Managing health problems in people with intellectual disabilities. *British Medical Journal*, 337, 1408-1412.

Appendix V



Salomons Campus at Tunbridge Wells

Head of Department

***** NHS Trust Research & Development Department

R&D Department Address

4th July 2011

Dear Head of R&D Department,

Re: Informed consent to healthcare: What influences someone's capacity to decide?

Thank you for approving the above research project on 12th August 2010. Data collection for the project is now complete and I am enclosing with this letter a summary of the research and its findings.

Please do not hesitate to contact me if you require further information.

Yours sincerely,

Heather Dilks-Hopper

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Informed consent to healthcare: What influences someone's capacity to decide?

Heather Dilks-Hopper, Trainee Clinical Psychologist, Canterbury Christ Church University

Supervised by: Professor Glynis Murphy and Ms Celia Heneage

Introduction

People with learning disabilities experience poorer healthcare and health outcomes than the general population (Van Schrojenstein Lantman-de Valk & Walsh, 2008) and capacity to consent has been identified as one of the significant barriers to healthcare faced by people with learning disabilities (Keywood, Forvargue & Flynn, 1999; Mencap, 2007). In order to improve understanding of capacity to consent, the literature has attempted to investigate factors that influence capacity to consent to healthcare.

This study examined how verbal ability, decision-making opportunities and previous experience of a health check interact to influence capacity to consent to a health check in adults with a learning disability. It explored the relationships between the variables using correlations, but then used a regression model to identify useful predictors, attempting to create a similar model to that identified by Suto et al. (2005) in financial decision-making. In addition, it also explored particular decision-making abilities in people with learning disabilities.

Method

Thirty-two adults with learning disabilities were recruited through *** and *** CLDT. Twenty-two carers also participated and three practice nurses from local GP surgeries.

Measures used were the Choice Questionnaire (Stancliffe & Parmenter, 1999); British Picture Vocabulary Scale – 2nd edition (Dunn et al., 1982); a newly designed Health Experience Questionnaire; and an assessment of capacity to consent, similar to that of Suto et al. (2005).

Findings

Model of Capacity to Consent

As predicted, verbal ability and previous health experience showed significant positive correlation with capacity to consent to a health check. However, the correlation with decision-making opportunities was not quite significant. In addition previous health experience and decision-making opportunities both showed significant positive correlation with verbal ability, but not with each other.

Importantly though the model of regression showed that only verbal ability was a useful predictor, which highlights the importance of not drawing too many assumptions from correlation.

Elements of Decision-Making

The results also showed that understanding advantages and disadvantages and ability to reason were the hardest elements of decision-making. Communicating a choice and understanding the right to say no seemed to be the easiest. This evidence helps identify potential areas of intervention, to improve capacity to consent to healthcare. Difficulties in understanding the consequences of a decision suggest we need to find better ways to communicate this information to people with learning disabilities.

In addition, although the results suggested that understanding their right to say no was one of the easier decision-making abilities, less than 50% gained full marks for this,

suggesting more than half of participants felt pressured or unable to say no at some point. It is therefore important that health professionals are aware of the pressure a person might feel to agree and that increased attempts are made to help people with learning disabilities understand they have a right to choose.

Assessing Capacity to Consent

Using strict Mental Capacity Act (2005) standards, only one person in this study had the capacity to consent. However, participants were often able to understand the decision to be made, who it would impact and communicate their decision, but may not have fully understood all the consequences or showed entirely rational reasoning. Relaxing the cut-off point to scoring 75% on the assessment of capacity, to allow some flexibility for these participants, meant that 66% of the participants could consent. Most interestingly this criterion produced similar numbers of people with capacity, as the criterion of clinical judgement.

Link between Predictor Variables and the elements of Decision-Making Abilities

Results showed that previous health experience was associated with an increased understanding of the advantages and disadvantages of health checks and the right to say no. This fits with Cea & Fisher's (2003) argument that understanding of factual information about a medical procedure would be improved if that person had had the procedure before.

Verbal ability was also linked to understanding advantages and disadvantages, as well as ability to reason, understand who the decision impacts and communication. This

could be because those with better verbal ability were more able to explain their reasoning and understanding than those with lesser verbal abilities.

Decision-making opportunities were linked to understanding advantages and disadvantages. It is not clear whether this is because as people make more decisions they become more aware that each choice has advantages and disadvantages, or whether participants with a greater understanding of the advantages and disadvantages of a decision, are more likely to be allowed to make their own decisions.

Feedback from Nurses

Feedback from nurses was very limited. However, their comments indicated that they relied significantly on four main criteria to assess capacity to consent: coming to appointments on their own; being able to answer questions; being able to have some sort of conversation; and agreeing to the procedure. None of them reported using the criteria set out by the Mental Capacity Act (2005).

Conclusions and Further Research

The study reveals the importance of looking at how factors that influence capacity to consent to healthcare interact with each other, rather than just acting individually. Further research is required to expand this model to include other variables and to replicate it in a larger participant sample, because this was just a pilot study. Further research is also needed into different decision-making abilities, with the aim of suggesting specific targets for intervention to help improve capacity to consent to healthcare in adults with learning disabilities.

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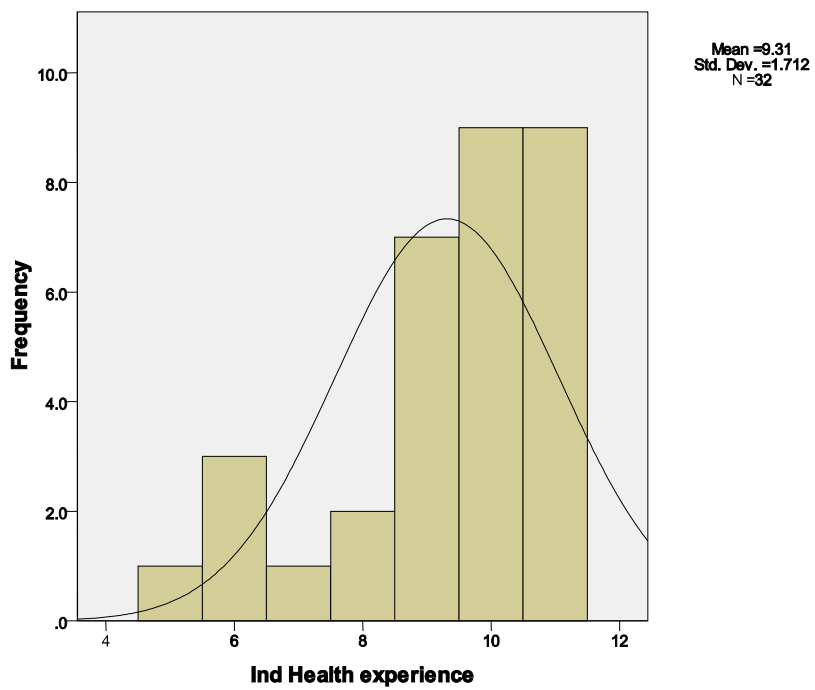
Appendix W

Data Inspection to Test for Normal Distribution

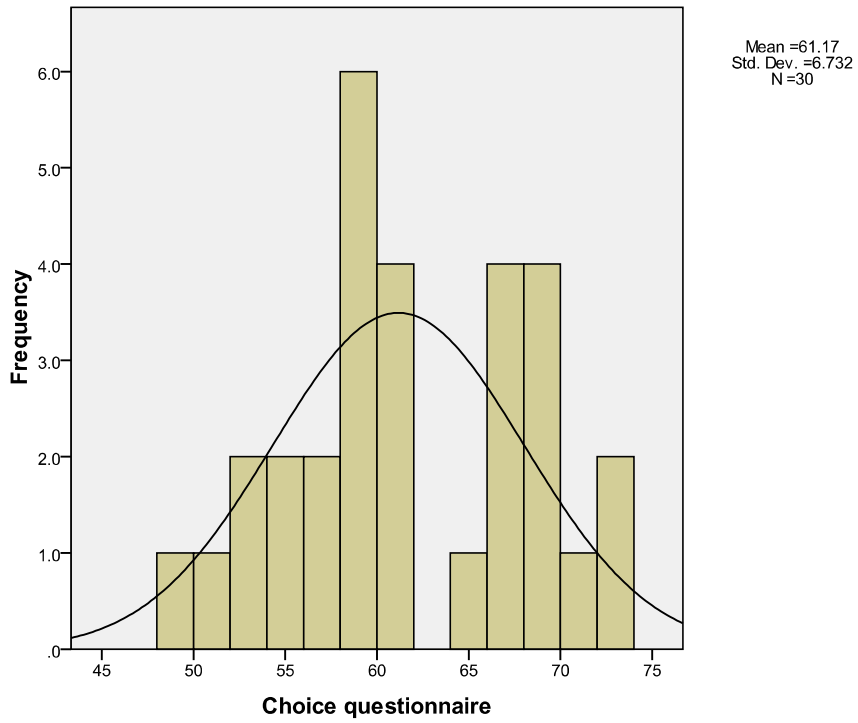
Four Main Variables

Inspection of the distribution graphs suggested that Previous Health Experience data may be skewed.

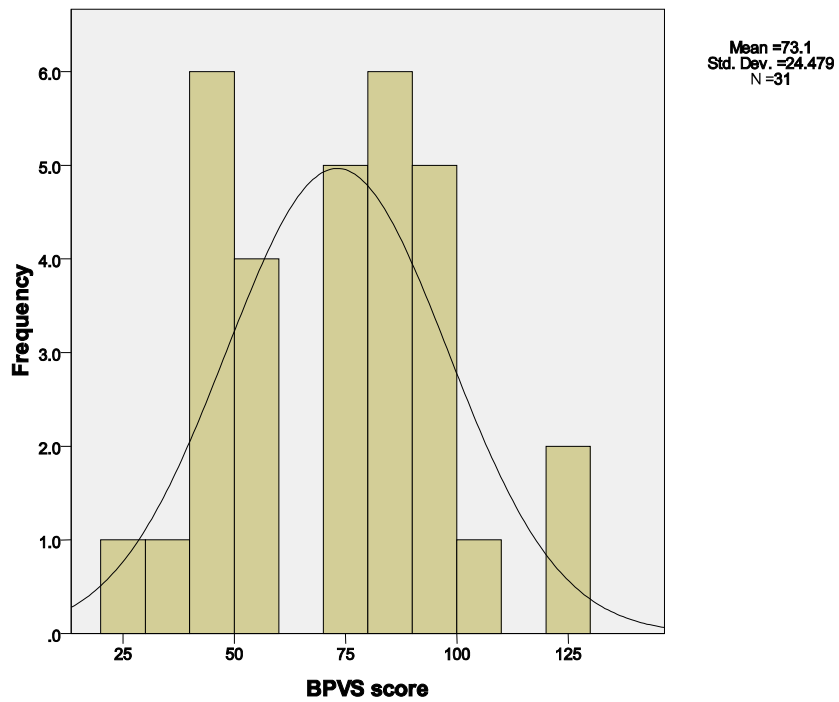
Previous Health Experience



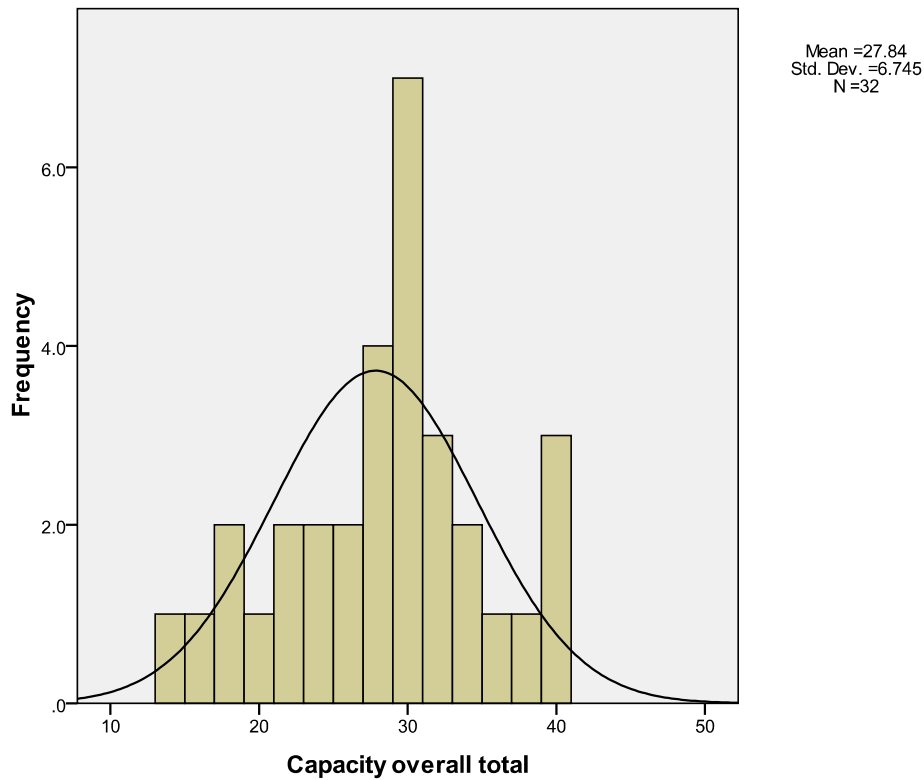
Choice Questionnaire



British Picture Vocabulary Scale



Capacity Assessment Total



Measures of skewness and kurtosis indicated a normal distribution for all the main variables, except HEQ scores. The z -values for skewness and kurtosis are shown in Table 1 below. Skewness was significant for HEQ: $z = 2.35, p < .05$.

Variable	Z skewness	Z kurtosis
Health Experience Questionnaire	2.35	0.17
Choice Questionnaire	0.05	1.24
BPVS score	0.27	0.76
Total Capacity score	0.33	0.45

Table 1: shows z -values for skewness and kurtosis for the four main variables.

The Kolmogorov-Smirnov test confirmed that scores on the HEQ were significantly different to a normal distribution: $D(29) = .212, p < .01$. Choice questionnaire scores, $D(29) = .14, p = .13$, BPVS scores, $D(29) = .13, p = .20$, and Total Capacity scores, $D(29) = .15, p = .09$, were not significantly different from a normal distribution.

Capacity Assessment Subtests and Decision-Making Abilities

Kolmogorov-Smirnov tests were also run to confirm whether the scores for the four components of the capacity assessment and the five decision-making abilities, were normal distributed. Results of the test are shown below in Table 2 and show that all these variables are significantly different from the normal distribution.

Variable	Result of Kolmogorov-Smirnov test	Significance
Capacity Assessment Part 1: Height and Weight	$D(32) = .18$	$p < .05$
Capacity Assessment Part 2: Ears, Blood Pressure and Chest	$D(32) = .23$	$p < .01$
Capacity Assessment Part 3: Urine and Medication	$D(32) = .21$	$p < .01$
Capacity Assessment Part 4: Injections and Blood Test	$D(32) = .17$	$p < .05$
Decision-making ability: Identification	$D(32) = .23$	$p < .01$
Decision-making ability: Understanding	$D(32) = .16$	$p < .05$

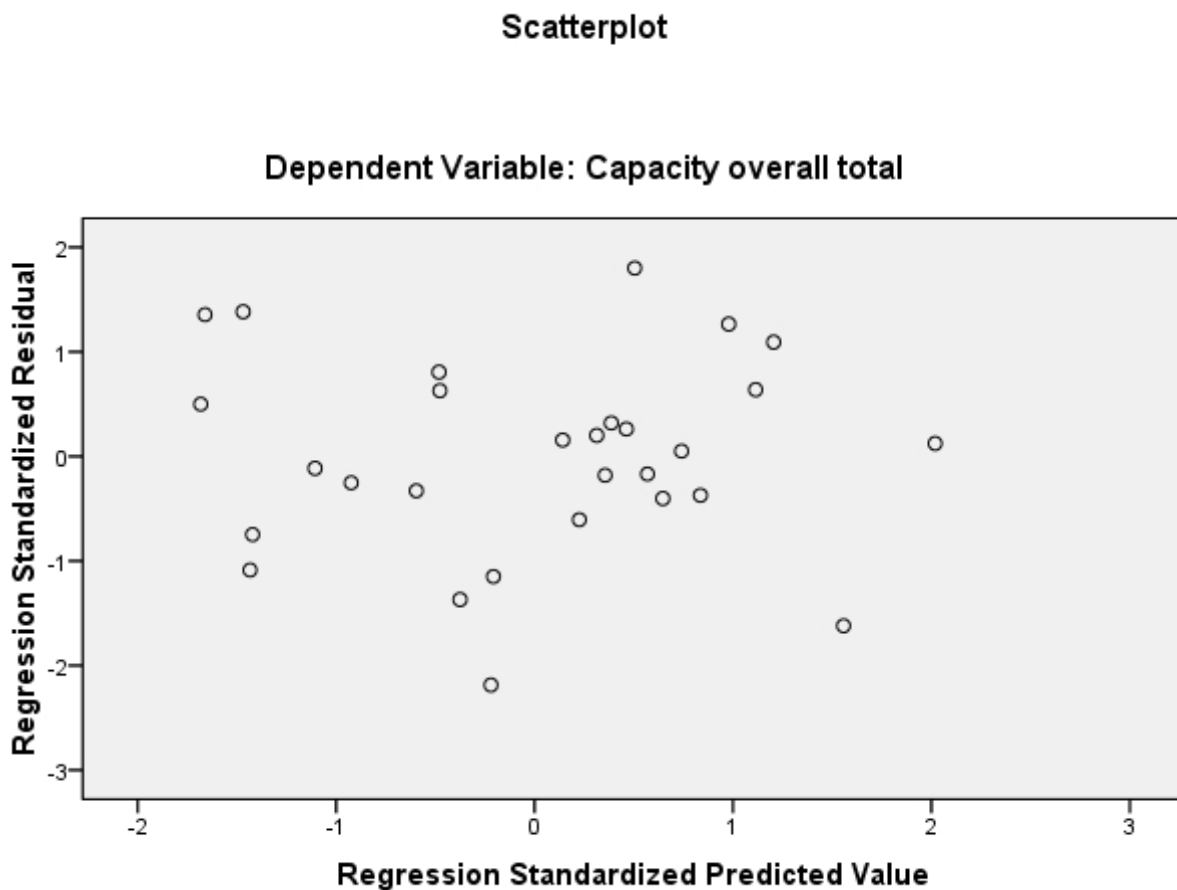
Decision-making ability: Reasoning	$D(32) = .25$	$p < .01$
Decision-making ability: Appreciation	$D(32) = .32$	$p < .01$
Decision-making ability: Communication	$D(32) = .48$	$p < .01$

Table 2: shows results of the Kolmogorov-Smirnov test for each part of the capacity assessment and each decision-making ability.

Appendix X

Testing Assumptions for Multiple Regression

The results for checking multicollinearity and autocorrelation are reported in the main document. Assessing homoscedasticity, linearity and normally distributed errors are reported here.

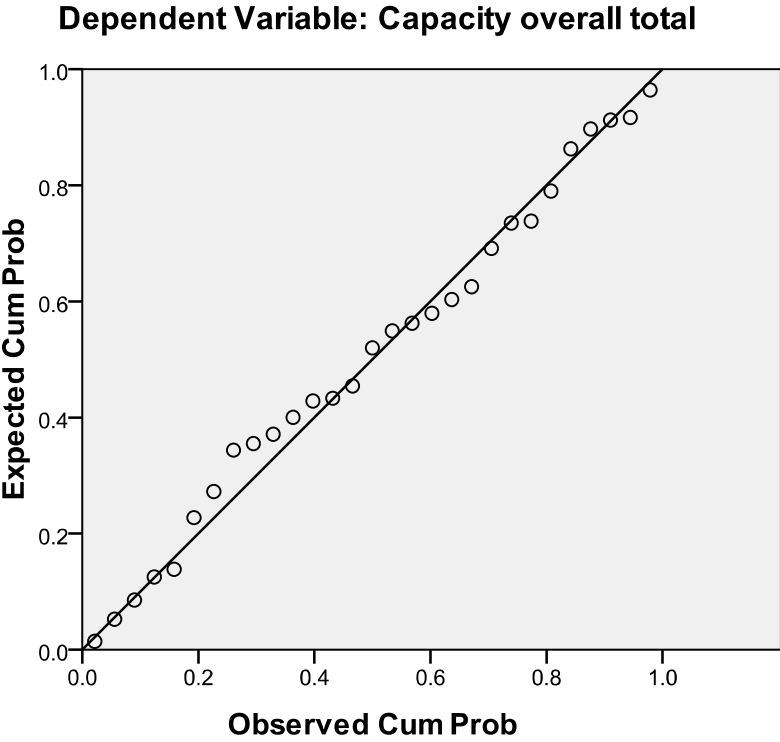


Graph 1: allows us to check for homoscedasticity and linearity in the data.

Graph 1 shows the standardised predicted values of the dependent variable plotted against the standard residuals of the data. Field (2009) recommends using this graph to check for homoscedasticity and linearity. As the graph does not show any funnel shape

or curves in the data, we can assume the data shows suitable homoscedasticity and linearity for multiple regression.

Graph 2 can be inspected to check the normality of the residuals. As the residuals fall approximately along the straight line, it suggests that the residuals are normally distributed (Field, 2009).



Graph 2: Normal Probability Plot

Appendix Y

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