Demystifying the process? A multi disciplinary approach to assessing capacity for adults with a learning disability

Rachael Skinner, Chris Joiner and Liz Chesters, Coventry and Warwickshire Partnership Trust, Community Learning Disability Team, The Loft, 60 George Street Ringway, Bedworth CV8 1BU, UK (E-mail: Liz.chesters@covwarkpt.nhs.uk), Louise Bates, Acorn’s Childrens Hospice Trust, Drakes Court, Alcester Road, Wythall, Birmingham, B47 6JR, UK and Louise Scrivener, Independent Speech and Language Therapist (self employed)

Accessible summary

- The Mental Capacity Act says that everyone has a right to make choices in their life.
- Some people find it hard to make a decision when it involves complex information.
- People who work in services can be unsure how to decide when people can make a hard decision.
- We developed a way of deciding if a person with a Learning Disability is able to make a choice (has capacity).
- We tried to make the process clear so that more people can use it.

Summary

There appears to be some degree of hesitation and lack of confidence among professionals in conducting capacity assessments. This document explains a two-phase process developed and implemented by a multi-disciplinary group of professionals during a pilot project. The first phase in the decision making process is to determine to what extent the person being assessed is able to process and recall information. The second phase involves understanding more detailed information specifically relating to the decision, in this case the procedure or intervention. The use of a two-phase process is illustrated via case studies. Over a 2-year period, 17 people who were referred from the eye unit to the capacity team were seen. Of those, two progressed to phase two of the process – and one person demonstrated capacity to make a decision. The process was based on a functional approach, and was used to avoid making decisions based on status approaches. The developed process was fed back to the professionals in the eye unit to enable them to assess capacity in relation to eye surgery. We hope to have demonstrated that capacity assessment skills are inherent in all practitioners working with people with a learning disability and are not the privileged possession of only particular professionals.

Keywords Capacity assessment, consent, learning disability, multi-disciplinary
Introduction

Although the principles of capacity assessment have been common law guidance for some time, there was an expectation that the advent of the Mental Capacity Act 2005 and associated Code of Practice would enhance confidence and competence in capacity assessment. However, anecdotally the reverse may be in evidence. There appears to be some degree of hesitation and lack of confidence among professionals in formulating capacity assessments. This may lead to reluctance and avoidance to take responsibility for executing an assessment and forming a judgement. Many practitioners are concerned that they are not armed with the correct experience, knowledge, training or skills to carry out such an assessment. They erroneously believe that capacity assessments are only within the remit of specific professionals such as psychologists or psychiatrists. Indeed, the Code of Practice may reinforce this belief by referring to the term ‘expert’ to describe the nature of professionals that may be involved in capacity assessment (Department for Constitutional Affairs 2007).

There seems to be an expectation that in order to answer the questions posed under the ‘test’ of capacity (Fig. 1), there is a complex, prescriptive formula, which only specially trained professionals are privy to. The term ‘test’ itself may cause anxiety to search for a comprehensive checklist or distinct tool comprising of specific questions to ask. In reality, there is no prescriptive formula, and developing questions to assess an individual’s ability to fulfil the four parts of the ‘test’ is an individualised process, which can and should take many forms. Relaying this to practitioners merely seems to reduce their confidence further with regard to what practical steps to take.

In the realm of the authors’ work, there is growing awareness of the implications of inappropriate practices regarding consent and capacity. At the one end of the scale, there is still evidence of the practice of others being asked to consent on behalf of adults lacking capacity. At the other end, there is avoidance of situations and decisions, which may involve additional work looking at an individual’s capacity. This avoidance may stem from a lack of clarity about where responsibility lies or anxiety about taking the lead in making a decision. The advent of Valuing People (Department of Health 2001a) and the Human Rights Act 1998 have facilitated a strengthened voice for individual rights and choice. Balancing the rights of individuals with issues of vulnerability, protection and the exercising of duty of care can be a difficult process. Under the Mental Capacity Act (2005), capacity must be assumed until proven otherwise. These Acts and guidance papers may inadvertently have led practitioners to become fearful of making judgements where an individual lacks capacity and where best interest decisions may need to be made, especially if these are contrary to the expressed wish of the individual concerned or their carers.

Multi-disciplinary working

In order to attempt to demystify the process, a multi-disciplinary team was set up and it created a structured system, alongside a set of documentation, to assess the capacity to consent of adults with a learning disability referred for proposed ophthalmic interventions. The original team (Capacity Assessment Team – CAT) consisted of two specialist nurses (one Sensory Impairment and one Acute care liaison nurse), a Psychiatrist, and a Speech and Language Therapist. The team was later complimented by a Clinical Psychologist. The work was undertaken using an action research process. Documentation was developed by practitioners engaging in a continuous reflective cycle and ongoing evaluation of its ability to meet the initial objectives.

In order to decide whether an individual has the mental capacity to make a particular decision, you must first decide whether there is an impairment of, or disturbance in, the functioning of the person’s mind or brain.

If so, the second question you must answer is does the disturbance make the person unable to make the particular decision?

A person is unable to make a decision for himself if he is unable to -

1. Understand information relevant to that decision
2. Retain that information
3. Use or weigh up that information as part of the process of making the decision
4. Communicate their decision (whether talking, using sign language or any other means.


Figure 1 The functional test of capacity.
for the project, i.e. of structuring capacity assessments (Henderson 2002). After the process was developed and trialled, the nature of the CAT changed to be more consultative, i.e. to help other professionals in their assessment of capacity.

The process

A project was therefore undertaken to test the feasibility of a two-part process for assessing capacity.

Other authors have commented upon the development of protocols and methods in an attempt to develop a functional approach to assessing capacity to consent. For example, the cognitive interview has been used as a basis for a very thorough assessment of an individual’s capacity to make a specific decision (Conboy-Hill 2006) and similarities in terms of the method of questioning (free account, open questions) contextual reinstatement (discussing patients recent hospital outpatient appointment) and semi-structured questions (using the leaflet to guide questions) can be seen in the method developed by ourselves. Suto et al. (2005) used vignettes and semi-structured interviews to look at the financial decision making abilities of men and women with mild intellectual disabilities. Vignettes were also used in a study by Arscott et al. (1999) to investigate the capacity of people with a learning disability to consent.

The main difference in this study is that we have introduced an initial ‘screening’ assessment phase rather than presenting detailed information about the eye procedure directly to the individual in the first instance. This phase allows for an assessment which considers the individual’s communication, their mental health status and fundamental understanding that there is a personal decision to be made. The initial leaflet (doc B) provides this information and by assessing their understanding and responses at this level enables a lot of information to be gathered about comprehension, information processing, memory (retention and recall), suggestibility and communication of even basic information. This ‘filter’ provides an alternative to either assuming incapacity on the basis of diagnosis or employing a time consuming detailed assessment specific to eyes which may clearly be beyond the individual’s comprehension.

The cognitive skills required to demonstrate fulfilment of the criteria for the test of capacity for complicated eye surgery are the same in nature as those required to understand the basic leaflet but are required at a higher degree. It is therefore relevant to test that these skills exist at an ‘easy’ level before testing them at a higher level. The information gathered at this initial step also assists clinicians in determining the level at which to pitch their information and also how to present this.

The first phase in the decision making process, we suggest, is to determine to what extent the person being assessed is able to process and recall information. Before the person can demonstrate a level of knowledge consistent with that required to make the specific decision, there needs to be evidence that the person knows there is a decision to be made, why and what this decision is. The second phase involves understanding more detailed information specifically relating to the decision, in this case the procedure or intervention.

Initial work was undertaken to search for areas of existing good practice. A number of care pathway documents were accessed via the UK Health and Learning Disability internet network (accessed at http://www.ldhealthnetwork.org.uk). A literature search was carried out using the National Electronic Library for Health (NELH). Many of the documents and articles found detailed lengthy processes but seemed to be missing the initial stage of determining the person’s level of ability to recognise there is a decision to be made. It was important that documentation was able not only to provide sufficient structure to the assessment but also detail a clear process for the professional to follow to guide their final outcome decision (Department of Health 2001a, Hutchinson 2005).

A series of meetings ensued that enabled practitioners to reflect on available evidence and make an ongoing review of the documentation developed to consider whether it was fit for purpose. A number of separate documents were designed to support the overall decision-making process (Fig. 2 – assessment flowchart). Case studies will now be used to illustrate how the two-stage process developed can assist with determining the level of information required alongside the efficient use of practitioner time.

The simplifying of information and a style of questioning has been shown to have a significant impact on the outcome of capacity assessments (Arscott et al. 1999). The team developed accessible documentation, incorporating symbols and photographs – using guidelines provided by Mencap (2000).

Case study 1

The referral

R, a 56-year-old woman, living in a group home in the local community was referred by the Ward Manager of the Eye Unit of the local acute hospital. R has diabetes and had experienced difficulty in tolerating a routine outpatient appointment to check important aspects of eye health as part of her diabetes care. The Consultant wanted to carry out an examination under general anaesthesia but was exercising caution as R had demonstrated a high level of distress during the outpatient appointment.

R was already known to the Community Learning Disability Team and a referral screening checklist (doc 7) could be completed from information available. Notes
confirmed that R had a diagnosed profound level of learning disability (‘impairment of the mind or brain’ as required under the Act.) and no known mental health problems (doc 8) – factors that may influence a current decision regarding capacity.

An accessible introductory leaflet (doc B) was sent to R and her carers (doc C) along with a letter for an initial appointment (doc 6). The leaflets described who we were and that we had been asked to visit to determine if R was able to decide about going to hospital.

**Assessment process**

*Phase one.* R was seen at a community clinic location by two members of the team along with a carer who knew her well. A communication screening checklist (doc 9) was completed that determined R was able to follow contextual information within her environment but could not understand beyond a one key word level. R was able to express communication through nonverbal cues, which were interpreted by carers who knew her well.

The accessible leaflet (doc B) was reviewed with R, but despite support from the CAT members and her carer, she was unable to demonstrate that she was aware of who we were or why we were meeting with her. R therefore was unable to demonstrate an awareness that there was a decision to be made regarding a proposed hospital admission.

A letter was then sent to the Consultant Ophthalmic Surgeon detailing that in assessment R was unable to demonstrate an awareness that there was a decision to be made, a preceding skill to being able to make a consent decision (doc 13). A decision would therefore need to be made by the Consultant based on R’s best interests.

![Flowchart of the assessment process and supporting documents.](image-url)
Community Learning Disability Team members known to R were detailed in order that they may be consulted if required regarding the best interests decision to be made.

**Phase two.** In this case, the capacity assessment was completed by the end of phase one and therefore progression to phase two was not indicated.

**Case study 2**

The referral

J, a 44-year-old woman living in supported accommodation, was referred by the Consultant Ophthalmic Surgeon. J had bilateral cataracts and was being offered cataract surgery under general anaesthesia as carers suggested that she would not tolerate the procedure under a local anaesthetic. There was uncertainty regarding her ability to provide consent following a discussion during an outpatient appointment. J was known to Psychiatrists within the Community Learning Disability Team. She had a history of mental health problems as identified in the mental health checklist (doc 8) but had been seen in clinic 2 months previously and had been well for at least the preceding 8 months. The accessible introductory leaflet (doc B) along with a letter for an initial appointment (doc 6) was sent.

**Assessment process**

**Phase one.** J was seen at a community clinic with two members of the team, along with a carer who knew her well. A communication checklist (doc 9) identified that J was able to understand fairly complex sentences. Her level of verbal communication was good but she appeared hesitant in her responses at times, looking to her carer for prompts.

The introductory leaflet (document B) was reviewed with J and she was then asked questions to determine her level of understanding regarding who we were, why we were there and in broad terms what we wanted to talk about (doc 10). J was clearly able to demonstrate that she understood who we were and that we had been asked to see her by a doctor who wanted to know if she could decide about having an operation on her eye. J demonstrated that she knew there was a decision to be made, i.e. she knew she had a sight condition and that she could choose about going into hospital to have treatment. Having demonstrated capacity to understand this level of information, she could move on to phase two of the assessment.

**Phase two.** Accessible information was collated relevant to this specific decision. This consisted of individualised visual materials, including symbols and photographs presenting information about:

- Why surgery was being suggested (the underlying illness/condition)?
- What was being proposed to treat this (the procedure)?
- Why it is being proposed (the outcome and benefits)?
- What would happen (the process, including how long it would take)?
- Were there any parts of the procedure that might go wrong (the risks)?
- What aftercare was required (constitutes part of the likely overall success of the procedure)?
- Were there any other options for treatment?
- Could the person change their mind and stop the procedure at any point?
- Does J feel under pressure in any way to make a decision (free from coercion)?

A document (doc 11) had been formulated to guide and record the delivery and response to all the questions posed earlier. An initial section was also available for the person to give a ‘free account’ of their understanding of what they had been told already.

When J was seen for the second phase appointment, she was able to give a good free account of what was being proposed. After discussing all relevant information, J was asked to recall all relevant factors. Two team members attended the appointment in order that one person could lead the discussion and the other could document the delivery and J’s responses.

J was able to recall and communicate all the relevant information required to fulfil the components of the test of capacity (Fig. 1). She commented that she liked the pictures as they had helped her to remember all the different parts of the procedure. J had told her carer that she was worried that she would forget something. This may have accounted for why J had been looking towards her carer at the first appointment. The use of visual material had served to prompt J’s memory and give her reassurance that she was able to contribute to the consent decision.

J was given a copy of the material to take home in order that she could discuss the procedure further with other carers and members of her family.

A letter was sent to the Consultant Ophthalmic Surgeon (doc 12) to state that at assessment J was able to demonstrate an ability to understand and recall relevant information and use it to voice a decision. Consent to the procedure would have to be confirmed by the Eye Unit team but J would have appropriate visual material available to bring into hospital with her.

This case study illustrates the application of both phases of the assessment process.

**Results**

Over an initial period of 12 months, nine individuals were referred by the Eye Unit for support in formulating an
opinion regarding their ability to provide consent to an intervention or examination under anaesthesia. Of the nine people seen, eight people were unable to progress further than phase one. That is, they were unable to demonstrate that they had an awareness or ability to communicate that there was a decision to be made regarding their care. One person progressed to the phase two part of the process but following the presentation of accessible material was not able to demonstrate that they had an ability to understand, retain or use the information regarding the nature of the intervention.

In the following 12-month period, a further eight people were referred and of those individuals one person went onto phase two of the process. This person went on to demonstrate that they had an ability to understand information regarding the eye procedure proposed, were able to retain the information and use it to communicate a decision regarding their care. In this instance, the eye unit were advised on the most appropriate way to present information to enable the individual to make a decision.

**Discussion**

The action research process utilised has demonstrated the value of a two-phase process when considering assessing capacity to consent.

Historically there have been three main methods of influencing capacity judgements; outcome, status and functional approaches. Outcome and status approaches have been rejected within law as inappropriate (Wong *et al.* 1999). A functional approach, whereby a judgement of capacity is made based on a person’s ability to make a decision within the context of their individual circumstances and specific to the decision being made, is now reinforced in statute law by the Mental Capacity Act 2005. Therefore, without clear evidence and documentation that a functional assessment process has been employed, practitioners may be accused of utilising a status approach to determine capacity whereby for example a person is judged as unable to provide capacity merely on the basis of their diagnosis of a learning disability.

A full assessment of capacity, in practise, is often reserved only for cases where there is a conflict about a decision or the individual is refusing or actively resisting intervention. Usually with the person’s best interests intended, interventions are carried out with the individual passively agreeing rather than as a result of a well-documented assessment. We hope this two phase process will help provide professionals with some of the tools they need to carry out a comprehensive person centred and time effective assessment.

We are aware that the CAT team was made up of the specialist practitioners we argued did not necessarily need to be involved in capacity assessments; this may lead to some confusion and appear as though we are contradicting ourselves. The aim of the project was always to pass the knowledge gained onto other practitioners and professionals to help them in their capacity assessments and decision making. Other service areas are now using the process themselves.

We have also been able to apply the process has to other situations for example regarding the management of financial affairs, choices about accommodation and access to other medical interventions. In these instances the authors have also acted to disseminate information regarding the process within their own and partner organisations by consultancy and joint working. This has enabled a wider range of colleagues to develop skills and confidence in assessing capacity.

**Conclusion**

This article has been developed with the aim of adding to the discussion regarding the pragmatics of assessing capacity to consent for adults with a learning disability. It was not formulated in an attempt to provide an indicative answer. We hope to have demonstrated that capacity assessment skills are inherent in all practitioners working with people with a learning disability and are not the privileged possession of only particular professionals.

**References**


Department of Health (2001a) *Department of health guidelines on consent*. London, DoH.


