



**Attorney General's**  
department of nsw

**Are the rights of people whose capacity is  
in question being adequately promoted  
and protected?**

**A Discussion Paper**

**28 March 2006**

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## Introduction

In March 2004, the Attorney General's Department of NSW convened a Capacity Roundtable Consultation to consider the issues of people whose capacity is in question.

The Roundtable Consultation considered the following problem definition, "Are the rights of people whose capacity is in question fully promoted or protected?"

The aim of the day was that the participants would:

- clarify current issues and concerns around capacity from both professional and community sectors; and
- put together a list of criteria which would be used by the Department to evaluate various policy/program options for capacity assessment in the future.

Invitations were sent to a diverse list of professionals and community groups. The list included legal practitioner and financial representative organisations, aged care and disability advocacy and professional groups, geriatricians, neuro-psychologists and various government department representatives.

I opened the Roundtable and the Public Trustee, Mr Peter Whitehead, chaired it. Over 100 delegates attended from the broad range of professional backgrounds and the community. Through presentations by various experts, case studies, interactive workshops and a concluding hypothetical, a lively and informative dialogue ensued. The participants discussed the triggers for capacity assessment, how to determine incapacity and the dilemma inherent in providing protection where needed without impinging on a person's human rights.

Those in attendance welcomed the opportunity to hear how others approached questions of capacity. They called for more information to be made available on how to define capacity, assess capacity and how to access general advice on capacity.

Specific recommendations from the Consultation included:

- the creation of a consistent approach to assessment of legal capacity; and
- the creation of resources for capacity assessors.

The Capacity Roundtable Consultation was an initial step in asking how NSW approaches questions about a person's capacity and the practice of assessment.

This Discussion Paper addresses issues related to legal capacity to make decisions affecting the person at civil law. Fitness to plead to a charge at criminal law is a separate issue, governed by its own Act: the Mental Health (Criminal Procedure) Act 1990 and is not in the scope of this paper.

The Attorney General's Department of NSW has prepared this Discussion Paper to obtain further stakeholder feedback in this area of law and practice. While the paper does not address all of the recommendations of the Roundtable, it has been developed to focus the discussion in some key areas of concern where there may be achievable outcomes.

Due to the complexity of the issues raised, it is anticipated that this may be the first stage of a larger review and that the comments received in relation to this Discussion Paper will feed into that larger review.

We have provided a consolidated list of the questions posed in the back of the paper along with instructions on how to submit your comments.

Thank you for your time and feedback on this important issue of protecting the human rights of people in NSW who may have their capacity questioned.

A handwritten signature in black ink that reads "Laurie Glanfield". The signature is written in a cursive, flowing style.

Laurie Glanfield  
Director General

## **Background**

### ***Why is capacity an issue we need to consider?***

There are many people in our community who at some time in their lives will not be able to make a legal decision. A person's capacity may be limited because of an impairment in cognitive functioning and the environment in which they find themselves. It may be limited either temporarily or over the longer term.

Often this limitation will not affect a person's day-to-day life, but will emerge at a time of crisis or when a legal decision must be made. Questions may arise as to whether or not the person is capable of making the decision. These are important questions since a determination that a person does not have the requisite capacity may result in the denial of a fundamental human right: the right to autonomous decision-making.

Capacity is not something that can always be accurately quantified. It is a construct that is based on the complexities of a person's abilities as they interact with their environment. It is also subject to fluctuation. A person's overall capacity to make decisions can be enhanced by personal strengths, good service provision, information and support. Personal limitations, poor service provision and lack of support can limit it.

In addition, the external environment will often influence or determine whether a person with an impairment makes decisions in areas where they are capable. For example, legislation which only provides for a finding of global incapacity automatically limits the opportunities for a person to make their own decisions in areas where they might otherwise be found to be capable.

Taken together, all these factors create major challenges for professionals and members of the community who are involved in capacity assessment.

This Discussion Paper seeks to propose how some of these challenges could be met.

### ***In what circumstances may capacity be questioned?***

People who have a cognitive impairment which results from a developmental disability, mental illness, dementia or brain injury are likely to have their capacity to make a legal decision questioned at some point in their lives. In Australia, approximately one in twelve people have an impairment that results in a need for assistance with communication and cognitive skills<sup>1</sup>.

Participants at the Roundtable Consultation reported that they were also more likely to question capacity when a person's circumstances included:

- the presence of a medical condition that affects cognition;
- out-of-character behaviour;

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<sup>1</sup> Survey of Disability, Ageing & Carers. Australian Bureau of Statistics, 2003

- risks associated with the decision;
- vulnerability or a suspicion that the person is being abused, neglected or exploited;
- concerns expressed by family members or friends;
- the person's lack of knowledge, education or language; or
- crisis in a person's life.

None of these factors alone indicates incapacity. To achieve an accurate assessment there needs to be an approach that fosters objectivity, reliability and transparency. This means giving thorough consideration to a person's ability to make a legal decision under certain circumstances. It also requires the assessor to engage the person in the assessment process in a skilful way and provide them with appropriate support.

While there are no specific figures available in Australia on the need for assistance with decision making, it has been estimated in the UK that 16,000 decisions a year were made for people who cannot make their own decisions and do not have an appointed decision maker.

### ***The New South Wales approach***

In NSW there are well-established legal mechanisms and government agencies<sup>2</sup> which respond to the needs of a person who requires a substitute decision maker *once* it has been determined that person is incapable of making a decision.

However there is no comprehensive approach to assessing or addressing the support needs of a person whose capacity is *in question*.

Participants at the Roundtable Consultation identified this as a critical point of concern. In particular, assessment practitioners report that they are short of information on best practice, lack access to specialist opinions when necessary and are concerned about making judgements without proper direction and experience.

Feedback provided at the Roundtable Consultation and a subsequent review of other common law jurisdictions, such as the United Kingdom and Ontario, Canada, suggest that there may be some gaps in the current NSW framework.

These relate to the possible need for:

- an agreed approach to an understanding of capacity;
- a definition of capacity so that the use of the terms *capacity* and *incapacity* is not arbitrary and a person is assessed according to a well-accepted standard;

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<sup>2</sup> The NSW Guardianship Act 1987 and the Protected Estates Act 1983 outline roles of the NSW Supreme Court, NSW Guardianship Tribunal, Mental Health Review Tribunal, a magistrate sitting in a psychiatric facility, the Office of the Protective Commissioner and the Office of the Public Guardian and identifies the roles and responsibilities of substitute decision makers. The Powers of Attorney Act (NSW) 2003 lists the roles and the responsibilities of the Attorney. The Public Trustees Act 1913 and Trustees Companies Act 1964 allow for professional attorneys.

- a greater availability of skilled and trained assessors using standard tools to avoid potential bias and discrimination; and
- easy and appropriate access to second opinions or appeal mechanisms.

Each of these issues will be explored further in the following sections of this Discussion Paper.

## **Issue 1: Creating a consistent approach to the understanding of legal capacity**

This section of the Discussion Paper looks at whether NSW law and practice would benefit from a more consistent understanding of legal capacity.

There is now greater recognition of the legal rights of people who have a cognitive impairment. Anti-discrimination and guardianship legislation and the development of statutory principles have sought to limit the intrusion by government and professionals into the life and decision-making of a person with an impairment.

This legislative recognition has effectively required decision-makers to presume that a person has capacity unless evidence is brought to the contrary. The “presumption of capacity” has significantly enhanced the protection of a person’s right to autonomous decision-making in areas in which they are capable.

### ***The need for a consistent approach to an understanding of capacity***

There are a number of approaches to the understanding of capacity which influence when and how to do an assessment. Each reflects a particular historical understanding of the nature of a person’s disability and the level of capacity which they are assumed to have. The three most common approaches are:

- the status approach;
- the outcome approach; and
- the functional approach (further refined as the decision specific approach).

In NSW, we have often seen a mix of these approaches.

### ***Status Approach***

*The status approach* sees a person with an impairment as having a global decision-making incapacity. For example, a person who is born with a severe developmental disability would be deemed to be permanently and globally incapable of making decisions.

This approach does not acknowledge the differing ways an impairment can influence people’s abilities, the notion of fluctuating capacity or the impact that learning or different circumstances can have on a person’s capacity. For example, a solicitor might not provide information to a person with cerebral palsy about a proposed transaction because he or she automatically assumes the person has no capacity to understand the information.

There are circumstances where a person might be globally incapable, for example, a person in a coma, but it is now recognised that this is not a useful approach to take in most circumstances.

### *Outcome Approach*

*The outcome approach* considers a person incapable if the outcome of a decision is considered illogical, risky or irresponsible. In using this approach, eccentricity could become a measure of incapacity. The English High Court dismissed this approach when it upheld the rights of a mentally ill person to refuse amputation of a gangrenous leg on the basis that, though he had a mental illness, his capacity to make the specific decision was not impaired.<sup>3</sup>

### *Functional Approach*

*The functional approach* is where capacity is measured in relation to the person's cognitive ability to make decisions about a specific area of his or her life at a point in time. For example, the NSW Guardianship Tribunal uses a functional approach when it appoints a decision maker with the authority to make accommodation decisions but not medical decisions, for a defined period of time.

### *Decision Specific Approach*

In recent times the functional approach has been further refined so that capacity is considered in relation to a *specific decision*, at a specific time and under specific circumstances. Arguably, this approach represents the most widely accepted modern capacity model. It now forms the basis of legislation on capacity in some other common law jurisdictions.<sup>4</sup>

This approach is useful as it recognises that capacity depends on the interaction between a person's underlying impairment and their circumstances. It promotes the provision of information and support to a person to enhance their capacity to make a particular decision and the review of the capacity assessment if circumstances change.

The decision specific approach underpins some NSW legislation but is not always practised by assessors. This may be particularly the case for professionals and members of the community who have limited experience of disability and the effects of impairment on a person's cognitive functioning.

### ***Different legislative models***

The following paragraphs highlight different legislative models which embody the approaches discussed above. They are included to provide some guidance about whether NSW would benefit from the legislative changes adopted more recently in some other jurisdictions such as Queensland, the UK and Ontario, Canada.

### *Definitions in New South Wales*

NSW currently has no single definition for capacity and relies on a range of common law and statute definitions.

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<sup>3</sup> English High Court in *Re C (Adult: Refusal of Medical Treatment)* 1994, 1 All ER 819

<sup>4</sup> See for example, Ontario Substitute Decisions Act 1992, United Kingdom Mental Capacity Act 2005

In NSW, there are two Acts that address decision-making capacity in the civil area:

- the NSW Guardianship Act 1987; and
- the Protected Estates Act 1983.

Neither Act defines capacity clearly. Below is a snapshot of sections which relate to the notion of capacity in NSW legislation.

### Guardianship Act 1987

For decisions about such areas as accommodation, services and health care, a *person in need of a guardian* is "a person who, because of a disability, is totally or partially incapable of managing his or her person". (See Definitions)

Furthermore, a *person with a disability* includes a person who has one or more named disabilities and as a result of that disability is restricted in one or more major life activities to such an extent that he or she requires supervision or social habilitation. (See Definitions)

In relation to *enduring guardianship*, evidence of a medical practitioner to the effect that the appointor was, on that day or during that period, totally or partially *incapable* of managing his or her person because of a *disability* is evidence of the fact that the appointor was a *person in need of a guardian*. (See section 6N)

In relation to medical treatment, a *person who is incapable of giving consent* to medical and dental treatment is defined as a person who is "incapable of understanding the general nature and effect of the proposed treatment, or is incapable of indicating whether or not she or she consents to the treatment being carried out". (See Part 5, Division 1(2)). (Note: This definition is more in line with a functional model that is decision specific.)

### Protected Estates Act 1983

An "incapable person" is defined as a person "who has been found to be incapable of managing his or her affairs".<sup>5</sup>

Justice Powell, of the NSW Supreme Court, provided further clarification of this:

"...a person is not shown to be 'incapable of managing his or her own affairs' unless at the least, it appears:

- a) that he or she appears incapable of dealing, in a reasonably competent fashion, with the ordinary routine affairs of man; and
- b) that, by reason of that lack of competence, there is shown to be a real risk that either :
  - i) he or she may be disadvantaged in the conduct of such affairs; or
  - ii) that such monies or property which he or she may possess may be dissipated or lost; it is not sufficient, in my view, merely to demonstrate that the person lacks the high level of ability needed to deal with complicated transactions or that he or she

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<sup>5</sup> NSW Protected Estates Act 1983

does not deal with even simple or routine transactions in the most efficient manner".<sup>6</sup>

### *Definitions in other Australian Jurisdictions*

In general, most definitions in guardianship legislation in other Australian jurisdictions are based on the status approach and define disability and not capacity.

The Queensland Guardianship and Administration Act 2000 is a notable exception. It defines capacity according to a decision specific approach to capacity assessment:

"Capacity for a person, for a matter, means the person is capable of -  
a) understanding the nature and effects of decisions about the matter; and  
b) freely and voluntarily making decisions about the matter; and  
c) communicating the decisions in some way."<sup>7</sup>

Furthermore the Queensland Act provides for a "presumption of capacity" and reinforces its fluctuating nature by recognising that:

"the capacity of an adult with impaired capacity to make decisions may differ according to:  
i. the nature and extent of the impairment; and  
ii. the type of decision to be made, including, for example, the complexity of the decision to be made; and  
iii. the support available from members of the adult's existing support network."<sup>8</sup>

The Queensland Guardianship and Administrative Tribunal also has the authority to make a declaration about a person's capacity to communicate a decision. It has an obligation to consider all possible augmentative communication options.

### *Definitions in overseas jurisdictions*

Ontario, Canada

In Ontario the Substitute Decisions Act 1992 defines capacity in two parts: the person must have the *ability to understand* information relevant for making decisions, and, *in addition*, show the *ability to appreciate* the consequences of a decision or lack of a decision.<sup>9</sup> This definition is applied in decisions related to finance, lifestyle, accommodation and medical treatment.

The Capacity Assessment Office in Ontario reports that it has deliberately chosen a decisional test to protect the rights of capable individuals who could otherwise be deemed in need of a guardian. Current assessment procedures were developed to

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<sup>6</sup> Justice Powell *PY v RJS* (1982) 2 NSWLR 700 @ 702.

<sup>7</sup> Guardianship & Administration Act 2000, Schedule 4: Definitions.

<sup>8</sup> Guardianship & Administration Act 2000, Chapter 2, section 5

<sup>9</sup> Guidelines for Conducting Assessments of Capacity, Capacity Assessment Office, Ontario Ministry of the Attorney General, May 2005, p.II.2

reflect these legal standards and to guide the collection of evidence that speaks to mental capacity as a legal and not a clinical construct.<sup>10</sup>

## United Kingdom

The UK's Mental Capacity Act 2005 links incapacity to the presence of an impairment or a disturbance in the functioning of the mind leading to:

“the inability to:

- a) understand the information relevant to the decision;
- b) to retain that information;
- c) to use or weigh that information as part of the process of making the decision; or
- d) to communicate his decision (whether by talking, using sign language or any other means).”<sup>11</sup>

### ***What should the standard definition be?***

Participants at the Roundtable Consultation were asked to consider the usefulness of developing a definition of capacity that could cover decisions about medical, legal, financial and lifestyle issues across disabilities and circumstances.

Responses were mixed, with the majority highlighting the need for a definition to be flexible, responsive to the individual and his/her circumstances and the decision at hand, initiated on a suitable trigger, with the possible requirement for a collaborative response from professionals involved in the person's life.

However, while recognising the need for flexibility, this Discussion Paper is seeking comment on whether there is benefit from a single legal definition of capacity that could be used for decision-making in all circumstances. For example, if a decision specific approach is favoured, such as in Queensland, the definition is likely to emphasise cognitive skills and may not make reference to disability or diagnosis. If this route is to be taken, there may also be some benefit in considering the model adopted in the UK legislation.

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<sup>10</sup> Capacity Assessment Office, Ontario, May 2005p.ii.2

<sup>11</sup> Mental Capacity Act 2005, S3 (1)

## **Questions on Issue 1**

### **Creating a consistent approach to the assessment of legal capacity**

1. Would NSW law benefit from a single legal definition of capacity that could be used in relation to legal decision-making in all circumstances?
2. If so, should that definition be based on a “decision specific” approach to capacity and include as the test “understanding and appreciation” as in the Queensland Guardianship & Administration Act 2000?
3. Should relevant legislation include a presumption of capacity?
4. Should the laws related to decision-making, such as the Guardianship Act 1987, the Protected Estates Act 1983 and the Powers of Attorney Act 2003 be changed to include a common standard definition based on the “decision specific approach”?
5. Would a single legal definition result in a more standardised capacity assessment in practice?

## **Issue 2: Creating resources for assessors**

This section of the Discussion Paper looks at the needs of those who are likely to be involved in assessing a person's capacity either in their role as a provider of professional services or as an involved or concerned family member or friend. It also looks at the kinds of resources which may be useful when an assessment of a person's capacity becomes necessary.

### ***Who are assessors of capacity in New South Wales?***

In NSW, there is a range of people in the community who have a responsibility to undertake assessment of a person's capacity. They include:

- solicitors, who have an obligation to consider a person's capacity to effect a variety of decisions about property transactions, civil and criminal litigation and estate planning;
- professionals from the financial sector, who must consider a person's capacity to give directions regarding their resources and assets;
- medical practitioners, seeking a valid consent for treatment from a patient;
- professionals, such as disability, social and allied health workers supporting a person with a disability to make a decision or to consent to actions; and
- in an informal sense, members of the public appointed as enduring guardians or with enduring powers of attorney who can only commence acting when the appointor has lost capacity.

### ***The needs of assessors***

#### **i) What do solicitors and professionals from the financial sector need?**

Solicitors, professionals from the financial sector need confidence to seek instructions from clients whose capacity might be in question, even where they may be unfamiliar with the nature of a person's impairment and how that affects the way the person thinks and communicates.

In NSW, solicitors have an obligation to undertake a capacity assessment to ensure a client is able to give instructions. The NSW Law Society has developed Client Capacity Guidelines<sup>12</sup> to assist solicitors in this area. The Guidelines warn solicitors against presuming incapacity on the basis of impairment or failing to take steps to facilitate communication.

In practice, it can be difficult for these professionals to seek the expertise needed to facilitate communication. More often than not, they are reliant on the information provided by attendant family or friends who may have a vested interest in the outcome of a proceeding.

Arguably, solicitors and professionals from the financial sector need access to expertise on disability for support, information and possibly second opinions.

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<sup>12</sup> NSW Law Society: *Client Capacity Guidelines*, 2003

However, referral to an expert in capacity assessment may also be an expensive decision to make on the client's behalf, particularly if the legal decision involved would otherwise have minimal costs associated with it.

## **ii) What do guardians and attorneys need?**

The Office of the Public Guardian's Private Guardian Support Unit reports anecdotal evidence that guardians and people with powers of attorney experience difficulty in having their view of the person's capacity accepted when there is conflict.

For example, a private guardian may view the parent, for whom they are an enduring guardian, as having capacity to make a decision on the basis that an opinion expressed by the parent is consistent with a past opinion. However, service providers may have concerns about the impact of the person's impairment and challenge the private guardian's right to act.

In these circumstances, the private guardian is able to make application to the Guardianship Tribunal for a declaration that the enduring guardianship appointment has effect.

Arguably, if a capacity assessment were available it may satisfy the needs of all those involved with minimal stress to the person and without a referral to the Guardianship Tribunal. This type of support may be more beneficial to guardians, financial managers and attorneys provided that it is reasonably priced, accessible and a recognised form of capacity assessment. Currently, professional assessments can be expensive as they take between six and sixteen hours to complete.

## **iii) What do medical practitioners need?**

Medical practitioners are routinely assessing a person's capacity to give consent to medical treatment. However time and resource pressures often mean that a doctor may not conduct a full and proper assessment, particularly where information may need to be provided over a period of time, or at particular times, or in a form that can assist the person's comprehension. This can be difficult to achieve, particularly in a hospital setting.

Arguably, medical practitioners also need access to assessors who can take the time to consider a person's circumstances, provide the necessary information that relates to the person's condition and support the person to understand the decisions at hand prior to assessing the person's capacity.

### ***Roundtable recommendations***

The Roundtable Consultation made recommendations on the needs of a range of practitioners and lay people. These recommendations include:

- the promotion of access to the expertise of professionals who regularly engage in capacity assessment;
- the need for a simple capacity assessment tool; and
- the need for greater cross-disciplinary training and communication.

## ***Resource options***

There are a number of possible resource options that could be considered. Some of these are outlined below as discussion points. Feedback is sought on their efficacy and any other possible options, which are realistic and achievable.

### **i) Professionals defining their role to include assessment**

At the Roundtable Consultation, it was suggested that capacity assessment ought to be incorporated into existing professional roles: for example, members of Aged Care Assessment Teams or psychologists. This could potentially reduce the costs of assessments and make them more accessible to people across NSW, particularly in rural and remote areas.

It was also suggested that information on capacity assessment ought to form part of undergraduate training for certain categories of professionals, who may need to undertake some form of capacity assessment. Increasing the opportunities for professionals involved in capacity assessment to have access to training as part of ongoing professional development was also discussed.

### **ii) Expert sources**

The Roundtable Consultation also identified a need for access to 'expert' sources of information and advice particularly in rural and remote areas. An expert source may be:

- a readily accessible set of assessment tools (see below);
- a network of assessors or professionals who can mentor or train others;
- a helpline that provides information on innovation and best practice; and
- a website or a number of affiliated websites to distribute information on best practice and resources available.

### **iii) Providing a simple assessment tool**

There are a number of capacity assessment tools in the market<sup>13</sup>, but currently there is no simple, widely endorsed capacity assessment tool. Other tools are under development and are designed to assist those making a capacity assessment without the benefit of specialised training but these tools need additional validation before they are ready for widespread use.

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<sup>13</sup> The Aid to Capacity Evaluation, the MacArthur Competence Assessment Tool, the Six Step Capacity Assessment Process.

The Standard Mini Mental State Examination<sup>14</sup> test is a test that is commonly used in NSW for assessing capacity, but participants at the Roundtable Consultation raised concern about its use. These concerns are also reflected in a range of literature; in particular, the tool is not sensitive enough to measure a person's capacity in relation to a particular decision that needs to be made.<sup>15</sup>

It is difficult to see at present how *one* standard tool could be identified and promoted across a broad range of circumstances. It would also not be desirable to attempt to hamper the development of new techniques and practices in the field of capacity assessment by adopting one standard tool.

#### **iv) Developing guiding principles**

Standardised guidelines and/or an assessment tool could be based on an agreed set of principles surrounding assessment and an agreed definition of capacity.

Currently there are principles in the NSW Guardianship Act 1987 which guide decision-making under the Act. These require that a decision-maker has regard to the following:

- the personal views of the person;
- the least restrictive option;
- respect for the person's autonomy; and
- the fostering of self-management.<sup>16</sup>

These principles are in line with principles guiding capacity assessment in other jurisdictions such as Ontario, Canada. Its Capacity Assessment Office has produced Guidelines which include a focus on:

- the right to self-determination;
- presumption of capacity;
- decisional capacity (person able to understand and appreciate factors related to a specific decision);
- incapacity is domain specific (incapacity limited to certain decisions or class of decisions); and
- guardianship as a last resort.<sup>17</sup>

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<sup>14</sup> Folstein, M.F., Folstein, S.E. and McHugh P.R. (1975), Mini-mental state: A practical method for grading the state of patients for the clinician, *Journal of Psychiatric Research*, 189-198

<sup>15</sup> Capacity, Assessment of Patient Capacity to Consent to Treatment, *Bioethics for Clinicians*, Journal 3, p 32; Darzins, Malloy & Strang (Eds), *Who Can Decide*, Memory Australia Press, 2000, p 7; 'Dementia and the will-making process: the role of the medical practitioner', C.Peisah & H. Brodaty in *MJA*, 1994 161 p 382

<sup>16</sup> Robin Creyke, *Who Can Decide? Legal Decision Making for Others*, Department of Human Services and Health, no 19, 1995

<sup>17</sup> Guidelines for Conducting Assessment of Capacity, Capacity Assessment Office, Ontario May 2005

In the United Kingdom, the principles underpinning the Mental Capacity Act 2005 include:

- a presumption of capacity;
- the right of individuals to be supported to make their own decisions;
- the right of individuals to make what might be seen as eccentric or unwise decisions;
- the best interests of the individual; and
- the least restrictive alternative.

If there were agreement in this area in NSW, a set of principles could be agreed upon by stakeholders as part of a best practice approach.

### **v) Developing practice guidelines**

The participants at the Roundtable Consultation made strong recommendations about the need for guidelines or minimum practising standards to be made widely available.

Participants suggested guidelines be developed to encompass:

- different professional needs;
- disability issues;
- cultural and linguistic factors;
- particular concerns around privacy and release of information;
- what circumstances should trigger an assessment; and
- an overarching set of principles or a standard for assessment.

A number of professional colleges have already starting developing guidelines on capacity assessment for their members. A further recommendation from the Roundtable Consultation was that these established guidelines be standardised to ensure consistency across professional groups.

#### *Developments in other jurisdictions*

NSW is not the only jurisdiction considering these issues. There has been considerable work undertaken by the Capacity Assessment Office in Ontario, Canada in the production of practice guidelines. This Office also produces standard forms for assessments and has a standard approach to testing.

The United Kingdom Mental Incapacity Act 2005 has a substantial code of practice for all professionals assessing capacity. The Code “provides guidance to all those working with and/or caring for adults who lack capacity, including family members, professionals and carers and describes their responsibilities when acting or making decisions with, or on behalf of, individuals who lack the capacity to do these things for themselves”.<sup>18</sup>

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<sup>18</sup> Draft Mental Capacity Bill: Code of Practice, United Kingdom, 2005. p.5

The Manitoba Law Reform Commission in a 1999 report on informal assessment of competence also found that “the vast majority of respondents were of the view that the government should provide guidelines, training and informational materials to assist health care workers, and the public in general, in dealing appropriately with persons whose competence may become an issue”.<sup>19</sup>

To develop guidelines that would meet the needs of the range of assessors it may be necessary to make provision for groups such as:

- members of the community, enduring guardians and attorneys;
- professionals in health, welfare and financial services; and
- professionals undertaking a capacity assessment for the purposes of evidence provision.

### ***Should a distinction be drawn between assessors?***

In other jurisdictions, distinctions have been drawn between formal assessment and informal assessment,<sup>20</sup> or screening.

*Informal assessment* and/or screening are terms commonly used to describe assessment undertaken by lay people in the community and professionals unskilled in the area of cognitive assessment.

*Formal assessment* is the term used for professional assessment based on valid tests/instruments used by psychologists, psychiatrists and psycho-geriatricians.

However the question may be posed: is this a useful distinction to make? Despite the difference in terminology, an assessment that the person is incapable has the same effect on that person's rights, regardless of whether it was made formally or informally. Once the determination of capacity is made, certain consequences will follow.

Lay people, it could be argued, can and do undertake a form of capacity assessment on a regular basis, but at times may need access to an expert assessor for a second opinion. For example, a general practitioner who has a patient with a developmental disability may undertake a brief capacity assessment to determine if the patient can understand the nature and effect of the treatment. If the practitioner remains uncertain about the patient's capacity, they could refer the patient to a psychologist for a professional opinion.

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<sup>19</sup> Informal Assessment of Competence, Manitoba Law Reform Commission, 1999, p.89

<sup>20</sup> Manitoba LRC,102, 1999 'Informal Assessment of Competence' p.27

In the UK, the Draft Code of Practice accompanying the Mental Capacity Act 2005 spells out the kind of situation where a referral to an expert for a second opinion on capacity may be necessary. The type of factors considered to indicate the need for professional involvement include:

- the gravity of the decision or its consequences;
- where the person concerned disputes a finding of incapacity; and
- where there is disagreement between family members, carers and/or professionals as to the person's capacity <sup>21</sup>.

The distinctions between the *formal and informal* groups of assessors may not be necessary if both groups operate from the same starting point, using a clear definition of capacity that determines the nature of the assessment.

Further comments are sought about the usefulness, or otherwise, of this distinction.

The need for greater access to second opinions is discussed in the next section of the Discussion Paper.

## **Questions on Issue 2**

### **Creating resources for capacity assessors**

1. Does this section of the Discussion Paper reflect the needs of the various assessors? If not, what additional issues do they face and how can their needs best be met?
2. What resource options listed would be most helpful if they were further developed?
3. Should a distinction be made between lay and professional assessments?

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<sup>21</sup> Mental Capacity Bill: Draft Code of Practice, United Kingdom p.26

### Issue 3: Promoting rights and enhancing protections

This section looks at difficulties faced by a person whose capacity has been questioned by their caregivers and who may wish to challenge their caregivers' views.

#### ***Assisted decision-making***

*When and how often does it occur?*

In the majority of circumstances, people who have a cognitive impairment that affects their decision-making capacity for a period of time will be *assisted* to make decisions by their family and friends or decisions.

In such situations, the need for capacity assessment does not immediately arise, as the family member or friend is *not* taking on a *substitute* decision-making role. They are still supporting the person to make their own decisions.

There are no specific figures available in Australia on the need for assistance with decision-making. In the UK, it has been estimated that 16,000 decisions a year are made for people who cannot make their own decisions and who do not have an appointed decision maker. This consists of around 6,000 decisions about serious medical treatment and 10,000 decisions about care moves.<sup>22</sup>

As Justice Michael Kirby AC CMG has stated: "there are thousands of decisions made every day, which are never scrutinised by a lawyer, let alone a court...Decisions made by individuals with great power and responsibility, affect in practice the rights of many".<sup>23</sup>

Approaches to capacity assessment, such as the Six Step Capacity Assessment Process<sup>24</sup>, are also beneficial to *assisted* decision-making. This is because they require that:

- the person with an impairment remains actively involved in decision-making for as long as possible;
- those assisting the person make every effort to understand the person's unique circumstances, their values and goals; and
- the person is provided with information or education to make their own decisions.

By virtue of this process, a person may actually increase their functional ability to make their own decisions. Up to a certain point, this negates the need for a capacity assessment.

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<sup>22</sup> UK IMCA Consultation, 2005, Executive Summary, p.4

<sup>23</sup> *Who Can Decide?*: P. Darzins, D.Malloy, D.Strang, (Eds) Memory Australia Press, Adelaide, 2000, p.vi

<sup>24</sup> *Who Can Decide?*: P. Darzins, D.Malloy, D.Strang, (Eds) Memory Australia Press, Adelaide, 2000

*What if there's conflict between a person and those who are assisting them to make decisions?*

It is clear that *assisted* decision-making can maintain the person's decision-making autonomy for as long, and in as many situations, as possible.

However, problems or conflict may sometimes arise between the person with the impairment and those assisting them to make decisions. This is often the case if the family member or friend comes to a view that the person may no longer have capacity to make certain decisions. This represents a kind of trigger point for an assessment of the person's capacity, particularly where:

- there is ambivalence about the person's need for assistance;
- the person with the impairment objects to (continuing) assistance; or
- family and friends may be unwilling or unable to provide (further) assistance.

*In such situations, what are the options?*

The Roundtable Consultation discussed the need for a better system of obtaining second opinions or else greater access to the justice system to help resolve questions of capacity in these circumstances. This is particularly critical where the person with the impairment cannot communicate easily.

When there is conflict, feedback from the Roundtable Consultation suggests that, in practice, service providers and family members who have concerns usually apply to the Guardianship Tribunal for an order for guardianship or financial management. Sometimes this occurs even in relation to matters where the Guardianship Tribunal has no jurisdiction, for example, about whether a person has capacity to marry.

### ***Support to challenge the view that the person's capacity is in question***

Participants at the Roundtable Consultation were asked to provide solutions to a situation where there are strong differences of opinion or conflict about a person's capacity. The two options raised and briefly discussed were:

- referral to an Aged Care Assessment Team; and
- referral to the Guardianship Tribunal for determination.

However, the following discussion suggests that these solutions may be limited in their application. Stakeholder feedback is sought on other possible options.

### ***NSW Aged Care Assessment Teams***

NSW Aged Care Assessment Teams (ACATs) undertake assessment on a regular basis in relation to a person's care needs. ACATs have no direct mandate to assess capacity and where they regularly do so, it may be the result of the development of internal expertise. ACATs also have no ability to provide a service to younger age groups.

### *Second opinions*

The ACAT suggestion is an attempt to identify the appropriate sources of second opinions about a person's capacity, either at the request of the person with the impairment or their family, friends or service providers. New South Wales seems to offer no obvious ways to seek a second opinion for a person whose capacity in question, or for their families, other than formally making an application to the NSW Supreme Court or the Guardianship Tribunal for guardianship or financial management.

Feedback is sought in more informal ways for the person or their caregivers to obtain help or support with assessing capacity at these trigger points.

### *Courts and Tribunals*

The NSW Supreme Court and the NSW Guardianship Tribunal may make determinations on matters where there is dispute regarding a person's capacity to make certain decisions. In reaching a decision, the Tribunal or the Court needs to be satisfied that there is a decision-making *incapacity*. However, capacity assessment is not the sole or primary purpose of the determination. The Tribunal's role is to weigh the evidence presented by professionals about capacity, not to do the assessment itself.

There are some mechanisms in legal proceedings to assist a person who is before a Court or Tribunal. Most courts also have procedural rules which enable them to appoint a 'guardian ad litem', tutor or 'case guardian' who provides instructions on behalf of the person with the disability. The Guardianship Tribunal and the Administrative Decisions Tribunal (ADT) can also appoint separate representatives for people with disabilities to represent the person's best interests. In some circumstances, such as applications for consent to sterilisation, a separate representative must be appointed.

The Mental Health Advocacy Service can also provide representation that is neither means nor merit tested at Guardianship Tribunal hearings for the person with a disability who is the subject of an application. They will also represent the person who is the subject of an order on appeal, if they are satisfied with the merits of their case.

A brief survey of matters before the ADT since February 2003 shows that there have been 47 appeals to the ADT against decisions of the Guardianship Tribunal. Fifteen of those appeals were lodged by the person who was the subject of the Guardianship Tribunal order<sup>25</sup>. Three of the 15 appellants were legally represented in the appeal. The majority of the appeals (8) were withdrawn before hearing or dismissed at a preliminary stage of proceedings. Of those seven appeals which proceeded to a full hearing, none were successful. One appellant was legally represented at the full hearing.

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<sup>25</sup> This represents 14 appellants as one appellant lodged two different appeals against different decisions of the Tribunal.

In most of these appeals, the appellant asserted that they had the capacity to make their own decisions, either in relation to personal or financial matters. In a minority of the appeals, the appellant accepted the need for a substitute decision-maker but disagreed with the choice of decision maker.

There is no strong evidence available that more people with an impairment might appeal a Court or Guardianship Tribunal order if they had adequate support. However, it seems logical that without a clear support framework, it may be difficult for a person with an impairment to find the support to initiate an appeal.

### ***Advocates to support a person***

Participants at the Roundtable Consultation put forward the idea of more Government funding for advocates to support a person whose capacity is in question.

In most Australian jurisdictions, advocates for a person with a disability are available to support individuals in being heard and recognised in decision-making processes. Advocates can assist a person to make his or her own decision and also challenge the role of an appointed decision maker.

#### *New South Wales*

In NSW, the Office of the Public Guardian can only advocate directly on behalf of a person under the guardianship of the Public Guardian, though the Public Guardian is able to report on systemic advocacy issues. There is also a range of peak and advocacy bodies in NSW providing support and assistance for decision-making but they do not do so with any formal authority.

#### *Other Australian states*

In Victoria, Western Australia and Queensland a Government advocate can intervene in matters without necessarily proceeding to an application for guardianship or financial management. It is at this stage, before an application is made, that issues around a person whose capacity is *in question* can be addressed.

In its 2004/05 Annual Report, the Public Advocate in Victoria reported that his office had provided advocacy support for 1,033 people and guardianship services to 524.

The kinds of advocacy the office can provide include:

- intervention to support people who have capacity but whose decision-making ability is being affected by other circumstances; and
- support for people who lack capacity by other means than through the appointment of a substitute decision maker.

#### *United Kingdom experience*

The Mental Incapacity Act 2005 UK established a regime of Independent Mental Capacity Advocates (IMCA). The IMCA is an appointed person who makes representations about the person's wishes, feelings, beliefs and values and, at the

same time, brings to the attention of the decision-maker all factors that are relevant to the decision. The IMCA can challenge the decision-maker on behalf of the person lacking capacity if necessary, including in the areas of long-term accommodation and medical treatment.<sup>26</sup>

### *Canadian developments*

In Ontario, Canada, no assessment proceeds if the person subject to the assessment objects unless a court order is then made in circumstances of potential harm. If there is conflict regarding the outcome of an assessment, the Consent and Capacity Board carries out a review process.

The Consent and Capacity Board has wide ranging review powers that include the ability to review a person's capacity to consent to certain lifestyle decisions and to review the appointment of a decision maker and the actions and decisions of that decision maker. The Board holds hearings under the relevant mental health legislation. Thirty percent of the Board's reviews were related to a finding of incapacity for financial or health care decisions.<sup>27</sup>

The Yukon Government also has a Capability and Consent Board that enables reviews of a care provider's determination of a person's capacity to make their own decisions in relation to health care, admission to a care facility or personal assistance services.

In 2004, the Manitoba Law Reform Commission made a recommendation to consider implementing a review and appeal mechanism for patients or other interested persons who are dissatisfied with, for example, a finding of incompetence.<sup>28</sup>

### **Questions on Issue 3** **Promoting and protecting rights**

1. How can a person whose capacity is questioned be supported to obtain a second opinion when necessary?
2. Is there an appropriate role for Courts and Tribunals, if a person whose capacity is questioned wishes to make a challenge but there is no existing Court or Tribunal order?
3. Is the current advocacy framework in NSW sufficient?

<sup>26</sup> United Kingdom, Mental Incapacity Act, Summary, 2005

<sup>27</sup> Consent and Capacity Board, Business Plan, 2005/2006, Ontario, Canada

<sup>28</sup> Manitoba LRC, Executive Summary Report 110, 2004

## Future directions

The Capacity Discussion Paper is being widely distributed to individuals and groups with an interest in capacity assessment and the promotion and protection of the rights of people with disabilities.

This Capacity Discussion Paper is available on the Attorney General's Department's Lawlink website [www.lawlink.nsw.gov.au/diversityservices](http://www.lawlink.nsw.gov.au/diversityservices)

Hard copies and alternative format versions for people with vision impairments can be obtained from Diversity Services of the Attorney General's Department of NSW.

Please send your feedback to the following questions from the Capacity Discussion Paper:

Electronically to: [diversity\\_services@agd.nsw.gov.au](mailto:diversity_services@agd.nsw.gov.au)  
By fax on: (02) 9228 7829  
Or in writing to: Attorney General's Department of NSW  
Diversity Services  
Goodsell Building, Level 18  
GPO Box 6  
Sydney NSW 2001

The Attorney General's Department of NSW is open to receiving comments on this Capacity Discussion Paper until **16 June 2006**.

Feedback received will be collated and recommendations will be made to the Director General for further consideration of these issues.

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## **Consolidated list of questions:**

### **Questions on Issue 1**

#### **Creating a consistent approach to the assessment of legal capacity**

1. Would NSW law benefit from a single legal definition of capacity that could be used in relation to legal decision-making in all circumstances?
2. If so, should that definition be based on a "decision specific" approach to capacity and include as the test "understanding and appreciation" as in the Queensland Guardianship & Administration Act 2000?
3. Should relevant legislation include a presumption of capacity?
4. Should the laws related to decision-making, such as the Guardianship Act, 1987, the Protected Estates Act 1983 and the Powers of Attorney Act 2003 be changed to include a common standard definition based on the "decision specific approach"?
5. Would a single legal definition result in a more standardised capacity assessment in practice?

### **Questions on Issue 2**

#### **Creating resources for capacity assessors**

1. Does this section of the Discussion Paper reflect the needs of the various assessors? If not, what additional issues do they face and how can their needs best be met?
2. What resource options listed would be most helpful if they were further developed?
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### **Questions on Issue 3**

#### **Promoting and protecting rights**

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