

# **Incapacity Assessments: A Review of Assessment and Screening Tools**

## **Final Report**

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## Table of Contents

<b>Executive Summary</b>	1
<b>Introduction</b>	4
<b>Part I: Exploring the Context of (In)Capacity Assessments</b>	5
• Assessment to do what?	5
• Models for conceptualizing capacity	6
• Establishing a 'gold standard' around assessments	7
• Clarifying language: Definitions	7
• Standards for determining capability	9
• What constitutes a good incapacity assessment?	11
• How should it be done?	12
• Specialized populations	14
• Summary	15
<b>Part II: Examining the Available Tools</b>	15
<b>1. Decisional Abilities Instruments (Capacity Assessment Tools)</b>	16
• Health care decision-making	17
• Personal care (everyday) decision-making	18
• Financial/property decisions	19
• Tools developed specific to assessing capacity: How do you choose?	23
• Summary	23
<b>2. Standardized Screening Tools used to Inform the Assessment of Incapacity</b>	23
• Cognitive Functioning	24
• Functional screens	28
• Summary and considerations	31

*Contents continued on next page*

## Table of Contents (continued)

<b>Part III: Overview of Selected Tools</b>	<b>31</b>
1. Health Decisions	
• The MacArthur Competence Assessment Tool for Treatment (MacCAT-T)	33
2. Financial Decisions	
• Financial Capacity Instrument (FCI)	35
• Financial Competence Assessment Inventory (FCAI)	38
3. Personal Care Decisions	40
• Assessment of Everyday Decision-making (ACED)	
4. Cognitive Screening	
• Mini-Mental Status Examination	42
• The Executive Clock Drawing Task (CLOX)	45
<b>Part IV – For Further Reading</b>	<b>46</b>
• General reading	46
• Reviews of treatment instruments	47
• Reviews of performance-based measures of functional living skills	48
Endnotes	49
References	54

## **Incapacity Assessments: A review of Assessment and Screening Tools**

### **Executive Summary**

This report was commissioned by the British Columbia Office of the Public Guardian and Trustee. The task was to critically review existing research in relation to the use of standardized assessment tools with a particular focus on identifying practices and research around property and personal guardianship decisions. This review is intended to assist professionals who are responsible for conducting assessments of incapacity.

An overview of the literature in this area suggests that the focus on assessing incapacity is a burgeoning area of research but still considered to be under-developed and under-conceptualized. There are trends emerging in this research which include the following:

- a move toward understanding capacity as multi-dimensional and context-specific;
- a focus on improving interdisciplinary overlap, particularly recognizing the need for a common language;
- attention to the limitations associated with a strictly cognitive understanding of capacity that currently dominates assessments of incapacity;
- a move toward a more functional approach that includes attention to executive capacity;
- the importance of an assessment that is context-sensitive and includes attention to culturally-laden values and beliefs; and
- the quest for a more open assessment process that promotes an ‘audit trail’ to support individual assessor’s opinions about capacity.

The use of standardized tools has been one way of responding to some of these issues - especially the need for a more consistent, comparable approach amongst different assessors. The use of standardized tools can be divided into two categories: those tools that have been developed specifically to assess capacity to make some decision; and those tools that have been developed for some other purpose but are thought to provide important information in relation to someone’s capacity. This latter group would include for example, diagnostic or cognitive screening tools, instruments assessing ability to perform activities of daily living; and neuropsychological testing.

Instruments specifically geared toward assessing capacity have been best developed in the area of health care decision-making. In this domain, the MacArthur Capacity Assessment Tool for treatment (MacCAT – T) is emerging as the gold standard. It assesses the adult’s ability to consent to treatment decision. In contrast to the focus on health care decision-making, other domain specific tools are far less developed but are beginning to emerge. In particular, the focus on conceptualizing and developing tools to assess financial decision-making has taken off in the past seven years with several promising tools now in existence. Instruments related to assessing everyday decision-making have only started to emerge within the past couple of years and these have yet to establish strong research foundations.

All of these tools attempt to operationalize some aspect(s) of four standards generally accepted as required for someone to evidence capable decision-making: understanding, appreciation, reasoning, and evidencing a choice. These tools are useful because they demonstrate concretely how to break down each of these standards in order to assess and document findings. The

drawback is that they are not necessarily consistent with specific provincial legal tests; this issue is rarely addressed in the research. Furthermore, more has been written about the use of these tools in research than in practice.

The use of standardized measures that have been developed for something other than assessing decision-making capacity – for example, evaluating functional or cognitive performance – are more commonly incorporated into the assessment of incapacity. This is at least partially because clinicians tend to be more familiar with these tools.

When examining the state of evidence for the strategic use of standardized diagnostic and cognitive screening instruments in the formal assessment of incapacity, key findings include the following:

- Cognitive screening tools are often inappropriately relied upon in relation to the assessment of incapacity. Largely this is related to inadequate evidence linking specific tests – and or measures of particular functions - to (in)capacity.
- The mini-mental status examination (MMSE) has the most research supporting its use, followed by the use of clock drawing tests.
- There are however drawbacks to the use of the MMSE – in particular there are questions regarding the association of mid-range scores with decisional capacity. Moreover, the instrument is not very sensitive, especially when the person being assessed has higher intelligence and/or educational level and/or subtle cognitive changes.
- The clock drawing tests may provide more insight into capacity issues as they are more sensitive to aspects of executive functioning. Research is clearly documenting the importance of executive brain functioning to decisional capacity. However, tests scores are not well-understood because there are so many different ways of administering and scoring.
- Two other tests, the Trails and Verbal Fluency, have research to support their use in relationship to assessments of incapacity.
- More complex screening tools such as the Montreal Cognitive Assessment (MoCA) may be useful but this test was not developed for assessing incapability and no research was found which examined how test scores correlate to decisions about capacity.

Key findings related to the use of standardized performance tests include the following:

- Increasingly, the importance of looking beyond cognitive aspects of decisional capacity to include performance – for example, ability and history of carrying out decisions under question – is being recognized and built into tests of incapability. This is consistent with proposed guidelines for new BC legislation around guardianship.
- Strategies for assessing this aspect however are not well developed;
- There is some reliance upon standardized measures of self-care and instrumental activities of daily living;
- Of these standards, performance based assessments – as opposed to proxy measures and/or self report – are recognized as superior.
- However no particular performance test emerges as a gold standard in the area of assessing incapacity;
- Moreover, little research exists which explicitly links the results of standardized tools of performance to (in)capacity. In other words, the correlation between performance on

standardized measures and actual behaviour in relation to decision-making is not yet well established.

### **Recommendations and Conclusions**

- Standardized tools must be carefully scrutinized to insure that they are consistent with BC tests of incapacity. In this review, none were found that clearly operationalized BC legal tests. This means that the information captured by these tools may provide interesting and useful descriptive insights around the adult's decision-making capacity but scores may not necessarily be relevant for reaching a conclusion about an adult's capacity.
- Existing tools for assessing capacity focus almost exclusively upon cognitive functioning. Given the cultural diversity of BC's population, as well as a trend toward prioritizing more holistic and functional-based assessments, research is required around developing more relevant BC tools.
- Particularly in more complex situations, standardized tools may have an important two-fold role: they can assist the assessor in concretely breaking down the components of decisional capacity in order to explore for their presence; and they help provide a way of comparing findings among different assessors. However, in light of the state of uncertainty surrounding the value of many of these tools in relation to what they say about capacity, it will be important that test scores are not prioritized, or given higher weighting, than less standardized approaches to the assessment. The research clearly indicates that the clinical interview remains the gold standard.
- A potentially appropriate and effective way of insuring consistency across assessments will be to focus on insuring a common foundation for training and understanding. This will include insuring consistency among assessors in applying and documenting the criteria (or test) that they are using as the basis for their opinion about decisional capacity.

## **Incapacity Assessments: A review of Assessment and Screening Tools** Final Report (Amended)

### **Introduction**

People are presumed to be capable in our society. However, at times, it becomes necessary to revoke a person's right to autonomous functioning and decision-making. Knowing when it is time to do this can be a challenge - Western society places high value on autonomy and independence and removing someone's right to act independently is not an action that is taken lightly. As a society, we struggle with the need to protect while still honouring people's rights to self-determination. Assessments of (in)capacity provide one route for resolving this tension.

The purpose of this report is to provide some assistance to those professionals who are responsible for conducting such assessments and making decisions about incapacity. Research suggests that some use of standardized tools can be helpful for insuring more consistency across assessments and for helping assessors to document findings and reach conclusions. This report identifies and describes some of the tools that are available to assist in the assessment process, including examining the evidence that is available to link specific tools to decisions about capacity. An important goal of the report will be to recognize the value that standardized tools can add, but to also recognize their limitations in terms of fostering holistic, person-centred assessments.

A systematic literature review was conducted to identify what tools are being used to assess incapacity. Four main search engines (Web of Science, Academic Search Premier, OVID, and Google Scholar) were searched using key words [capacity and/or competence and/or decision-making ability] and [guardianship and/or substitute decision-making] and [instrument or tool or protocol]. This search was then progressively refined to search specifically for these words in relation to: specific domains of decision-making [financial and/or property and/or resource management; everyday and/or personal care; and health care and/or treatment]; specific tools; and special populations [cultur\*<sup>1</sup> and/or dementia and/or mental illness and/or specific types of mental illness]. This data was supplemented by reviewing the reference lists of retrieved articles and through personal communications (including email correspondences) with relevant experts in the area.

Retrieved articles were critically reviewed based on the following research questions:

- a) What is the general state of knowledge regarding the assessment of incapacity, particularly in terms of how these should be conducted?
- b) What tools have been developed directly to assess capacity? What is the evidence for each of the tools? What are the strengths and weaknesses of each?
- c) What additional screening tools are being used to *inform* the assessment of incapability? What is the level of support for linking these tools to capacity?

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<sup>1</sup> Use of an asterisk will draw search for any word beginning with cultur – for example, culture, cultural, cultures  
Report completed by: Deborah O'Connor  
15/04/09

Because this is a rapidly expanding area, I paid particular attention to individual research published after 2000 and to any review articles that summarized previous research.

An attempt was made initially to be as comprehensive as possible and then to narrow on what was doable given the time frames. To this end there are three delimitations:

- Research related to intellectual disability is not included in this review;
- After an initial first sweep of the literature, I chose to focus attention on the three domains that are most pertinent to this project: financial decisions, health care decisions, and personal care decisions (especially in relation to living independently). These correspond most closely to BC Adult Guardianship Legislation - both current and anticipated. I do not address other domains such as driving, voting, testamentary capacity...
- I did not conduct an indepth examination of discipline-specific tools – for example, tools that required explicit disciplinary expertise and/or qualifications.

Finally, a caveat is necessary. While standardized tools can help in an assessment, they do not replace clinical judgment and skill. These ‘softer’ –but equally (if not more) critical – aspects of the assessment of incapability are not dealt with in this report. In particular, this report does not address the clinical interview or interviewing strategies.

This report is organized into four sections. **Part I** provides an overview of the topic of assessing (in)capacity, summarizing the key issues related to the state of knowledge around the standardized assessment of incapacity. **Part II** begins to focus more explicitly on the actual tools and is divided into two sections: (1) the development of tools explicitly for the purpose of assessing capacity; and (2) other screening tools that are commonly used to inform the assessment process. **Part III** examines selected tools that were seen as particularly important/relevant and/or most commonly used. There is a general overview of the tool followed by a discussion of its strengths and weakness, including the degree of research support it has. **Part IV** identifies relevant readings and a reference list.

## **Part I: Exploring the Context of (In)Capacity Assessments**

Since the early 1990’s, there has been a growing body of research related to the assessment of capacity. There have also been several trends nationally and internationally that are reflected in BC, and which will help to set the parameters of this report.

### Assessment to do what?

First, there has been a move away from a global concept of competence to one that considers capacity “not as an all-or-nothing state, but as a multiple functional abilities concept along a continuum that can vary according to the context and also over time”<sup>1</sup>. This has lead to a focus on domain specific capacity - BC Adult Guardianship legislation has increasingly reflected this more domain-specific approach.

Specific domains that have been identified in the research are related to issues such as driving, financial management, ability to live independently, testamentary capacity, and ability to give



informed health care/treatment consent or legal directives. While research around the assessment of capacity is very active, some domains have been better developed than others. The two areas that are best developed are related to consent for medical treatment and for participation in research. Other areas like financial capacity have been gaining increasing attention and are being actively developed, while still others like testamentary capacity, advanced care planning and vulnerability to undue influences have, to date, been more neglected.<sup>2</sup>

Reflecting the domain-specific approach, this report will consider the state of knowledge around assessment tools to determine the need for guardianship or a substitute decision-maker in the following areas: health care, financial, and personal care decisions (especially around independent living.)

### Models for conceptualizing capacity

Second, there has more recently been a call to expand assessments of capacity to include a more functional approach. Three models for conceptualizing capacity have been identified:<sup>3</sup>

- 1) Cognitive model (philosophical/legal): This model assumes that mental capacity results from being able to express desires, understand pertinent risks and benefits, appreciate the ramifications of a decision, and think rationally. This approach underpins the development of many, if not all, of the assessment tools – for example, the MacArthur Competence Assessment Tool (MacCAT-T). This approach has the most empirical research and is linked most closely to the assessment of decisional capacity. However, it has serious limitations, especially when dealing with decisions about everyday living and care.<sup>4</sup>
- 2) Medical model: This approach is sometimes also referenced as ‘status’ competence because medical symptoms are linked to incapacity. Here individuals who have neurological or psychiatric symptoms and are considered unable to perform certain cognitive tasks and, therefore have impaired mental capacity. This approach may use standardized screening tests like the MMSE to identify a condition and assumes the presence of this condition (for example, dementia) equals incapacity. Although very common, the problem with this approach has been in establishing a relationship between the clinical symptoms and functioning in the real world. Moreover, research clearly indicates that while there are trends among different groups – for example people with dementia are more likely to have impaired decisional abilities – there is also considerable heterogeneity within each group making it inappropriate to draw conclusions about an individual’s capacity based solely on his/her diagnosis.<sup>5</sup>
- 3) Functional: Here the focus is on observable behaviour, and attention is paid to measurable and adaptive behaviours that the adult shows in everyday life. This approach begins to capture the dual concepts of decisional and executive capacity: decisional capacity asks if the person is capable of making the decision, while executive capacity asks if the person is able to implement and adapt those decisions. There is considerably less research using this approach. It is the direction that is being taken under proposed BC Adult Guardianship legislation.

The degree to which these approaches are consistent with particular pieces of legislation is important to consider. Arguably in BC, Part III of the Adult Guardianship Act incorporates a

more cognitive approach where the test of incapacity is essentially based upon the person's ability to understand what is being offered to him/her in terms of a Support and Assistance Plan (SAP), why it is being offered, and possible consequences of turning down the proposed plan. In contrast, the Mental Health Act uses more of a medical model where the person must have a mental health diagnosis and be in imminent risk (to self or others) – but his/her actual capacity to CHOOSE that risk is, theoretically, not considered. The trend toward a more functional model is demonstrated in the proposed Adult Guardianship Act where for example, the test of financial capacity that is being recommended includes a statement to the effect that the opinion of the assessor must be based not only on whether the adult demonstrates an understanding of the factors identified in the specific test, but also whether the adult demonstrates that he or she is able to take appropriate steps to ensure that his or her decisions about his or her financial affairs can be implemented. A similar statement is made in relationship to personal care decisions.<sup>ii</sup>

Hence, understanding that there are different approaches is important when considering the use of tools. *Some well-researched tools may have unexpected limitations because they are not appropriate and/or sufficient in relation to the actual test of incapacity under a particular piece of legislation.* This highlights the need to carefully consider tools within the context of their conceptual and legislative underpinnings.

#### Establishing a 'gold standard' around assessments

The third issue is linked to the state of knowledge around best practice standards for conducting of the assessment. Although there is growing interest in developing standardized instruments, the general consensus seems to be that the clinical interview remains the gold standard. There are, however, no clear best practices established on how to do this interview, and without training, some research has demonstrated that comparability of findings between two different assessors using their own personal guidelines for assessment and decision-making is less than chance.<sup>6</sup> The very limited number of research studies conducted related to the assessment of incapacity for adult guardianship points to “suboptimal evaluations”<sup>7</sup>, unreliable use of clinical interviews<sup>8</sup>, and a general agreement that more research is needed to establish the reliability and validity of tools.<sup>9</sup> In other words, despite the growing interest and research in this area, there are no empirically-based ‘best practices’ around standards and procedures. Rather, there is an acute and growing need for evidence-based assessments practices.<sup>10</sup>

Although not a substitute for clinical judgement, there are some recognized advantages to using standardized measures in assessments. For example, one study found that the use of standardized tools made it easier to give feedback to the patient and the family in a way that they could better understand and accept<sup>11</sup>. As well, there is an assumption that standardized tools provide better support for decisions and promotes more consistency across assessors. However, it bears repeating that there is very clear recognition that these tools are not a substitute for the clinical interview and need to be used appropriately and selectively.

#### Clarifying language: Definitions

The fourth issue is that discussions about incapability cross several disciplinary thresholds and fields including the legal, clinical and ethical. One result of this has been that there is some

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<sup>ii</sup> At the time of writing (March 2009) new Adult Guardianship legislation has received royal assent but remains unproclaimed. This proposed legislation and draft regulations will make important changes to the process of assessing incapacity, including leading to the repeal of the Patient's Property Act.

confusion around the use of language and concepts. In order to clarify understanding, I will begin by defining some of the concepts where there seems to be the most confusion.

1) Competence or Capacity?

One place where there is often confusion is around the use of the terms ‘capacity’ or ‘competence’ (or conversely, incapacity and incompetence). Most frequently, these are described as two related but distinct concepts. A common method for distinguishing between the two is that capacity denotes a clinical status that is determined by a health care professional, while competence refers to a legal status as judged by a legal professional.

However, this usage is not consistent. Some have used this general parameter but have developed more specific usage. For example, Moye and colleagues – leading researchers in the area - make reference to decisional capacity (related to patients’ decision-making *processes*), competency (related to decision by clinician as to whether a patient is capable of carrying out a specific act based on the assessment of patient’s decision-making abilities to make this determination) and legal competency (judge or legal decision).<sup>12</sup> Still others, (see for example, Appelbaum, 2007 – another leading researcher in the area) highlight that distinctions based on clinical or legal statuses or practice, are too simplistic and not consistently reflected in either medical or legal usage – he chooses to use the words interchangeably.

Royall,<sup>13</sup> on the other hand, extends the distinction between the two but in a slightly different way; to him ‘capacity can be thought of as a functional ability intrinsic to the individual whereas competency is a social status conveyed upon them’ (p.1885). His definition moves beyond the health/legal divide and begins to capture the shift that is currently underway from more global notions of competence to more specific assessments of capacity. Using this definition, capacity can be operationalized as the ability to perform a certain task or make a specific decision. This is the usage I will apply – hence, I will largely be discussing capacity rather than competence when discussing the use of standardized tools.

In BC, reflecting the notion that people are presumed to be capable until the contrary is demonstrated, discussions may focus around capacity, but the assessment is explicitly recognized as an assessment of *incapacity*. Other jurisdictions have been less overt about making this distinction even though the presumption of competence underlying the assessment remains the same. This means that most published tools refer to assessing capacity, not incapacity.

One step removed from the broader discussion of competence and capacity, there are three more concepts that require clarification: decisional capacity, executive capacity and mental capacity.

a) Decisional capacity: This concept refers to the process of making a decision or extending that power to another. Generally, there are four abilities<sup>iii</sup> associated with decisional capacity: understanding basic facts surrounding a decision; appreciating the personal impact

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<sup>iii</sup> See following section for a more comprehensive discussion of this

of the decision, including one's capabilities and limitations; having a reasoning process for comparing options and predicting the consequences of alternative choices; and being able to make a choice. These four abilities are cognitively based and ground many of the existing decisional abilities assessment tools (also referenced as capacity assessment tools).

b) Executive capacity: Increasingly it is being recognized that capacity is not just based on cognitive functioning such as understanding and appreciation. Instead, more emphasis is being placed on the ability of the person to execute a decision – this links to a more functional approach for assessing (in)capacity. New BC legislation reflects this trend as does the Yukon legislation. Naik et al.<sup>14</sup> have operationalized this concept into three components: ability of the person to develop a pre-determined plan; ability to adapt this plan to changing or unexpected circumstances; and ability to carry out or delegate responsibilities when physically unable to carry out plan.

c) Mental capacity: Mental capacity is the term being used particularly in the UK as a contrast to a discussion about mental health status. It is a multi-dimensional construct that is a central determinant of an individual's ability to make autonomous decisions.<sup>15</sup> New UK legislation focuses on mental capacity rather than mental health which is seen as tending to take a 'status' approach whereby a wide range of treatments can be given to the patient on the basis of certain general conditions being met;<sup>16</sup> however, using the concept of capacity as defined in newer legislation, treatments are only provided in the patient's best interest. Literature coming out of the UK often uses the language of mental capacity while American research in this area tends to use the language of capacity or competence.

#### Standards for determining capability

A fifth issue centers on the use of 'standards'. Within the literature, there are four standards<sup>iv</sup> that are most often cited as being critical to any assessment of incapacity: expressing a choice; understanding the information required for a decision; appreciating how the information being given pertains to the person's own life and circumstances; and logical reasoning using the information presented<sup>17</sup> This set of standards come out of earlier work by Roth et al.,<sup>18</sup> where there were initially seven criteria and is the result of a review of emergent case law literature in USA.<sup>19</sup> This is important – it means that these standards were developed in relation to American legislation, not Canadian. The standards are sometimes, but not always, considered hierarchical – for example, expressing a choice is seen as a lower threshold than reasoning, being able to understand information is a less stringent test than appreciation.

The discussion around standards represents an area where there is some disjunction between research and practice. Specifically, researchers often present standards as though they are universal givens; in other words, always considered as part of the determination about capacity. In fact, standards are linked to legal tests of incapacity, which may or may not include all or some of these standards. This means that how directly these standards link to actual pieces of legislation varies. For example, in BC, the notion of 'appreciation' is not actually used, but the

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<sup>iv</sup> There is some inconsistency in the literature about whether these constitute *abilities* or *standards*. They initially were positioned as standards, but increasingly they are used to reference abilities in relationship to the concept of capacity. In this report, I will selectively reference them in both contexts: That is, both as standards which tests of incapability try to address, and as abilities that are seen as important components of capacity.

ideas underpinning it are arguably captured in the standard that the person recognizes that the information applies to him/her. Similarly, some pieces of legislation appear to assume – rather than test for – an expression of a choice. For example, in Part 3 of the AGA, if the adult is not accepting the Support and Assistance Plan there is an assumption that they are turning it down – and hence the test of capacity does not explicitly build in the expression of choice as one of the standards. This can – and has been – problematic in some situations where in fact, no choice – or inconsistent choice – is being made.

Although there seems to be some agreement that these standards<sup>v</sup> are relevant for understanding and determining capacity, beyond their fit with legal standards and tests of incapability, four further issues emerge when considered in relation to standardized tools.

1. Although most of the existing tools attempt in some fashion to operationalize these concepts, they do not always do so consistently. For example, in one review of the tools to assess capacity to consent to treatment<sup>20</sup> the researchers draw attention to the “fundamental challenge in selecting an instrument” related to the lack of consistency across instruments in what is being measured, despite the use of similar labels for these constructs. They then demonstrate how ‘reasoning’, ‘appreciation’, and even ‘understanding’ are operationalized differently in each of the tools.<sup>21</sup>
2. At least some of the time, there are concerns that how these standards are operationalized may – or may not – be measuring the actual ability thought to relate to capacity. For example, does a measure of ‘understanding’ in an instrument actually lead to insight about understanding, or is it actually measuring memory? This is important because these are substantially different concepts.
3. There is some expectation that any threshold for determining what constitutes a minimally accepted level of understanding, appreciation or reasoning should be decision-specific and dependent upon a risk-benefit ratio; this, however, is not always included as a consideration. (For example, higher thresholds need to be associated with situations where being wrong carries greater danger).
4. It is recognized that these standards do not capture executive capacity – in other words, the ability to carry out the decisions. Here a fifth standard is emerging, the ability to carry out, or delegate, a plan.

The point here is that, arguably, from a research perspective there is some consensus about what is required for a person to demonstrate decisional capacity: Understanding, appreciation, reasoning and choice should be evident. In some way, these standards underpin most, if not all, of the instruments that are being designed to assess decision-making capacity. However, practically speaking, these four standards (or abilities?) are reflected differently in legal standards and tests of capacity, hence standardized instruments for assessing capacity may be more, or less, applicable in particular jurisdictions for particular pieces of legislation. Moreover,

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<sup>v</sup> There is some inconsistency in this body of literature about whether these constitute ‘abilities’ or ‘standards’. They initially were proposed as standards, but increasingly seem to be used more often to reference abilities, in relationship to the concept of capacity.

research has not reached the point where there is clear agreement on how to measure these four standards.

*What constitutes a good incapability assessment?*

The sixth issue revolves around describing a best practice assessment. Specifically, there is another disjunction in the literature between what is conceptually considered a best practice assessment and what is actually being done in practice. Conceptually, there appears to be some consensus – especially in more recent works - that a good assessment is contextual and includes an assessment of psychosocial (including values and social functioning), cognitive, functional and medical factors, as well as the assessment of the adult’s decision-making process.<sup>22</sup> In particular, the importance of emotional and socio-cultural contextual variables for influencing decision-making has been identified as a critical component of an incapability assessment.

One of the arguments being put forward to broaden the focus of the assessment of incapacity is that mental functioning requires at least three functionally distinct, but interactive systems: intellect, emotionality, and control/intentionality. The intellect is a person’s information handling system and includes thought processing, perception, orientation, memory, judgment and intelligence. Emotionality includes feelings and motivations, and control (also referenced as performance) refers to the expression of behaviour.<sup>23</sup> Modern emotion theory views emotions as containing basic values and goals which are important to making competent decisions.<sup>24</sup> Since values are culturally bounded and prescribed<sup>vi</sup> the importance of an assessment that is holistic and contextual becomes a priority.

Despite this rhetoric about the importance of incorporating a broader, more holistic understanding of mental functioning, there is growing concern that too frequently assessments are decontextualized and focus almost entirely upon cognition.<sup>25</sup> Thus, although there is some recognition that emotion and behavioural expressions may interfere with mental functioning, these aspects have largely been ignored in practice when considering capacity, especially in relation to standardized approaches. Rather, most attempts to develop standardized approaches have been criticized as considering almost exclusively only the domain of intellect, with decisions about capacity being almost exclusively grounded in cognitive tests.<sup>26</sup> Personal, social and environment-related factors are seen as making potentially important but, as yet, undetermined contributions<sup>27</sup> and further consideration of social and environmental factors that frame decision-making abilities is called for.<sup>28</sup> This means that practitioners have to be cautious about relying too heavily upon research-based tools at this point because there is considerable concern that they are inadequate and too narrowly focused.

Some templates are beginning to emerge. For example, Moye and colleagues (2007) have developed a conceptual and evaluation template that includes the following: medical condition; cognition, functional abilities, values, risk of harm and level of supervision needed; and means to enhance capacity. This is an important step forward but the template has not been tested or validated as a prescribed protocol yet.

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<sup>vi</sup> Note, culture is being used broadly here to denote social positioning with broader communities including ethnic, familial, religious, gender, socio-economic location...

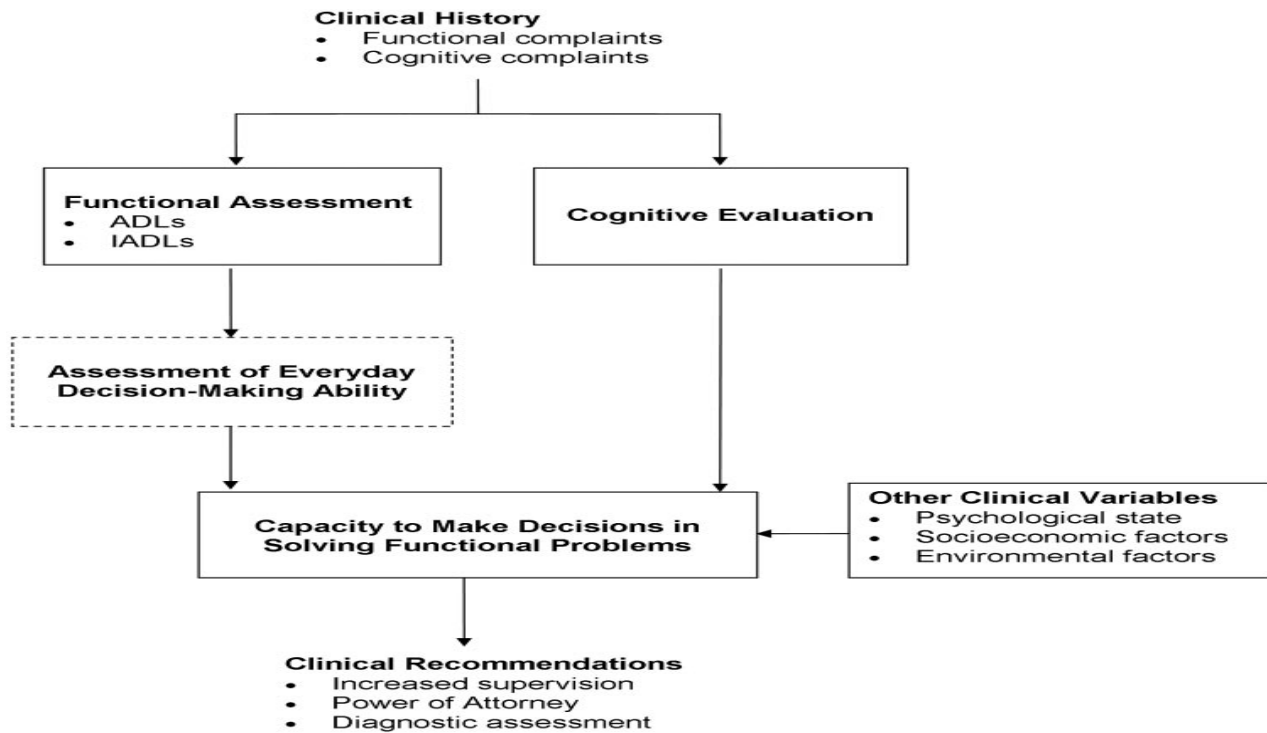
*How should it be done?*

The further issue centres on how the assessment should actually be carried out and by whom. The capacity assessment is generally considered as a two-step process: gathering relevant background information, and the capacity interview. There is relatively clear consensus that complex cases benefit from a team approach<sup>29</sup> although it is also recognized that often this is not feasible and that someone must be responsible for a final decision. I found no literature which actually addressed how responsibilities should be delegated.

There also seems to be strong support for the importance of consistency in the conduct of assessments: several studies have found that when a consistent approach is taken in the assessment of (in)capacity, two or more assessors demonstrate a high level of agreement when making a binary (capable vs. not capable) decision of the person's capacity.<sup>30</sup> At a minimum, a more consistent approach requires insuring that all assessors are applying similar criteria to inform their decisions and explicitly invoking the same test of incapability. Interesting, only one researcher<sup>31</sup> makes explicit the importance of articulating the legal standards being used when conducting an assessment of incapacity, despite widespread acknowledgement that this is a critical piece of information when making determinations about capacity.

Lai and Karlawish<sup>32</sup> provide a helpful model for picturing the process of assessing capacity to make decisions about everyday decision-making issues (see below). In this model – and consistent with those proposed by others - the process begins with obtaining a clinical history including documenting functional and cognitive complaints. Background information is then developed through the use of a functional assessment (IADL and ADL) and a cognitive evaluation. The functional assessment leads to an assessment of everyday decision-making ability - they propose a structured instrument for this. Based on the cognitive evaluation and the assessment of decision-making, an opinion is formed related to the capacity to make decisions, considered in the context of other clinical variables including psychological state, socioeconomic factors and environmental factors. This then leads clinical recommendations that might include delegation to a surrogate decision-making. Figure 1 depicts their process:

**FIGURE 1: Model for Assessing the Capacity to Make Decisions<sup>vii</sup>**



In terms of gathering the above information, there is some consensus that best practice is a combined personalized approach (for example, the use of narrative interviewing) with selected standardized, validated instruments. On the one hand, structured tools have the advantage that they can be more easily replicated and (usually) have demonstrated reliability and validity. On the other hand, less structured or narrative interviewing facilitates a more comfortable and individualized approach which can be less threatening to the adult, build on that person’s strengths, and facilitate more in-depth understanding for the assessor.

Consistent with the above point, research is beginning to emerge regarding how to maximize the person’s functioning during the assessment interview – this is considered the duty, or obligation, of the assessor in order to insure that the person is given the benefit of the doubt. Ideas include, for example, recognizing that the concept of comprehension is larger than simply free recall. Some work is being done to explore ways to enhance short term memory (or perhaps bypass it

<sup>vii</sup> Lai, J. M., & Karlawish, J. (2007). Assessing the capacity to make everyday decisions: A guide for clinicians and an agenda for future research. *American Journal of Geriatric Psychiatry, 15*(2), 101-111.



entirely by use of written memory aids) in persons with mild or moderate dementia, as a means of supporting the autonomy of those who may otherwise be seen as incompetent.<sup>33</sup> Additionally, as already noted, there is increasing emphasis upon performance-based measurement and the need to move beyond simple cognitive appraisal. Particularly in jurisdictions where new legislation has been promoting more person-centred care, attention is being given to moving beyond capacity per se, to maximizing participation and insuring least intrusive standards.<sup>34</sup> Of course, underpinning this is also the recognition that more personalized approaches to assessments can promote higher functioning on the adult's part by decreasing elements of anxiety associated with the process – this includes for example considering time and location of the meeting as important factors.

### *Specialized populations*

In understanding the state of research around issues of capacity, one final issue emerges – who have tests been developed and tested on? To whom are they relevant? What emerges is that there is little diversity in terms of the populations underpinning the research. That is, the research generally lacks gender and cultural sensitivity and has focused most heavily upon a select sub-sample of disorders.

Specifically, most of the research in this area has focused on older adults with cognitive impairment, particularly those with dementia in general, or Alzheimer's disease. A smaller, but substantial body of research has examined capacity issues in relationship to schizophrenia, and a still smaller body of research has examined decision-making capacity among hospitalized elderly individuals, persons with brain injury, and alcohol or addiction-related issues.

Some key findings from this research indicate that how decision-making capacity is influenced varies across the type of disorder that underpins it. (It should be noted that the MacCAT-T has been employed most frequently as at least one of the tools for establishing these differences – this tool will be discussed later in this report). For example, one study found that decision-making is more likely to be impaired in those with dementia – even in early stages – than those with schizophrenia.<sup>35</sup> However, when compared to the normal population, unsurprisingly, people with schizophrenia – especially inpatients – are more likely to perform poorly in relation to understanding and reasoning.<sup>36</sup> Another study highlighted differences between people with schizophrenia with those diagnosed with depression: Specifically, using the MacCAT-T, Grisso et al. (1997) found 52% of patients with schizophrenia had impaired capacity as opposed to 24% of those with depression. For those with schizophrenia, difficulties in decision-making included appreciation, understanding and reasoning but for those with depression problems related to appreciation presented as the main deficit: Similar results were reported by Bredin and Vollman.<sup>37</sup> This body of research however is sparse. Moreover, although the complexity related to assessing those with a brain injury and addictions issue has been highlighted, these issues have been poorly addressed in terms of actual research.

There are some screening tools used to inform the assessment that have been validated with other cultural groups (for example, the MMSE and clock drawing test). In Canada, the Rural Dementia Care Team at the University of Saskatchewan have also been focussing on developing

assessment tools that are more culturally appropriate to aboriginal people.<sup>viii</sup> However, I found no research specifically focused on developing a culturally-sensitive approach to assessing capacity per se. Some studies have analyzed findings using ethnicity as a variable; a review of this research indicates that ethnicity has not been found to have any association with capacity in the majority of these studies.<sup>38</sup> Moving beyond this very narrow notion of culture as ethnicity, there is a small body of research that is beginning to address limitations associated with current understandings of capacity as culturally bounded by broader western notions of autonomy and independence that may not be relevant to other cultural groups.<sup>39</sup> The importance of avoiding assessment criteria that include concepts such as ‘reasonable decision’ or ‘rational decision’ have also been identified in relation to culturally-sensitive assessments – this recommendation is based on concern that decisions about what is ‘reasonable’ are inherently culturally-bounded. Moye and colleagues<sup>40</sup> attempt to address this through their conceptual model by incorporating values and beliefs – but to date, I found no ‘standardized tools’ that have even considered culture.

### Summary

The focus on assessing incapacity is a burgeoning research area but still considered to be under-developed and under-conceptualized. There are trends emerging in this research which include the following:

- a move toward understanding capacity as multi-dimensional and context-specific;
- a focus on improving interdisciplinary overlap, particularly recognizing the need for a common language;
- attention to the limitations associated with a strictly cognitive understanding of capacity that currently dominates assessments of incapacity;
- a move toward a more functional approach that includes attention to executive capacity;
- the importance of an assessment that is context-sensitive and includes attention to culturally-laden values and beliefs; and
- the quest for a more open assessment process that promotes an ‘audit trail’ to support individual assessor’s opinions about capacity.

The use of standardized tools has been one way of responding to some of these issues - especially the need for a more consistent, comparable approach that allows different assessor’s opinions to be seen in relation to one another.

## **Part II: Examining the Available Tools**

Tools related to the incapability assessment can be broken into two main categories: those developed specifically for assessing capacity in some area – or decisional abilities instruments<sup>41</sup> - and those used to inform the decisions about capacity by providing information relevant to the assessment. Returning to Lai and Karlawash’s (2007) model (Figure 1, p.9) those tools

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<sup>viii</sup> This group is focused on developing culturally appropriate assessment protocols for assessment of dementia in aboriginal older adults. However, I was unable to locate any publications at this point, linked to specific instruments used in the assessment of incapacity. Further details about this team can be found at: (<http://www.cchsa-ccssma.usask.ca/ruraldementiacare/index.htm>)

frequently referenced in the research as ‘capacity assessment instruments’ would provide insight into the decision-making abilities; and instruments being described as screening tools to inform the process would provide insights into the functional assessment, the cognitive evaluation and the assessment of other clinical variables. This latter set of instruments captures those that have been developed for purposes other than assessing capacity, but are presumed to be relevant to the assessment of incapacity. Table 1 below attempts (inadequately I suspect) to graphically represent this distinction by capturing some of the main instruments currently in use and by depicting where they fit within this conceptualization.

**Table 1: Two Approaches for incorporating standardized instruments into the assessment of incapacity**

	<b>Personal Care</b>	<b>Health Care</b>	<b>Financial/Property</b>
<b>Capacity Assessment Instruments</b>	ACED	MacCAT-T	FCI
<b>Specific tools for aspects of Assessment</b> <sup>ix</sup> <ul style="list-style-type: none"> <li>• <b>Cognitive</b></li> <li>• <b>Functional</b></li> <li>• <b>Mental health</b></li> </ul>	MMSE... ILS FBI, DRS...	MMSE ILS FBI	MMSE ILS FBI

Based on this two-pronged conceptualization, Part 2 of this report will be broken into two subsections – decisional abilities instruments (also known as capacity assessment instruments); and screening tools.

**Decisional Abilities Instrument (aka Capacity Assessment Tools)**

In the last decade, considerable research has focused on developing capacity assessment instruments to assess decisional abilities. Most of this work has been directed toward designing instruments that assist researchers or clinicians to assess capacity to make decisions about medical treatments and/or research decisions. This however, is not the main interest of this report. Hence, following a brief overview of the health-care decision-making tools, the bulk of

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<sup>ix</sup> These tests INFORM the process by providing information that is relevant but do not actually EVALUATE or ASSESS capacity

this section will focus on everyday decision-making tools and financial decision-making. These latter two areas are just beginning to develop within the past four years.

### Health care decision-making

As noted above, this is the area where the bulk of research related to developing standardized tools for assessing capacity in decision-making has been focused. Research into this area can be broken into three sub-categories: competence to consent to treatment (including admission to a psychiatric facility but not a long-term care facility), competence to give advanced directives (more marginal focus), and capacity to participate in research.

Largely since the mid 1990s, a plethora of instruments employing different strategies for assessing decision-making abilities have emerged<sup>42</sup> In one of the most comprehensive reviews, Kim, Karlawish and Caine<sup>43</sup> found that of 32 articles – representing 28 studies – four used clinical interviews/impressions and the remaining 24 studies used 18 different instruments to measure various decisional abilities! With few exceptions every research group developed its own instrument for measuring decisional abilities.<sup>44</sup> More recently, Dunn and colleagues<sup>45</sup> identified 15 different instruments for assessing capacity in relation to treatment issues.

Gradually, trends seem to be emerging in this body of research. First, the developing tools have employed a continuum of approaches for assessing. These have included:

- Structured interviews (ie. Competency Interview Schedule; Hopkins Competency Assessment Test);
- Hypothetical vignettes with structured interview [for example, Competency to Consent to Treatment Instrument (CCTI)];
- Structured interview guides [(MacArthur Competency Assessment Tool for Treatment (MacCAT-T)]; and
- Semi-structured interviewing (Ontario Competency Questionnaire).

Clinical and research needs diverge somewhat in terms of what is the best approach to follow. Specifically, research benefits from a more structured, pre-determined set of information because then the instrument will achieve better reliability. However, it is recognized that people make real-life decisions differently than decision-making in a hypothetical situation; hence a trade-off appears to be happening between reliability and validity with tools attempting to personalize the scenarios in order to make them as realistic as possible. Some of these are still reporting good reliability.

Second, almost all of these tools are attempting to find ways to measure some aspect of cognition determined to be relevant to capacity in decision-making as defined by the four abilities approach (understanding, appreciation, reasoning and choice).<sup>46</sup> This has become increasingly refined as the tools have developed. The advantage of this is that it provides clinician with clear ways of operationalizing each of these standards, or abilities. The limitation is that how these standards are operationalized is not consistent across tools, and some tools emphasize different aspects than others.<sup>47</sup>

Third, while there have been a large number of tools developed, the one that appears to be taking the lead is the MacArthur Competence Assessment Tool (MacCAT-T).<sup>48</sup> It is now being

described as the emerging gold standard and has the most research supporting it.<sup>49</sup> It forms the foundation of much of the research in this area, including being used as the comparison for establishing validity and relevance of other instruments, including the MMSE. (See Part 3 for a more detailed discussion of this tool).

### Personal care (everyday) decision-making

This is an exciting area that is just beginning to be addressed in the research. While we have been able to develop increasingly refined diagnostic tools, how impairments actually impact one's ability to live independently has been poorly researched. Specifically, information that is assumed to be required by the court in order to make decisions about guardianship would intuitively include: a) what loss of functional capacity results from the diagnosed condition; b) what about that condition results in the dysfunction and c) what the person's ability is to provide for his/her essential needs (ie. medical care, nutrition, safety, shelter...) and/or direct others to meet those need.<sup>50</sup> In 2007, Lai and Karlawish argue that while there are many tools for assessing functional tasks, "clinicians have not had equally valid or clinically applicable methods to assess a patient's capacity to make everyday decisions. Specifically, they do not have instruments that are able to assess if a patient is capable of solving problems in performing his or her ADLs".<sup>51</sup>

Two (inter-connected) groups of researchers are working in this area. Naik and colleagues have focused on developing a conceptual framework for exploring how potential impairments manifest within the context of functional domains related to safe and independent living. Their work is particularly helpful because they outline a two step method, the Articulate-Demonstrate method, for evaluating two dimensions of capacity: decisional and executive. They identify five broad categories related to the ability to live independently: personal needs and hygiene, condition of home environment; activities for daily living; medical self-care; and financial affairs. At a practical level, they have developed a set of screening questions to assess functional domains of capacity for self-care and self-protection in each of these areas.<sup>52</sup> These provide extremely useful guidelines for assessors. However, these have not been developed into a formal tool, and reliability and validity of the semi-structured questions have not been established. They do however provide an excellent set of guidelines, particularly pertinent to BC's Part 3 of the Adult Guardianship Act.

The Assessment of Everyday Decision-making (ACED) is the first tool available with data supporting its reliability and validity to effectively address decision-making ability around the refusal of help in managing an instrumental activity of daily living.<sup>53</sup> It is geared toward older adults living in the community with cognitive impairment. ACED is a semi-structured interview that is designed to be administered in about ten minutes and can be used by a variety of health professionals with minimal training. The adult being assessed is presented with a known functional problem - the tool can be easily personalized to make it relevant - and then asks a prescribed series of questions. (See Part 3 for a more detailed description of this tool).

ACED appears to build upon work done by Anderer<sup>54</sup> who developed the Decision-making Instrument for Guardianship (DIG) as part of her doctoral thesis work. While this instrument was developed to evaluate the capacity of elderly persons to make personal care and financial decisions, it is not a clinically applicable instrument because it is used to assess capacity to make

decisions about *potential* not actual problems. Although it is considered comprehensive (8 hypothetical problems such as hygiene, money management....) the reliance upon hypothetical scenarios has two short-comings: 1) patient must be able to grasp the abstract, initial premise of the evaluation, which may unduly complicate the process; and 2) the clinical value related to the hypothetical situation response diminishes the further the situation is removed from patient's actual problems – in other words to provide the most useful insight the scenario has to be relevant to the person being assessed. As well, DIG does not assess the person's ability to appreciate his/her functional problems.<sup>55</sup>

In addition to these decisional capacity tests, the following have also been used:

- Independent Living Scales (Loeb, 1996): This tool is developed as a performance-based ADL tool. It assesses performance but not decision-making (See this section for fuller discussion of the tool)
- Independent Living Decisions: The work of Canadian researcher, Silberfeld, uses this tool but to date, I have not located references regarding its reliability and validity.

### Financial/property decisions

Financial skills and abilities have been identified as one of the first places where older adults with dementia will first show decline: often it is these changes that initially raise a red flag with family members (and sometimes the person him/herself) that something is wrong<sup>56</sup>. Marson, one of the key researchers in this area, describes loss of financial skills as the 'litmus for declining capacity to live independently and care for oneself.'<sup>57</sup> Declining financial abilities set individuals up for financial abuse, and questions about financial abilities motivate more court applications for guardianship or other forms of assisted or substitute decision-making than health or personal care.

To date there is no gold standard for the assessment of financial capacity.<sup>58</sup> A number of tools, such as Lawton's Instrument of Daily Living, contain (a) question(s) about ability to manage finances, but do not explore this in any depth. It is perhaps unsurprising then, that researchers have identified the 'pressing need for systematic research in the area of financial capacity and the elderly.'<sup>59</sup>

This research is beginning to emerge. Recent developments in the assessment of financial incapacity are increasingly adopting a performance-based definition of incapacity that focuses on discovering where and when performance deficits occur. This helps to pinpoint where external assistance and interventions may be required.<sup>60</sup> The focus has been on beginning to tease apart what it means to be financially capable and to develop tasks that will shed light on specific aspects of financial management.

The work of Marson and colleagues dominates the research activities in the past ten years around assessing financial capacity. They have conceptualized financial capacity as having three core knowledge types:

- 1) Declarative financial knowledge – the established store of semantic and episodic facts, concepts and events related to financial knowledge that is accessible to conscious recollection and manipulation (for example, naming coins, understanding bank transactions)

- 2) Procedural financial knowledge – involves automatic skills and routines that are performance based and not consciously recalled or manipulated (for example, counting coins/currency, writing a cheque, simple cash transactions). Some of these draw on executive functioning.
- 3) Judgemental financial knowledge – involves the ability to predict the consequences of financial decisions in novel situations (for example, detecting mail fraud).<sup>61</sup>

Using this conceptualization, this group has led in the development of the Financial Capacity Instrument (FCI) – this is a standardized psychometric instrument designed to directly assess the financial performance of older adults. It is a comprehensive instrument used to evaluate judgement, understanding and appreciation for managing one’s financial affairs and estates as well as the capacity to perform several executive tasks related to financial transactions. Specifically, it assesses financial knowledge, the ability to perform financial activities, and judgment in performing relevant monetary transactions.<sup>62</sup> It comes out of the work of Marson and colleagues at the University of Alabama, and appears to be emerging as the instrument with the strongest research support.

This structured questionnaire breaks the demands of everyday money management into eight domains (or activities): basic monetary skills; financial conceptual knowledge; cash transactions; chequebook management; bank statement management; financial judgement; bill payment, and; personal financial knowledge. These are operationalized using 19 behaviourally-anchored assessment tasks. Task difficulty of each is assigned as either simple (ie. Name coins) or complex (ie understand an investment option and make a choice). Except for the 8<sup>th</sup> domain - knowledge of assets/estate - all of the domains have very good to excellent reliability at the domain level (.82 -.93). More mixed reliability at the specific task level has been reported, and hence work is ongoing related to the tasks.<sup>63</sup> The test shows some ability to discriminate between people with dementia and a control group<sup>64</sup>

The administration time for the test is estimated at between 45 – 60 minutes. No research was found which identified level of training to do the test – since it is publicly available however there are no proprietary rights related to its use. See Part III for a more comprehensive discussion of this tool.

In addition to the FCI, there are a number of other tools developed to assess financial ability. Many of these come out of the work that Marson and colleagues are doing. Table 2 identifies the tests that were discussed in the research related to financial decision-making.

**Table 2: Assessments related to financial decision-making**

	Description of Tool	Strengths	Limitations
<b>Financial Capacity Instrument (FCI)<sup>65</sup></b>	<ul style="list-style-type: none"> <li>• 2<sup>nd</sup> stage development (FCI-8)</li> <li>• Evaluates 8 domains (areas) with 19 tasks</li> </ul>	<ul style="list-style-type: none"> <li>• Direct, standardized and quantified assessment</li> <li>• Global overview score</li> <li>• Multi-dimensional</li> <li>• Includes functional component;</li> <li>• Clinically relevant and useful;</li> <li>• Conceptually well-grounded</li> <li>• Research-based</li> </ul>	<ul style="list-style-type: none"> <li>• Time-consuming to administer</li> <li>• Relevancy only established with cognitively impaired, community-dwelling elders;</li> <li>• Pioneer-stage research</li> </ul>
<b>Measure of Awareness of Financial Skills (MAFS)<sup>66</sup></b>	<ul style="list-style-type: none"> <li>• 32 item</li> <li>• Participant self-rating</li> <li>• Informant parallel questions</li> <li>• Performance on six financial tasks</li> <li>• 15 minutes administration</li> </ul>	<ul style="list-style-type: none"> <li>• Can compare self reports, informant reports and objective performance;</li> <li>• Research-based</li> </ul>	<ul style="list-style-type: none"> <li>• Minimal research to date (but used by UVic)</li> </ul>
<b>Direct Assessment Functional Status Scale (DAFS)<sup>67</sup></b>	<ul style="list-style-type: none"> <li>• 21 items that measure five functional abilities: identifying currency; counting currency; writing a cheque; balancing a cheque-book; and making change</li> <li>• Each domain has a cut-off score indicating impairment: <ul style="list-style-type: none"> <li>- Identifying currency &lt;7;</li> <li>- counting &lt;3;</li> <li>- writing a cheque &lt;4 pts;</li> <li>- counting change &lt; 2 pts</li> </ul> </li> <li>• Summary subscale score is obtained by adding the sum of correct performance for each domain. (Score &lt;19 = overall impaired score.)</li> </ul>	<ul style="list-style-type: none"> <li>• Good research to support use: High inter-rater and test-retest reliabilities<sup>68</sup></li> <li>• Well validated among those with dementia and schizophrenia</li> </ul>	<ul style="list-style-type: none"> <li>• Not considered 'gold standard' because it does not assess all important components including: financial judgment and knowledge of important financial concepts.</li> </ul>



<p><b>Self-reported financial skills scale</b><sup>69</sup></p>	<ul style="list-style-type: none"> <li>• 6 item scale that corresponds to 5 DAFS subscales,</li> <li>• Self-rank each as independent/not independent</li> <li>• 1 overview item – do you manage own finances independently</li> </ul>	<ul style="list-style-type: none"> <li>• Very brief administration (5 min.)</li> </ul>	<ul style="list-style-type: none"> <li>• Developmental phase: Not validated, no data on reliability</li> </ul>
<p><b>Prior Financial capacity Form (PFCF) and Current Financial capacity Form (CFCF)</b></p>	<ul style="list-style-type: none"> <li>• Provides comparison between premorbid (PFCF) and current (CFCF) financial capacity</li> <li>• Global judgment and judgment about functioning in 8 domains and 20 associated tasks</li> <li>• 3 level scoring: capable, marginally capable, incapable</li> </ul>	<ul style="list-style-type: none"> <li>• Functioning is appraised over time in everyday life settings;</li> <li>• 10 – 15 min. administration</li> <li>• First tool to address relevance of premorbid functioning to current abilities;</li> </ul>	<ul style="list-style-type: none"> <li>• Risk of bias and errors because information is obtained via collateral sources;</li> <li>• In developmental stage but looks promising: High level of stability over 1 month period established<sup>70</sup></li> </ul>
<p><b>Clinical Assessment Interview for Financial Capacity (CAIFC)</b><sup>71</sup></p>	<ul style="list-style-type: none"> <li>• Interview format and specific test items</li> <li>• Examine competency in each of eight domains of the Marson conceptual model.</li> <li>• Shares same domain organization as FCI but is entirely distinct and independent.</li> </ul>	<ul style="list-style-type: none"> <li>• Combines the flexibility of an interview dialogue with many of the aspects of standardized testing</li> </ul>	<ul style="list-style-type: none"> <li>• Potential for considerable variability in outcomes related to clinician assessments of competency.</li> </ul>
<p><b>Hopemont Capacity Assessment Interview (HCAI) – Financial Scale</b><sup>72</sup></p>		<ul style="list-style-type: none"> <li>• Good inter-rater reliability reported</li> </ul>	<ul style="list-style-type: none"> <li>• Rarely cited in research (more focus on medical decision-making component)</li> </ul>
<p><b>Financial Competency Assessment Inventory (FCAI)</b></p>	<ul style="list-style-type: none"> <li>• Structured interview format and observation of performance</li> <li>• 38 items (questions and tasks)</li> <li>• Six tasks: everyday financial abilities; financial judgement; estate management; cognitive functioning related to financial task; debt</li> </ul>	<ul style="list-style-type: none"> <li>• Correlates well with ILS Money Management Scale and HCAI financial decision-making;</li> <li>• Tested on 4 populations: ABI,<sup>x</sup> dementia, schizophrenia, ID</li> <li>• Good reliability and validity established</li> </ul>	<ul style="list-style-type: none"> <li>• Administration skill and time not identified</li> <li>• In developmental stage</li> </ul>

<sup>x</sup> ILS: Independent Living Scale; HCAI; Hopemont Capacity Assessment Interview; ABI = acquired brain injury (including alcohol-related); ID= persons with intellectual disabilities

	<p>management; support resources.</p> <ul style="list-style-type: none"> <li>• Tool can be recoded to assess understanding, appreciation, reasoning, and expressing a choice.</li> </ul>	<p>in 1 study only;</p> <ul style="list-style-type: none"> <li>• Multi-dimensional approach</li> <li>• One of few tools to include support resources</li> </ul>	
<p><b>Independent Living Scales (ILS) <sup>73</sup> Money Management subscale</b></p>	<ul style="list-style-type: none"> <li>• One subscale of the ILS</li> </ul>	<ul style="list-style-type: none"> <li>• Provides feedback around money management</li> <li>• Reliability and validity of ILS is well-established</li> </ul>	<ul style="list-style-type: none"> <li>• Very limited as assessment of financial capacity; financial capacity is not developed as a multi-dimensional concept</li> </ul>

Tools developed specific to assessing capacity: How do you choose?

In considering which tools to use in assessing capacity several considerations emerge. First, what component of decisional capacity is being measured? The instruments developed have unique focuses and measure different components of capacity. The MacCAT-T is being recognized increasingly as a ‘gold standard’ in relation to medical care decision-making because it is the most inclusive in terms of what it assesses (understanding, appreciation, reasoning and choice). However, this leads to the second point, which is the need to consider the relevance of each tool to the specific legal tests being used to determine incapacity. In other words, when considering the use of one of these tools, congruence between what is being measured by the standardized test and the legal standards that are being used to make decisions about the adult’s capacity, is critical. The third consideration in selecting a tool is finding one that has been developed and tested on the particular population of interest – many of these tools are most appropriate for persons with dementia and their validity in relation to other populations is less well-established. Finally, how sensitive is the area being assessed, what are the risks associated with making the ‘wrong’ decision about the person’s ability? Some tools are quicker to administer but may have lower established levels of sensitivity and specificity.

Summary

There is growing interest in the development of standardized tools for assessing capacity related to specific areas of decision-making: These tools show promise because they provide structured ways of examining information that can lead to similar conclusions by different assessors<sup>74</sup>. However, research into different tools is by and large, still in early developmental phase and there is limited information about their reliability and validity.<sup>75</sup> Moreover, the extent that these tools are being used outside of a research environment is unclear.

**Standardized Screening Tools used to Inform the Assessment of Incapacity**

A more common practice for implementing standardization of the incapacity assessment process is to rely upon existing instruments to inform the assessment of incapacity. The distinction I am making here is that these screening tools have been developed to assess something *other* than decisional capacity, or incapacity, per se, but are felt to provide relevant and important information about capacity. These can roughly be categorized into two broad categories:

cognitive screening tools (including diagnostic screens and neuropsychological testing); and functional living skills assessment instruments. Assessment of ‘insight’ is another area that is emerging as also important, but attempts to develop relevant standardized measures are, at best, in infancy.

### Cognitive Functioning

There is clear recognition that cognition plays an important role in decision-making capacity. Hence, it is unsurprising that the most common way of incorporating standardized instruments into the assessment of incapacity is through the use of cognitive screening tools. In fact, these tools are often considered such an integral part of the assessment of incapacity that there is considerable concern that they are being used as de facto ‘assessments of capacity’; for example some studies have found that physicians had difficulty distinguishing between a mental status examination and an assessment of capacity.<sup>76</sup>

In terms of understanding the overall use of these tests in the assessment of incapacity, two main issues emerge. The first, as alluded to above, is the inappropriate use of these tests. Too frequently they are used to explain findings about capacity, despite the fact that this is not what they are actually measuring. For example, an adult being tested receives an MMSE score of 19 and this is used to explain the decision that s/he is incompetent. The issue here is that the person’s cognition has been assessed, NOT his/her capacity. While there is some reason to believe that a score of 19 suggests that the person may be incapable, this score in and of itself does not prove incapability.

This leads to the second point: despite their wide-spread use, research is still exploring the actual relevance of many of these tests for understanding issues of decisional and executive capacity. Specifically, while the importance of cognition has been well recognized, what aspects of it are most related to capacity, and which instruments actually provide the most insight into these aspects, is an area of active ongoing research. In particular, there is expectation that neuropsychological testing may improve validity and reliability of capacity evaluations by elucidating the cognitive processes essential to each decisional ability; however, determining what these processes are and how they are being evaluated is still being examined as an important area of research.<sup>77</sup>

There are important results emerging in this research; perhaps the most consistent is the importance of executive functioning (EF) on capacity. EF describes the ability to “orchestrate relatively simple ideas, movements or actions into complex, goal-directed behavior”.<sup>78</sup> In other words, it captures the ability to plan, organize and problem-solve. Classic research by Faden and Beauchamp<sup>79</sup> begins to provide a conceptual framework for understanding executive functioning. Consistent with a more functional approach, they describe three components of autonomous action: understanding, intentionality and voluntariness. Both intentionality (an action willed in accordance with a plan) and voluntariness (not being controlled or coerced by others into making and implementing a decision) are tied into executive functioning. Patients with impairments of intentionality or voluntariness have difficulty making and carrying out plans and resisting influence from those who might take advantage of them. The work of Faden, Beauchamp, and others recognizes that defects that result from impaired executive function may have a more profound adverse effect on patient’s autonomy than do impairments of memory and cognition.<sup>80</sup>

The importance of executive functioning in terms of all four of the standard abilities associated with decisional capacity (understanding, appreciation, reasoning, and choice) as well as executive capacity (the ability to carry out a decision) is now solidly established in the research. The importance of this in terms of selecting standardized tools is that tools which focus on executive functioning may have more relevance for providing insight into the assessment of incapacity.

A second important finding in this research is that while memory – especially verbal memory - is unquestionably linked to one’s capacity, its role (or how it contributes) - particularly in comparison to executive functioning - is still under review. This becomes a crucial issue in the assessment of adults who do not have dementia – for example, psychiatric patients. It also becomes a question when determining how to interpret results of a cognitive screen. For example, how much weighting should be given to memory components? Does poor short term memory always translate to incapacity?

Although a number of screening tools exist, the Mini-Mental Status Examination (MMSE)<sup>81</sup> is unquestionably the most widely used tool both in practice and in research. It was originally created as a screening tool to differentiate between organic and functional psychiatric patients and to provide a quantitative estimate of the severity of cognitive impairment and a tool for documenting cognitive change over time.<sup>82</sup> It was never intended to be used on its own as a diagnostic tool nor was it developed as an assessment of capacity. Despite this, research has established that it is a useful tool in relation to understanding (in)capacity, particularly on test scores below 17 and over 26. However, it is not very sensitive and is particularly non-discriminating for those with higher education and/or who have milder symptoms of cognitive impairment. It has been validated in other cultures, but its cultural relevancy nevertheless remains suspect. There is a Chinese version of the MMSE (CMMSE). See Part 3 for a more detailed description of this tool and the research that has been done linking it to capacity.

More intensive testing is underway in relation to various other neuropsychological assessments. A comprehensive review of this area is beyond the scope of this report, but Table 3 below summarizes some of the screening tools that have received the most interest in relation to decisions about capacity. A particular area of interest is on establishing the “ecological validity of neuropsychological testing<sup>83</sup> - that is, how well do these test scores actually reflect real world performance?

**Table 3: Summary of Cognitive Screening Tools Most Commonly Identified in Research**

<b>Instrument</b>	<b>Description</b>	<b>Strengths</b>	<b>Limitations</b>
<b>Mini-mental Status examination (MMSE)<sup>84</sup></b>	<ul style="list-style-type: none"> <li>• 30 items</li> <li>Assesses: orientation; registration; attention and calculation; recall; language; visual</li> </ul>	<ul style="list-style-type: none"> <li>• Most commonly used tool so high comparative value</li> <li>• Strong research base establishing</li> </ul>	<ul style="list-style-type: none"> <li>• Erroneous use as a tool of a measure of decisional capacity;</li> <li>• Limited focus on executive</li> </ul>

	<p>construction;</p> <ul style="list-style-type: none"> <li>• Score 0 – 30 (higher score = higher performance)</li> <li>• 10-15 min. administration</li> </ul>	<p>reliability</p> <ul style="list-style-type: none"> <li>• Internationally recognized</li> <li>• Fast, easy to use</li> <li>• Research supports link to capacity for scores less than 19 and over 26.</li> </ul>	<p>functioning so not considered the ‘best’ tool</p> <ul style="list-style-type: none"> <li>• Mid-range (18 – 24) lack of accuracy in predicting capacity<sup>85</sup></li> <li>• ‘Blunt’ instrument’ for ascertaining capacity<sup>86</sup></li> <li>• Education, age and culture bias</li> </ul>
<p><b>Modified Mini Mental Status Exam (3MS)<sup>87</sup></b></p>	<ul style="list-style-type: none"> <li>• Basic MMSE format but content modified and new items added</li> <li>• Assesses: orientation, attention/concentration, immediate &amp; delayed recall, word fluency, similarities; copy a pentagon</li> <li>• 15 – 20 min. administration</li> <li>• Score: 0 – 100 (higher number = higher function)</li> </ul>	<ul style="list-style-type: none"> <li>• Recommended over MMSE because considered to have higher validity and reliability than MMSE<sup>88</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Less frequently used in capacity research ;</li> <li>• Takes longer to administer and mark</li> </ul>
<p><b>Trails A and B<sup>89</sup></b></p>	<ul style="list-style-type: none"> <li>• These can be part of a battery of neuropsychological tests</li> </ul>	<ul style="list-style-type: none"> <li>• Assesses executive functioning</li> <li>• Simple, useful tool</li> <li>• Link to capacity is well-supported especially in relation to financial ability<sup>90</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Not well described,</li> </ul>
<p><b>Word Fluency</b></p>		<ul style="list-style-type: none"> <li>• Research has linked it to incapability</li> </ul>	<ul style="list-style-type: none"> <li>• Not well described</li> </ul>
<p><b>Clock Drawing Task (CDT)<sup>91</sup>(CLOX)</b></p>	<ul style="list-style-type: none"> <li>• Described in literature as both CDT and CLOX</li> <li>• CLOX: Clox1 –clock drawing task (executive function);Clox2 – clock copying task (constructional praxis)</li> <li>• 10 min. administration</li> <li>• Assesses: comprehension</li> </ul>	<ul style="list-style-type: none"> <li>• Measures executive functioning aspects linked to capacity</li> <li>• Easy to administer</li> <li>• Good inter-rater and test/re-test reliability</li> <li>• Good sensitivity</li> <li>• Good concurrent</li> </ul>	<ul style="list-style-type: none"> <li>• Diverse methods for scoring</li> <li>• Recommended that it be used in conjunction with other screening tools</li> <li>• Diverse ways of administering</li> </ul>

	(auditory), planning, visual memory and reconstruction in a graphic image, visuo-spatial abilities, motor programming and execution, numerical knowledge, abstract thinking, concentration and frustration tolerance <sup>92</sup>	validity <ul style="list-style-type: none"> <li>• Culturally more friendly, validated in Asian populations;</li> </ul>	<ul style="list-style-type: none"> <li>• Difficulty comparing findings because of diverse scoring and ways of administering;</li> </ul>
<b>Executive Interview (EXIT25)</b> <sup>93</sup>	<ul style="list-style-type: none"> <li>• 25 item multi-task assessment of executive function</li> <li>• Categories: perseveration, imitation behaviour, intrusions, frontal impulse control, spontaneity, disinhibition, utilization behaviour</li> <li>• Score 0 – 50 (lower score = better performance)</li> <li>• 10 min. administration</li> </ul>	<ul style="list-style-type: none"> <li>• Solid body of research supporting link to measurement of capacity<sup>94</sup></li> <li>• Assesses executive functioning</li> <li>• Bedside assessment</li> <li>• 3 studies show the score predicts level of care, behaviour and IADL needs.</li> <li>• More responsive to change than MMSE</li> </ul>	<ul style="list-style-type: none"> <li>• Not commonly used</li> <li>• Requires further standardization of scoring and administration<sup>95</sup></li> </ul>
<b>Frontal Behavioral Inventory (FBI)</b> <sup>96</sup>	<ul style="list-style-type: none"> <li>• 24-item inventory used to screen for frontal lobe dementia (FLD)</li> </ul>	<ul style="list-style-type: none"> <li>• FLD is associated with disturbances to executive functioning, so tool helps identify cases where this may be an issue</li> </ul>	<ul style="list-style-type: none"> <li>• Not a test of capacity; no research found linking it to assessments of capacity</li> <li>• Relies upon proxy report</li> </ul>

In addition to these singular tests, a number of ‘composite’ instruments have been developed which incorporate aspects of many of the above tests. This includes for example, and the Montreal Cognitive Screen (MoCA)<sup>97</sup> which includes Trails, Cube, Clock, Naming, Memory, Digit span, Letter A, serial 7, sentence repetition, verbal fluency F, abstraction and orientation. While I found no research explicitly linking these composite tools specifically to capacity, the expectation is that these tools are more comprehensive while still being short and portable, and hence have an advantage over any single screening test. In comparison to the MMSE, MoCa is considered far more sensitive to detecting more mild impairment.

Functional screens

There is considerable agreement on the importance of functional ability assessment in relationship to assessments of incapacity. There is also some agreement that these tests are typically under-utilized in assessments.<sup>98</sup>

A functional assessment approach advocates that courts look more objectively at behavioural evidence of functional abilities in the person's daily activities when determining that person's need for a substitute decision-maker.<sup>99</sup> It is the process of gathering information to develop insight into how the individual with a disability is currently functioning in a decision-making capacity on a day-to-day basis within various environmental settings that they encounter.<sup>100</sup> The focus is on identifying: the overall level of adaptive functioning (ie. Activities of Daily Living (ADL) and/or Instrumental Activities of Daily Living (IADL)); the strengths and limitations in specific adaptive behaviors; the level and type of environmental demands where decisions must be made, and; resources to assist in abilities for decision-making.<sup>101</sup>

There are a number of tools that have been developed and used extensively for this purpose at the clinical assessment level. Modalities for generating information that these tools incorporate include: self-report, caregiver/collateral reports, informal assessments based on clinical history and exam, performance-based assessments of everyday functioning, and direct observation. Moore and colleagues provide an excellent overview of performance-based tools from both a research perspective<sup>102</sup> and a clinical perspective.<sup>103</sup> While there are no gold standards at this point, consistent themes are emerging regarding what is important.

First, there is a preference for some sort of direct observation or performance-based tools. These tools rely upon role-play, mock settings and/or actual activities to allow the person being assessed to show how s/he performs the specified activities. The tasks are presented in a standardized format. This approach is useful because it allows some separation between cognitive insight, communication and actual performance; since research has identified discrepancies between self-report measures and performance-based objective measures this is important.<sup>104</sup> Performance-based tools are also generally considered superior to sole reliance upon collateral or proxy sources since research is finding that caregiver appraisals of needs and abilities do not always correspond with the subjective appraisal and/or performance of the adult being assessed.<sup>105</sup> Finally, the tests are considered to have greater ecological validity because they are more relevant to the person being assessed and have better reliability than open-ended observation or informal assessment, but are less time-consuming than direct, unstructured observation of an activity.

However, even performance-based tools have drawbacks in relationship to assessments of capacity. These include:

- These tools demonstrate what a person *can* do; they do not demonstrate what the person *does* do in relationship to his/her habitual environment. Moore et al. (2008) draw attention to the importance of this distinction, noting that in some disorders it is not the lack of capacity that impairs performance but rather a failure to translate functional capacity into self-initiated functional performance (p. 19).

- They do not capture the multi-tasking complexity of daily life (for example phone ringing in the middle of a task; someone arrives at the front door...). As a result, they may overestimate abilities and/or conversely, underestimate because environmentally-driven cues that would generally be used may not be present.<sup>106</sup>
- None of the tools developed to date have established predictive validity - this means that it has not been established how the scores on these tests measure real world independence, or predict a level of competency.<sup>107</sup>

Thus, the need for a performance-based, standardized tool to assist in the assessment of capacity is seen as advantageous – but not a panacea!

A second theme emerging is that the selection of a particular tool may be situation-specific. For example, some functional tools are domain specific (for example, medication management, financial management). Other may have unique features that make them particularly appropriate in a given situation: For example, the Kohlman Evaluation of Living Skills (KELS) is identified as well-suited to situations of neglect<sup>108</sup> while the Individual Functional Assessment (IFA) has been developed explicitly for assisting long-term care facilities to determine residents need for guardianship or other protective service<sup>109</sup>.

There is a plethora of instruments and a complete overview of these is beyond the scope of this report. Alison, Letts and Liu (2008) provide a comprehensive overview of these in relation to the occupational therapy. Below, some of the most common tools cited in the research related to the assessment of capacity are identified with, where possible, their respective strengths and limitations in relation to the insights they provide around the assessment of (in)capacity.

**Table 4: Functional Assessment tools most commonly identified in the research<sup>110</sup>**

	<b>Description of Tool</b>	<b>Strengths</b>	<b>Limitations</b>
<b>Direct Assessment of Functional Abilities (DAFS)<sup>111</sup></b>	<ul style="list-style-type: none"> <li>• 7 subscales, 21 items</li> <li>• Areas assessed: communication, grooming eating, time, shopping, financial and transportation.</li> <li>• 25-40 min. administration</li> </ul>	<ul style="list-style-type: none"> <li>• Multi-dimensional</li> <li>• Strong use in research</li> <li>• Reliability/validity established with both dementia and older adults;</li> <li>• Assesses IADLs and ADLs</li> </ul>	<ul style="list-style-type: none"> <li>• Meal preparation not included</li> <li>• Clinic-based administration – not very portable</li> </ul>
<b>Independent Living Scales (ILS)<sup>112</sup></b>	<ul style="list-style-type: none"> <li>• 7 subscales, 68 items</li> <li>• Areas assessed: communication, time, safety, financial skills, shopping, transportation, medication, chores...</li> <li>• 45 min administration</li> </ul>	<ul style="list-style-type: none"> <li>• Multi-dimensional related to IADL</li> <li>• Assesses safety</li> <li>• Clinic-based but easily portable;</li> <li>• Reliability established</li> <li>• Validated on wide</li> </ul>	<ul style="list-style-type: none"> <li>• Does not assess ADL</li> <li>• Some documentation is difficult to access</li> <li>• Use of ILS scores for determination of capacity is controversial<sup>113</sup></li> </ul>



		sample base;	
<b>Kohlman Evaluation of Living Skills (KELS)</b> <sup>114</sup>	<ul style="list-style-type: none"> <li>• 5 subscales, 17 areas</li> <li>• Areas assessed: self-care, safety and health, money management, transportation and telephone, work and leisure.</li> <li>• 20-30 min administration</li> <li>• 3 components: Self-report, observation, performance</li> <li>• Score 0 – 16 (higher score means higher need; &lt;5 = independent)</li> </ul>	<ul style="list-style-type: none"> <li>• Multi-dimensional</li> <li>• Clinic or community administered</li> <li>• Validated in relation to situations of self-neglect<sup>115</sup></li> <li>• Assesses IADL and ADL</li> <li>• Good prognostic validity as a measure of safe and independent living in community<sup>116</sup></li> <li>• Designed as a tool to assist with discharge planning</li> <li>• More predictive of functioning than MMSE<sup>117</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Data to support reliability and validity only available in unpublished sources</li> </ul>
<b>Instrumental Activities of Daily Living (IADL)</b> <sup>118</sup>	<ul style="list-style-type: none"> <li>• Self-report or proxy</li> <li>• 8 items</li> <li>• Score 0 – 8 (higher score means more dependent)</li> </ul>	<ul style="list-style-type: none"> <li>• Most commonly used</li> <li>• Assesses IADL</li> </ul>	<ul style="list-style-type: none"> <li>• Descriptive only – link to capacity not established;</li> <li>• Proxy or direct observation</li> </ul>
<b>University of California Performance-based Skills Assessment Brief (UPSA - Brief)</b> <sup>119</sup>	<ul style="list-style-type: none"> <li>• Brief: 2 subscales (communication and financial)</li> <li>• 10 – 15 min administration</li> <li>• Abbreviation of UPSA, which has strong support as a predictor of person’s ability to live independently</li> </ul>	<ul style="list-style-type: none"> <li>• Validated with persons with schizophrenia</li> <li>• High correlation with other areas of functioning</li> <li>• Ability to predict person’s ability to live independently;</li> <li>• Scores are sensitive to change via interventions</li> <li>• Very brief to administer</li> </ul>	<ul style="list-style-type: none"> <li>• While UPSA has strong research, support and development, this ‘Brief’ version is very recent addition to the literature</li> <li>• Financial component limited to count change, read a bill and write a cheque</li> </ul>

In addition to the tools identified in the above table, other tools identified as being used in some way toward an assessment of incapacity include:

- SAFER tool<sup>120</sup>
- Vineland Adaptive Behavior Interview<sup>121</sup>
- Observed Tasks of Daily Living<sup>122</sup>
- Scales of Independent Behavior – Revised<sup>123</sup>
- \*Blessed<sup>124</sup>
- \*Structured Assessment of Independent Living Skills (SAILS)<sup>125</sup>
- \*Everyday Problems Test (EPT)<sup>126</sup>

- Activities of Daily Living Efficacy Scale <sup>127</sup>

These were not widely cited, nor were they linked to decisions about capacity and hence are not examined in further depth.

### Summary and considerations

Without question, it is a more common practice to incorporate standardized tools that have been developed for purposes other than assessing capacity - rather than those that have been - into the assessment of (in)capacity. This is at least partially related to the familiarity of these tools to clinicians. These tools can provide useful information to help make decisions about an adult's capacity by helping to establish a context for understanding where deficits may lie, what decisions are required, and what actions that are being taken. Because they are standardized they facilitate comparison and provide support for decisions. Interestingly, although assessors often rely more on the global quantitative score, the tools often provide excellent qualitative information that is highly relevant to the assessment which unfortunately, is not always considered or documented. <sup>128</sup>

However, these tools are not actually assessments of capacity and for most – especially the functional tests – the link to decisions about incapacity is not clearly established.

## **Part III: Overview of Selected Tools**

In Part 2, I focused on providing a context and overview of standardized instruments being considered in relation to the assessment of incapacity. In this section, I have pulled out selected instruments for further discussions. These instruments were selected because they met at least one of the following criteria:

- The instrument is identified as a 'gold standard' tool (for example, the MacCAT-T)
- The instrument seems particularly relevant within a BC context. For example, the ACED is the only tool that focuses on independent living. Even if not used in its entirety, it provides an interesting process for exploring decision-making around independent living that is adaptable and operationalizes relevant aspects of incapacity. Similarly, the FCI and the FCAI, two of the most common financial capacity instruments, provide important and relevant insight into the operationalization of financial capacity from a more functional, multi-dimensional perspective. Again, even if not used in their entirety, they provide interesting guidelines for structuring a comprehensive assessment.
- The instrument is one of the more recommended screening instruments (for example, the MMSE) and has research to establish its link to the assessment of incapacity.

### **Decision-making Abilities Tools (Capability Assessment Instrument)**

- MacArthur (MacCAT-T)
- ACED

## Assessing Incapacity: Review of tools

- FCI
- FCAI

### **Cognitive assessment screening instruments**

- Mini-Mental Status Examination
- Clock- drawing

## **The MacArthur Competence Assessment Tool for Treatment (MacCAT-T)**

### *Description*

This is one of the most widely used structured interview scales and is emerging as the ‘gold standard’ for assessing capacity to consent to medical treatment.<sup>129</sup> The tool was developed by Grisso and Appelbaum and is based on their four ability model of competence. It is a semi-structured interview guide which is designed to examine four components of capacity in a clinical setting: 1) understanding of the disorder and its treatment, including associated benefits/risks; 2) appreciation of the disorder and its treatment (requires insight into how these will affect the patient individually); 3) reasoning, which examines why and how a decision was made and the potential to compare consequences; and 4) ability to express a choice.<sup>130</sup>

This tool is a derivative of the MacCAT which was developed for research and has only standardized content that does not allow for assessments in the context of the patient’s own symptoms and treatment options. It also took between 60 and 90 minutes to administer with a scoring system that was quite detailed and complex (in order to insure inter-rater reliability). The MacCAT-T comes out of this tool, but is intended to be clinically useful. It takes approximately 15 – 20 minutes to administer and requires some training.

The tool is not designed to determine global competence, and hence does not give an overall rating. In other words, there are no cut-off scores that differentiate between capacity and incapacity. This is not seen as a limitation since it is argued that there needs to be a sliding threshold related to the severity of risk associated with a decision.<sup>131</sup> Instead, the tool provides insight into the various abilities identified as relevant to decision-making capacity.

### *Strengths*

- It is the tool that has been best validated with a variety of populations including dementia, depression, schizophrenia, acutely ill and normal control subjects
- Training materials are available
- This is considered the most comprehensive tool available to assess capacity to consent to treatment and it grounds a number of other tools
- It is also considered the most ‘sophisticated’ tool<sup>132</sup> with clear conceptualization and precisely defined criteria comprising legal and ethical standards that are exemplary.
- By using information from the patient’s chart, the test can be personally relevant and has excellent applicability in clinical practice
- The tool has the best research current available establishing validity and reliability.

### *Limitations*

- One critique of this tool is that the empirical documentation of the psychometric equivalence of tailored versions is lacking;
- Use of the tool requires substantial training, especially if using the more research-oriented version;
- Some research findings suggest the need for further refinement of the appreciations and reasoning subscales.<sup>133</sup>

- This approach takes a strictly cognitive approach to understanding capacity. The four abilities that underpin it are conceptualized, operationalized and measured as cognitive or intellectual functions. This is problematic because it gives the illusion that ‘objective’ standards are normative and that people rely solely upon rational thought processes for making decisions (rather than emotional and subjective meaning making). Breden and Vollman (2004) provide an excellent discussion of the issues here in relation to each of the standards. They highlight that competence in decision-making requires at least, but not only, cognitive abilities: “A decision that seems irrational and meaningless when viewed as an isolated act by an external observer can be appropriate when biographical, social and contextual factors are taken into consideration”<sup>134</sup> They go on to note that at no point in their theoretical reflections do the authors of MacCAT-T mention the patient’s values as criteria for decision-making. “But the restriction to only logical rationality runs the risk of neglecting the patient’s normative orientation”.<sup>135</sup>
- One result of the above is that there may be some tendency the use of a tool such as the MacCAT-T is more likely to result in person being declared incompetent than clinician assessment using a clinical interview.<sup>136</sup>

### Selected Research

This tool has the most research associated with it. It is also the tool against which other tools are measured. For example, validity of a tool will be established based on how well it correlates with the MacCAT-T. A brief review of some of the most significant and recent studies developing this tool are summarized below:

- Grisso, Appelbaum and Hill-Tofouhi (1997) reported on the initial trial of MacCAT-T that was used to establish the instruments validity and reliability.
  - Sample: n= 40 recently hospitalized patients with schizophrenia or schizo-affective disorder compared with n= 40 matched community-dwelling subjects without mental illness.
  - One finding was a high degree of ease of use (user-friendly) and high inter-rater reliability;
  - Treatment group as a whole performed significantly more poorly than control on understandings and reasoning (some individuals were comparable though);
  - Poor performance (measured using Brief Psychiatric Rating Scale) related to some psychiatric symptoms including hallucinations, conceptual disorganization and disorientation;
  - It is noted that 80% -85% of sample were male but gender has not been examined.
- Dunn et al. (2007) have used the MacCAT-T to develop better understanding of capacity issues in relation to adults with schizophrenia.
  - They tried (unsuccessfully) to set up a cut-off score and concluded that the problem with doing this is that the MacArthur protocols have an excessive weight on understanding (0-26) whereas appreciation (rank 0-6) and reasoning (rank 0-8) play a lesser role.
  - Their study raised questions regarding how the different components of capacity should be combined. This point is picked up by Calcedo-Barba et al. (2007) who suggest that the research to date does not provide an answer to this, but they also note

that the more reasoning and appreciation are included in general standards of capacity the more patients will be declared incapacitated.

- Raymont et al. (2007) compared MacCAT-T and Thinking Rationally about Treatment (TRAT).
  - They found a high level of agreement for those clearly incapable and those clearly capable. There was more disagreement on those who feel in between
- Lai, Gill et al. (2008) compared ACED with MacCAT-T
  - They found modest to strong correlation.
- Karlawish et al. (2005) compared the MacArthur protocol with the MMSE. They concluded that:
  - the MacArthur protocol was superior for classifying people as competent or incompetent compared to the MMSE;
  - They identified the presence of a strong relationship between degree of insight and determination of capacity – people who recognized memory and thinking problems scored better on reasoning and appreciation despite similar levels of cognitive decline as those who didn't recognize they had a problem. This suggests that level of insight in addition to cognition may be important to measure.

## **Financial Capacity Instrument (FCI)**

### *Description*

This is a standardized psychometric instrument designed to directly assess the financial performance of older adults. It is a comprehensive instrument used to evaluate judgment, understanding and appreciation for managing one’s financial affairs and estates as well as the capacity to perform several executive tasks related to financial transactions. Specifically, it assesses financial knowledge, the ability to perform financial activities, and judgment in performing relevant monetary transactions.<sup>137</sup> It comes out of the work of Marson and colleagues at the University of Alabama, and appears to be emerging as the instrument with the strongest research support.

This structured questionnaire breaks the demands of everyday money management into eight domains (or activities): basic monetary skills; financial conceptual knowledge; cash transactions; chequebook management; bank statement management; financial judgement; bill payment, and; personal financial knowledge. These are operationalized using 19 behaviourally-anchored assessment tasks. Task difficulty of each is assigned as either simple (ie. Name coins) or complex (ie understand an investment option and make a choice).

Table 1. Description of FCI Domains and Tasks.<sup>xi</sup>

<b>FCI Domain</b>	<b>Task Description</b>	<b>Core Knowledge</b>
Domain 1: Basic Monetary Skill <ul style="list-style-type: none"> <li>• Naming coins/currency</li> <li>• Valuing coins/currency</li> <li>• Counting coins/currency</li> </ul>	Identify specific coins and currency Indicate relative monetary values of coins/currency Accurate count groups of coins/currency	Declarative Declarative Procedural
Domain 2: Financial Conceptual knowledge <ul style="list-style-type: none"> <li>• Define financial concepts</li> <li>• Apply financial concepts</li> </ul>	Define a variety of simple financial concepts Practical application using computation using financial concepts	Declarative Declarative/procedural
Domain 3: Cash Transactions <ul style="list-style-type: none"> <li>• 1 item grocery transaction</li> <li>• 3 item grocery transaction</li> <li>• Vending machine transaction</li> </ul> Tipping	Enter into a stimulated 1 item transaction and verify change; As above but using 3 items Obtain proper change for a vending machine and verify change Calculate an appropriate tip based on the amount of a bill	Procedural Procedural Procedural Procedural
Domain 4: Checkbook management <ul style="list-style-type: none"> <li>• Understanding checkbook</li> <li>• Using checkbook</li> </ul>	Identify and explain parts of a cheque and cheque register Enter into stimulated transaction – pay by cheque	Declarative Procedural

<sup>xi</sup> Source: Wadley, Harrell & Marson (2003) Self and Informant report of Financial Abilities in Patients with Alzheimer’s Disease: Reliable and Valid? JAGS 51(1) 1621-1626.

<p>Domain 5: Bank statement management</p> <ul style="list-style-type: none"> <li>• Understanding bank statement</li> <li>• Using bank statement</li> </ul>	<p>Identify and explain parts of a bank statement</p> <p>Identify aspects of a specific transaction on a bank statement</p>	<p>Declarative/judgmental</p> <p>Declarative/judgmental</p>
<p>Financial judgement</p> <ul style="list-style-type: none"> <li>• Detect mail fraud risk</li> <li>• Investment decision</li> <li>• Detect telephone fraud risk</li> </ul>	<p>Detect and explain risk in mail fraud solicitation</p> <p>Understand investment situation and make an investment decision;</p> <p>Detect and explain risk in a telephone fraud situation</p>	<p>Declarative/judgmental</p> <p>Declarative/ judgmental</p> <p>Declarative/judgmental</p>
<p>Domain 7: bill payment</p> <ul style="list-style-type: none"> <li>• Understanding bills</li> <li>• Identifying and prioritizing bills</li> <li>• Preparing bills for mailing</li> </ul>	<p>Explain the reason for paying bills</p> <p>Identify and explain parts of bill and prioritizing payments</p> <p>Complete necessary steps for preparing bill for mailing</p>	<p>Declarative</p> <p>Declarative/judgmental</p> <p>Procedural</p>
<p>Domain 8: Personal financial knowledge</p>	<p>Understand personal financial situation</p>	<p>Declarative</p>

Except for the 8<sup>th</sup> domain - knowledge of assets/estate - all of the domains have very good to excellent reliability at the domain level (.82 -.93). More mixed reliability at the specific task level has been reported; hence work is ongoing related to the tasks.<sup>138</sup> The test shows some ability to discriminate between people with dementia and a control group.<sup>139</sup>

The administration time for the test is estimated at between 45 – 60 minutes. No research was found which identified level of training to do the test – since it is publicly available however there appear to be no proprietary rights related to its use.

### Strengths

- direct, standardized and quantified assessment – the inclusion of an overview score is particularly useful
- the instrument is specific to the construct of financial capacity;
- It captures some of the complexity and multi-dimensional aspects associated with managing one’s financial affairs, including some focus on performance;
- The behaviourally-anchored tasks make it clinically relevant and useful;
- The tool is conceptually well grounded.

### Limitations

- It is relatively time-consuming (45 – 60 minutes)
- The research that has been done has been on samples that are too small to establish meaningful psychometric cut-off scores for identifying capacity status<sup>140</sup>
- The test has been developed largely in relation to *community dwelling older adults* likely to be *compromised by dementia*. Marson believes that it probably has relevance in other populations including neurologic, psychiatric and developmental populations, but to date, this has not been established.
- The domains captured on this test are not easily comparable to the newly emerging Australian test, the FCAI.
- Performance on tasks that are operationally defined as ‘simple’ or ‘complex’ was not found to correlate with severity of dementia<sup>141</sup>



## **Financial Competence Assessment Inventory (FCAI)**<sup>142</sup>

### Description

This tool has been developed for professional use in order to more effectively safeguard people's rights using a valid and reliable measure of financial competence. There is no universal definition of financial competence in Australia; this is an attempt to begin to address this gap.

The tool employs structured interviewing and observation of some activities. It is composed of 38 questions and tasks (initially 41) that provide details on six dimensions considered to be relevant to financial competence: everyday financial abilities (EFA); financial judgment (FJ); estate management (EM); cognitive functioning related to financial task (CFRFT); debt management (DM); and support resources (SR). These dimensions are conceptually grounded in previous research by the authors. No details are provided regarding actual questions in each dimension, author would need to be contacted for this. In order to make the test more comparable to North American tools, the tasks can be rearranged to give scores related to four standards: understanding, appreciation, reasoning and choice.

### Strengths

- The tool is multi-dimensional and includes a performance part
- The tool was developed for professional practice, not as a research tool;
- The authors report good internal consistency on five (EFA; FJ; EM; CFRFT; DM) of the six sub-scales (.84 - .91).
- The tool has been tested on four populations: dementia, acquired brain injury (ABI), persons with learning disabilities (LD); and schizophrenia. It demonstrated differences in how the various groups responded on the sub-scales, with those with dementia demonstrating overall poorer scores while people with schizophrenia and ABI scored better on all sub-scales but not as well as those in the control group. The test demonstrates the difficulty that might be encountered assessing someone with ABI. For example, FCAI total score was 153.75 for the control group, 130.78 for those with ABI, 123.34 for those with schizophrenia, and only 82.81 and 85.23 for those with dementia and learning disabilities.
- The tool can be used to give information related to understanding, appreciation, reasoning and expressing a choice. Since these are typically linked to legal standards this option is useful.

### Limitations

- One sub-scale, SM had low internal consistency (.54). This is important because one of the rationales for the need for developing a new tool is that this item is not included on other tools.
- The tool is in infancy stage – no other research related to its use was found.
- It is unknown how long it takes to administer.
- Categories seem less intuitive than the FCI.

### Comparison to other tools

- Demonstrated good correlation with Hopemont Capacity Assessment Interview (HCAI) and ILS- Money management sub-scale;

- Significant positive correlation between scores on FCAI sub-scales and MMSE scores. Correlation is lower however for ABI than other groups; and MMSE was not related to estate management, debt management or support resources domains for the ABI group. This lead the researchers to conclude that: “MMSE may not be a good indicator of financial abilities in people without cognitive impairment or for people with ABI” (p. 48)
- MMSE not correlated with support resource subscale.

## **Assessment of Everyday Decision-making (ACED)**

### *Description*

The Assessment of Everyday Decision-making (ACED)<sup>143</sup> is the first tool available with data supporting its reliability and validity to address everyday decision-making ability related to ability to live independently.<sup>144xii</sup> It is geared toward older adults living in the community with cognitive impairment who are refusing an intervention to help manage an instrumental activity of daily living (IADL). The key developers are Jason Karlawish (University of Pennsylvania) and James Lai (Yale).

The purpose of the tool is to measure the capacity to make decisions about solving functional problems. It uses a semi-structured interview to assess the four decision-making abilities: understanding, appreciation, reasoning, and expressing a choice. (This tool is based on the work of Grisso and Applebaum, and uses the principals behind MacCAT-T). Interviews take 15 – 20 minutes to conduct.

Karlawish and Lai provide a detailed manual outlining the administration. The protocol they describe includes the following:

- The first step in the process is for the interviewer to collect information from knowledgeable informant(s) regarding the functional deficits, or areas of concern. The ACED is then tailored to the issues being identified as a problem for that individual. The assessor describes the problem to the person, determines whether s/he thinks s/he has a problem and then goes through the options and potential benefits and downsides of each option, continuously asking the person to paraphrase in his/her own words the information being provided.
- Interviewer scores response using three point scale [0 = inadequate (wholly incorrect); 1= marginal; 2 = adequate (correct)]. Higher scores indicate better performance. Sub test scores: understanding (0-10); appreciation (0 – 8); reasoning (0-10); expressing a choice (0 – 2). A global score is calculated by totalling the sub-scores.
- Decision-making assessed in relation to: understanding, appreciation, reasoning, expressing a choice and are operationalized in the following way:
  - Understanding: understanding the problem, understanding the alternatives available; understanding advantages/disadvantages of alternatives;
  - Appreciation: appreciating patient-specific deficits and the potential impact of new alternatives to everyday life
  - Reasoning: comparative and consequential reasoning about choice
  - Expressing a choice: ability to express a single clear choice of how to solve an everyday problem; logical consistency of choice with patient’s reasoning

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<sup>xii</sup> Note, the work being done by Naik et al. shares members with the work being done to develop ACED (Lai and Karlawish).

### Strengths

- Clinically relevant: Clinicians have the opportunity to evaluate decision-making abilities with respect to an actual decision the patient currently faces. There are several classic scenarios, but there is also a format for individualizing the particular issue. As long as structured questioning doesn't change, personalizing the issues does not influence reliability and validity of the instrument according to the researchers.
- A structured questioning approach has been documented to improve clinicians' ability to distinguish patients with impaired decision-making over clinical judgment alone.<sup>145</sup>
- The test forces the interviewer to very carefully and sequentially break down the tasks of decision-making. The step-by-step process does a nice job operationalizing the different abilities
- With minimal training it can be used by a variety of health professionals
- A free manual is available that methodically goes through an example using the tool. It's an effective teaching tool.
- This tool is very relevant to Part 3 of the AGA, especially the pieces that evaluate understanding

### Limitations

- The use of caregiver-derived information and subjective scoring of the adult's responses may impact overall reliability and test/retest characteristics of tool;
- With increased adaptability comes increased complexity, and extra training for some clinicians may be required to reach the same level of psychometric performance as could be reached in research
- This tool is based solely on decisional capacity and NOT Executive capacity – it uses the four cognitive standards (Choice, understanding, appreciation, reasoning) but does not assess the ability to carry out decisions
- Test performance is very heavily based upon memory for understanding component. For example, information is provided and then the person is asked about the information/choices given. There is some concern that the instrument may be testing the ability to take in this information (and immediate recall) more than it is testing the person's ability to really 'understand' what the situation is.
- One of the standard scenarios is around managing money. This tool is restricted as a tool for assessing decision-making around finances because: 1)the interviewer does not have any idea whether the person actually knows what her financial situation is, and; 2) the interviewer does not know if the person has any previous experience managing finances.

### Selected Research

- Lai, Gill, Cooney, Bradley, Hawkins, Karlawish (2008) examined reliability in relation to several other tools: They found:
  - Moderate to strong correlation to MacCAT -T assessment tool for treatment.
  - Inter-rater reliability: .72 (understanding); .69 (appreciation); .65 (reasoning) ; .93 (choice)
  - Moderate to strong correlation with MMSE;
  - Among three measures of executive functioning (Trails A & B; Controlled Oral Word Fluency Test) there was moderate association with understanding and reasoning but no correlation with appreciation.

## **Mini-Mental Status Examination**

### *Description:*

Although a number of screening tools exist, the Mini-Mental Status Examination (MMSE)<sup>146</sup> is unquestionably the most widely used tool both in practice and in research. It was originally created as a screening tool to differentiate between organic vs. functional psychiatric patients and to provide a quantitative estimate of the severity of cognitive impairment and a tool for documenting cognitive change over time.<sup>147</sup> The tool assesses: registration, attention and calculation, recall, language, and visual construction. It can be quickly administered (10 – 15 minutes) by diverse health professionals with minor training. It is scored out of 30 with a higher score depicting better functioning. A score of over 26 has generally been considered to be consistent with normal cognition.

Can a brief cognitive test serve as a useful screening method to identify patients who need more intensive evaluations of competence? This is a question Kim et al. (2002) asked in their review of the 32 different research studies. They found that research varied in terms of their support regarding the usefulness of the MMSE as a predictor of decisional impairment. While at least one study did not support its use, most established good predictability at both ends of the scale. However, the mid range of the score did not receive good support, although studies differed in terms of what constituted the mid range scores. For example: one study found that most useful scores were below 16 or over 24, another identified the optimal cut-off as 20, and yet another indicated that scores between 19 and 23 were not reliable indicators. From this review, Kim et al. (2002) concluded that the main limitation of the MMSE is its lack of accuracy in the middle range of scores (from about 18 to 24). They suggest the test does make a modest but significant contribution to decisions about capacity when test scores are below 17 or over 26. More recent research seems to also support that there is a 'grey zone' in which the MMSE is not particularly discriminating but the actual span of this zone continues to vary.

### *Strengths*

- The instrument has considerable research backing it to demonstrate its reliability and validity as a screening tool. Tombaugh and McIntyre (1992) reviewed 25 studies and provide an excellent overview of this research. (It is dated but still seems to be the review most cited).
- It is internationally recognized and used both clinically and in research;
- There is a modest but significant relationship to capacity, suggesting the tool can provide some helpful insight;
- It is easy and quick to administer.
- There is a validated Chinese version (CMMSE)

### *Limitations*

- There are several versions of the instrument in use, and these are not always compatible. For example, the spelling of WORLD backwards and the subtraction of 7 from 100 are often used as interchangeable tasks, but research does not support that they are in fact measuring the same thing.
- The instrument is considered to have high sensitivity for moderate to severe levels of dementia but there is concern that it is less attuned to more subtle changes and earlier cognitive impairment, especially when education level is high. In other words, the tool may

not be very sensitive, particularly in picking up people in earlier stages of dementia with higher education;

- While the tool definitely helps to differentiate between those who are capable and those who are not, several studies have demonstrated that it lacks sensitivity on those who score between 18 and 24.
- The tool is a poor measure of executive functioning.
- Some researchers have identified the importance of insuring that the functional abilities being assessed should have close conceptual relationship with the appropriate standards of competence. If this criterion is applied, a test of general cognitive abilities, such as the MMSE would not be an appropriate instrument for gauging the more specific, context-dependent ability to make a decision.<sup>148</sup>
- Too often the MMSE is treated as though it were a test of incapacity. This is a misuse of the tool and provides inadequate information upon which to base a decision about capacity.

Research correlating the MMSE to other tests of capacity

- Karlawish et al. (2005) compared findings of capacity between the MacArthur protocol and MMSE for adults with mild to moderate dementia (n=48). They found that MMSE scores below 19 were not likely to label many competent persons as incompetent and scores over 23 were not likely to label incompetent people as competent. But scores between 20 and 22 represented a ‘grey zone’.
- Kim & Caine (2002) analyzed the research examining utility of MMSE as a screening tool for assessing the capacity of patients with AD to participate in research (n=37 people with a MMSE scores ranging between 21 and 25). They found that the MMSE significantly added to the identification of incapability but that the significant effect was modest. It was best for scores below 19 and over 26. They suggest that the modest discriminatory power of the MMSE may reflect the instrument’s relative insensitivity in detecting executive dysfunction.
- Vellinga et al. (2004), using the criteria of sensitivity and specificity, found in their review of the research that capacity assessment tools did a better job determining competence than brief mental screening tools, including the MMSE.
- Sturman’s (2005) review of the tools used to assess incapacity also found that the cut-off point above 24 – 26 and above was relatively good at identifying competence, and scores 16-20 and below correctly predicted incompetence. In his review, scores between 20 and 24 were not good predictors. He concludes his review by suggesting that MMSE should be viewed as a “blunt instrument for ascertaining competency”.
- Schillerstrom et al. (2007) found that MMSE performance did not correlate significantly with ‘appreciation’ on MacCAT-T.
- Napier, Barrett et al. (2007) included the MMSE as one of the measurement tools they used in comparing two groups with serious mental illness (one group had guardians and the other was financially independent) with a control group of adults who did not have a mental health diagnosis and were financially independent. They found that MMSE scores were

lower for both groups with mental illness when compared to the control group. However, and quite important, *MMSE scores did not differ significantly between the two mental illness groups irrespective of whether or not they were financially dependent*. Similar to other research, they also found that MMSE was significantly and moderately correlated with financial subscale of DAFS.

- Kelly, Earnst et al. (2003) found that the counting backwards sub-test on the MMSE was linked to financial capacity as measured by the FCI. It was noted that counting forward was not correlated to financial capacity.
- Bassett (1999) found that measures of global impairment such as MMSE and Clinical Dementia Rating Scale (CDRS) were not useful in estimating a patient's competency for financial decision-making. She found the Trails A and Word Recall were more significantly correlated to capacity, using the Hopkins Capacity Test with the Trails A predicting over 80% of the variance.
- Royall et al. (1998) compared the use of the EXIT interview with the MMSE and found that EXIT interview was a better predictor of nursing home placement than the MMSE;
- Naik et al. (2006) compared the MMSE scores between a group of adults who self-neglected and another group who did not. They found that the MMSE was not significantly different between those who self-neglected and those who did not.
- Kershaw and Webber (2008) used the MMSE as a measure of global cognitive functioning in their research to establish the reliability and validity of a new assessment tool for assessing financial capacity (FCAI). They found that the MMSE was positively correlated to FCAI but that this looked different depending upon the population. In particular, they found a lower correlation for the group who had a brain injury on the overall rating of the FCAI and it did not correlate to some subscales of this test at all. One of their conclusions is that the findings suggest that, although the MMSE appears to be measuring some of the same underlying abilities as the FCAI in some people with cognitive impairment, the MMSE may not be a good indicator of financial ability without cognitive impairment or for people with brain injury.

When combined, this research suggests there is some merit to the MMSE but that it most definitely does not stand up as a test of capacity to be used in isolation.

## **The Executive Clock Drawing Task (CLOX)**

### *Description*

Clock drawing as a screening tool appears to be written about in a number of ways. It is sometimes simply referenced as a 'clock drawing test (CDT)' but it is also more formally described in relation to two components: the CLOX 1 and CLOX 2 test. CLOX1 is a command directed clock-drawing task described as being sensitive to executive functioning while CLOX 2 is a clock-copying task sensitive to constructional praxis. Both clocks are scored from 0 – 15 with high scores representing better performance

Shulman (2000), a Canadian geriatric psychiatrist reviewed the research conducted using the clock drawing test between 1983 and 2000. He concludes that it is an ideal cognitive screening test. It is quick and easy to administer and less culturally-bound than verbal tests. It may provide a better assessment of executive functioning than the MMSE and assesses the following:

- comprehension (auditory);
- planning and organization;
- visual memory and reconstruction in a graphic image;
- visuo-spatial abilities;
- motor programming and execution;
- numerical knowledge;
- abstract thinking (semantic instructions); and
- concentration and frustration tolerance.

### *Strengths*

- The test is being used internationally and some research has found that it is a particularly useful tool to use with non-English speaking adults. Research also suggests that it may be more sensitive to early dementia than the MMSE.
- Test is a particularly good one for measuring executive functioning which has been well linked to capacity.
- CDT is characterized by ease of administration, economic advantage, lack of ethnic and educational bias, and good acceptance among elderly patients.<sup>149</sup>

### *Limitations*

- There is considerable variation in how this test is administered. Some use pre-drawn circles and ask the person to make it look like the face of the clock, others give a blank piece of paper. As well, different time settling exercises are used. Research is beginning to emerge to suggest that these are not equivalent.
- Additionally, there is a wide range in scoring procedures. Shulman (2000) identifies over a dozen ways of scoring it. They are not all compatible because of differing emphasis on visuo-spatial, executive, quantitative and especially qualitative issues.
- As an global screening tool, there is some lack of sensitivity in cases where very mild dementia is reported but well correlated with other dementia scales including MMSE, Blessed Dementia Scale, Global Deterioration Scale, and Cambridge Cognitive Examination<sup>150</sup>



## Part IV – For Further Reading

### Recommended readings

Cooney, L.M., Kennedy, G.A., Hawkins, K.A., & Hurme, S.B. (2004). Who can stay at home? Assessing the capacity to choose to live in the community. *Archives of Internal Medicine*, 164, 357-360.

- Provides a very readable overview of the information required when assessing someone's capacity for independent living. Provides a nice overview of executive functioning and how to assess.

Kennedy, G. J. & Smyth, C.A. (2008). Screening older adults for executive dysfunction: An essential refinement in cognitive assessment. *American Journal of Nursing*, 108(12), 62-72.

- Training video can be viewed at: <<http://links.lww.com/A326>>
- This article provides a practical demonstration of how to assess executive functioning in older adults. Executive functioning is being directly linked to decisional capacity and this training program draws on several tools that are established as relevant and useful (ie. Trails, CLOX, COWAT). It outlines the tools, how to administer and how to rate.

Kim, S. Y.H., Karlawish, J. and Caine, E. D. (2002). Current state of research on decision-making competence of cognitively impaired elderly persons. *American Journal of Geriatric Psychiatry*, 10(2), 151-165.

- This article provides a review of 32 relevant studies examining decision-making capacity of elderly persons with dementia or cognitive impairment. It provides an excellent overview of the state of research in this area in 2002. The area has developed somewhat since this article was written but many of the findings remain relevant.

Lai, J. & Karlawish, J. (2007) Assessing the capacity to make everyday decisions: A guide for clinicians and an agenda for future research. *American Journal of Geriatric Psychiatry*, 15(2), 101-111.

- Using MacCAT-T as a foundation, this group of researchers is developing a tool for assessing everyday decision-making. It is practical and relevant, however, validity and reliability is not yet established. Clear overview of the issues related to assessing capacity in everyday decision-making including an overview of why it is an important part of clinical practice and intervention planning.

Marson, D. (2001) Loss of financial competency in dementia: Conceptual and empirical approaches. *Aging, Neuropsychology and Cognition*, 8(3), 164-181.

- This article provides the conceptual model used to develop the Financial Capacity Instrument (FCI). It provides an excellent overview of the abilities thought to be relevant to financial capacity. It forms the foundation for probably the largest body of research examining financial capacity.

Moore, D., Moseley, S., & Palmer, B. (2008). The clinical usefulness of performance-based assessments of daily functioning for older adults. *Geriatrics*, 63(9), 16-20.

- This article provides an excellent overview of the strengths and limitations of various tools for assessing daily functioning. It is geared toward use by clinicians.

Naik, A., Lai, J., Kunik, M., & Dyer, C. (2008). Assessing capacity in suspected cases of self-neglect. *Geriatrics*, 63(2), 24 -31.

- This article provides an excellent overview of the assessment including outlining relevant functional assessment tools. It outlines an approach to assessment that combines individual and standardized assessment processes. Very readable, especially relevant to Part 3.

New South Wales Government: Attorney General's Department (2008) *Capacity toolkit* [www.lawlink.nsw.gov.au/diversityservices](http://www.lawlink.nsw.gov.au/diversityservices).

- This booklet is a user-friendly overview of some of the issues and protocol associated with understanding and assessing capacity. It is developed for a lay audience and provides a useful framework for considering capacity issues but it should be kept in mind that standards and protocol are not necessarily reflective of BC legislation and practices. Although described as a 'tool-kit' it does not actually address the use of standardized tools.

#### Reviews of treatment instruments

Dunn, L., Nowrangi, M., Palmer, B., Jeste, D., & Saks, E. (2006) Assessing decisional capacity for clinical research or treatment: A review of instruments. *American Journal of Geriatric Psychiatry*, 163(8),1323-1334.

Jeste, D. & Saks, E. (2006). Decisional capacity in mental illness and substance use disorders: Empirical data base and policy implications. *Behavioral Sciences and the Law*, 24, 607-628.

- Reviewed tools for assessing research participation and treatment. Identified 11 tools which are described. The article provides a good overview of the research, especially related to non-dementia related disorders.

Okai, D., Owen, G., McGuire, H., Singh, S., Churchill, R. & Hotopf, M. (2007). Mental capacity in psychiatric patients. *British Journal of Psychiatry*, 191, 291-297.

- Reviewed 37 studies linked to health care decision-making by psychiatric patients. Excluded delirium and dementia; and intellectual ability.

Sturman, E. D. (2005). The capacity to consent to treatment and research: A review of standardized assessment tools. *Clinical Psychology Review*, 25(7), 954-974.

Vellinga, A., Smit, J., van Leeuwen, E., van Tilburg, W. & Jonker, C. (2004) Instruments to assess decision-making capacity: An overview. *International Psychogeriatrics*, 16(4), 397-419.

Reviews of performance-based measures of functional living skills

Alison, D., Letts, L. & Liu, L. (2008). Review of cognitive assessments for older adults.

*Physical & Occupational Therapy in Geriatrics*, 26(4), 13- 43.

- Instrument review of occupational therapy literature to identify tools relevant for assessing cognitive functioning in older adults. 32 tools are reviewed – helpful chart provides a comparison of various tools. The instruments are broken into two types: body function under 30 minutes (which includes MMSE and 3MS) and; body function over 30 minutes.

McKibbin, C.L., Brekke J.S., Sires, D., Jeste, D., & Patterson, T. (2004). Direct assessment of functional abilities: relevance to persons with schizophrenia. *Schizophrenia Research*, 72(1), 53-67.

- Reviewed 8 tools that are relevant to persons with psychotic episodes

Moore, D., Palmer, B., Patterson, T. & Jeste, D. (2007). A review of performance-based measures of functional living skills. *Journal of Psychiatric Research*, 41, 97-118.

- Reviewed 94 relevant articles covering 31 instruments related to assessing functional living skills. Identifies the strength and weaknesses of each tool from a research perspective.

Moore, D., Moseley, S., & Palmer, B. (2008). The clinical usefulness of performance-based assessments of daily functioning for older adults. *Geriatrics*, 63(9),16-20.

- This article provides an excellent overview of the strengths and limitations of various tools for assessing daily functioning. It is geared toward use by clinicians.

## Notes

<sup>1</sup> Jeste, D. & Saks, E. (2006, p. 611)

<sup>2</sup> I am drawing here on the work of Calcedo-Barba, Garcia-Solano, Fraguas and Chapela (2007) who, citing Blum (2005) articulate these three different approaches most explicitly

<sup>3</sup> Calcedo-Barba, Garcia-Solano, Fraguas & Chapela (2007)

<sup>4</sup> See Perkins, Naik et al.(2007) for a good discussion of this

<sup>5</sup> For a fuller discussion of this point, see for example: Jeste, D. & Saks, E. (2006)

<sup>6</sup> See Marson, McInturff, Hawkins,, Bartolucci,, & Harrell (1997). This study found that the clinical judgement among five 'experts' (physicians) was slightly less than change alone. However, with training around assessment protocol, another study by this same group demonstrated that higher inter-rater reliability was established. Kim et al. (2002) also note that the research supports that a structured 'capacity interview' increases the reliability of expert judges categorical competency judgements. In their review of the literature, Okai et al.(2007) also found that when interviewers used consistent approach, there is high level of agreement on binary assessment of whether competent or not. When expert, or clinical impression, findings were compared with formalized tool use, agreement was also well above chance but not as high as when assessors used the same tools. A noted difference that requires further exploration is that that clinicians tended to find fewer patients lacking mental capacity than did researchers.

<sup>7</sup> Moye, Wood et al. (2007)

<sup>8</sup> See Moye, Karel et al. (2004, p. 166) for a list of citations finding this

<sup>9</sup> (ibid)

<sup>10</sup> Validated methods for assessing decisional capacity in the context of the domains of medical self-care, personal needs and hygiene are limited (Naik et al., 2008); Moberg & Rick (2008) assert there is an acute and growing need for evidence-based assessments; the work of Moye, Karel, Azar & Gurrera (2004) show that more research is needed to establish reliability and validity of assessments tools and capacity constructs.

<sup>11</sup> Reference required for this point

<sup>12</sup> Moye, Dymek & Karlawish (2001).

<sup>13</sup> Royall (2002)

<sup>14</sup> Naik et al. (2008)

<sup>15</sup> Okai, et al. (2007)

<sup>16</sup> Okai et al. (2007 p. 291) do a nice job outlining the differences between these two approaches - mental capacity approach and mental health approach.

<sup>17</sup> Grisso & Appelbaum (1998).

<sup>18</sup> Roth et al, 1977

<sup>19</sup> Grisso et al. (1997)

<sup>20</sup> , Dunn, Nowrangi, Palmer, Jeste & Saks (2006, p.1331)

<sup>21</sup> Sturman, (2005) provides a chart that outlines which of these standards are present in each of 10 tools used to assess capacity related to treatment decisions. For example, MacCAT-T measures choice, understanding, appreciation, and reasoning, while CCTI measures choice, understanding, appreciation reasoning AND reasonable decision.

<sup>22</sup> Sources: Moye, Wood et al. (2007 p. 605); American Bar Association Commission on Law and Aging and American Psychological Association (2006). *Determining capacity of older adults in guardianship proceedings: A handbook for judges*. Washington, DC: American Bar Association and American Psychological Association (cited in Moy Wood et al., 2007); Pachet, Newberry & Erkin, (2007-review of Canadian practices); Moberg & Rick, (2008).

<sup>23</sup> White, B.C. (1994) *Competence to Consent*. Washington, DC: Georgetown University Press.

<sup>24</sup> Buchanen & Brock (1999); Vellinga et al. (2004)

<sup>25</sup> O'Connor, Hall & Donnelly (2009); Tsai (2009); Hulko & Stern (2009) Moye, Butz, Marson, Wood & the ABA-APA Capacity Assessments of Older Adults Working group (2007). Breden & Vollmann (2004) make similar points – they highlight the need for a more comprehensive model that includes a non-cognitive dimension. As well, Calcedo-Barba et al. (2007) make the point that the decision that clinician has to make must be based not only on the elements of the construct of capacity (i.e. Making a choice, understanding, appreciation and reasoning) but also on other elements that arise from the specific context and how patients react to particular situations (p. 504) They highlight the need to analyze the mechanisms of defence the patient is using. Their definition of context includes particular environment of the individual under study and the values of society expressed in the law and medical professions

- <sup>26</sup> Kim et al. (2002)
- <sup>27</sup> Jeste & Saks (2006); see also Moye et al. (2007)
- <sup>28</sup> Naik et al. (2007, p. 29). In determining best instrument, there are questions about whether any instrument can gauge decisional capacity adequately without considering contextual and individual factors (Dunn et al., 2006)
- <sup>29</sup> Pachet, Newberry & Erskine (2007, p.175) provide a useful review related to who and how the assessment is carried out.
- <sup>30</sup> Okai, et al.(2007). This is one of their conclusions following a systematic review of research in this area – the studies that lead to this conclusion are cited in their report.
- <sup>31</sup> Moberg & Rick (2008) make explicit the importance of articulating the legal standards being used when conducting an assessment of incapacity.
- <sup>32</sup> Lai & Karlawish (2007)
- <sup>33</sup> See Kim et al.
- <sup>34</sup> See for example, Manthorpe (2009); Boyle (2008); O’Connor, Purves & Downs (2009)
- <sup>35</sup> Kim et al
- <sup>36</sup> For a comprehensive review of the research comparing different diagnostic groups, see Jeste and Saks (2006).
- <sup>37</sup> Breden and Vollman et al. (2003)
- <sup>38</sup> See Okai et al. (2007) for a review of this research
- <sup>39</sup> See for example, Tsai (2009)
- <sup>40</sup> Moye et al.(2007)
- <sup>41</sup> Kim, Karlawish & Caine (2002) make the point most explicitly that these tools are not ‘capacity instruments’ but rather can be better understood as ‘decisional abilities instruments’.
- <sup>42</sup> It is not my aim to review all of these tools as there are several very comprehensive reviews which already do this. These are listed in Part IV of this report and include: Dunn, L., Nowrangi, M., Palmer, B., Jeste, D., & Saks, E. (2006); Jeste, D. & Saks, E. (2006); Okai, D., Owen, G., McGuire, H., Singh, S., Churchill, R. & Hotopf, M. (2007); Sturman, E.D. (2005); Vellinga, A., Smit, J., van Leeuwen, E., van Tilburg, W. & Jonker, C. (2004). Several of these have developed excellent comparison charts.
- <sup>43</sup> Kim, Karlawish and Caine (2002)
- <sup>44</sup> Kim, Karlawish and Caine- See page 153 – 158 for a discussion of each of the various tools found in this literature review.
- <sup>45</sup> Dunn et al. (2006)
- <sup>46</sup> Vellinga et al. (2004), review the tools related to how they have operationalized these standards
- <sup>47</sup> Sturman (2005) and
- <sup>48</sup> Grisso and Appelbaum, 1998
- <sup>49</sup> Vellinga et al. (2004); Sturman (2005); Dunn et al. (2006); Raymont, Buchanen et al. (2007)
- <sup>50</sup> Cooney et al. (2004) provide an excellent discussion about this
- <sup>51</sup> Lai and Karlawish (2007, p.102).
- <sup>52</sup> Naik, Lai, Kunik & Dyer (2008) p. 27
- <sup>53</sup> Karlawish & Lai (2009)
- <sup>54</sup> Anderer (1997) Unpublished doctoral dissertation. Allegheny University of the Health Sciences.
- <sup>55</sup> See Lai & Karlawish (2007) for a good discussion of this tool
- <sup>56</sup> Marson, D. C. (2001)
- <sup>57</sup> Marson, D. C., Sawrie. S.M., Snyder. S., McInturff. B., Stalvey, T. Boothe. A., Aldridge. T. Chatterjee. A. & Harrell, L. (2000)
- <sup>58</sup> Napier, Barret et al. (2007)
- <sup>59</sup> Marson (2001)
- <sup>60</sup> Van Wieringen, Tuokko, Cramer, Mateer, & Hultsch (2004)
- <sup>61</sup> Kelly, Earnst et al. (2003) provide an overview of these three abilities
- <sup>62</sup> Lai & Karlawish (2007)
- <sup>63</sup> Marson (2001)
- <sup>64</sup> Ibid; See also: *Research*:
- Wadley, Harrell, & Marson (2003) – compared to self and informant reports –
  - Kelly, Earnest et al. (in Marson, 2001) – examined in relation to AD and working memory
  - Marson (2001) demonstrated that even early on in AD there is significant impairment of financial capacity.

- <sup>65</sup> Marson (2001)
- <sup>66</sup> Cramer, K., Tuokko, H.A., Mateer, C.A. & Hultsch, D.F. (2004) Note: this tool is developed in BC (University of Victoria)
- <sup>67</sup> Loewenstein et al. (1989)
- <sup>68</sup> See Napier et al. (2007, p.317) for a list of research
- <sup>69</sup> Napier et al. (2007)
- <sup>70</sup> Wadley et al. (2003)
- <sup>71</sup> Marson, Sawrie, Snyder, McInturff., Stalvey, , Boothe., (2000). Team
- <sup>72</sup> Edelstein, B. Nygren, M. Northrop, L., Staats, N. & Poole, D. (1993). Assessment of capacity to make financial and medical decisions. Paper presented at the meeting of the American Psychological Association, Toronto, Canada (unpublished). Discussed in Kershaw & Webber (2008); also discussed in Grisso (2003). This was the first reference to the financial component – more work has been related to the medical decision-making component
- <sup>73</sup> Anderton Loeb, P. (1996)
- <sup>74</sup> Okai et al. (2007) found that when interviewers use a consistent approach, there is high level of agreement on binary assessment of whether competent or not. When expert or clinical impressions compared with a formalized tool, agreement is well above chance but not as high as when assessors use the same tool.
- <sup>75</sup> Moye, Karel et al. (2004)
- <sup>76</sup> Vellinga et al. (2004a); they also cite Fitten et al. (1990) and Kitamura & Kitamura (2000)
- <sup>77</sup> Mullaly, E., Kinsella, G., Berberovic, N., Cohen, Y., Dedda, K., Froud, B., et al. (2007)
- <sup>78</sup> Royall, D. R. & Gray, K. F. (1992)
- <sup>79</sup> Faden and Beauchamp, as cited in Cooney et al. (2004). Their work is cited in a number of articles when discussing executive functioning and decisional capacity.
- <sup>80</sup> See Cooney et al. (2004) for a discussion of this.
- <sup>81</sup> Folstein , Folstein & McHugh (1975)
- <sup>82</sup> Tombaugh & McIntyre (1992, p. 922). This article provides an excellent review of this tool including summarizing the research done around establishing validity and reliability.
- <sup>83</sup> See for example, Moberg and Rick (2008) for a more comprehensive discussion of this issue.
- <sup>84</sup> Folstein , Folstein, & McHugh (1975)
- <sup>85</sup> Kim, Karlawish, & Caine (2002). They provide a good overview of the research linking MMSE scores to capacity.
- <sup>86</sup> Conclusion made by Sturman, (2005) based on his review of the research linking MMSE to capacity.
- <sup>87</sup> Teng & Chiu (1987)
- <sup>88</sup> Tombaugh & McIntyre (1992)
- <sup>89</sup> Bassett (1999)
- <sup>90</sup> The most intensive work being done in this area of neuropsychological functioning and capacity is by Marson and colleagues. They have done extensive work related to executive function and working memory. One important aspect of their research has focused on examining how particular neuro-cognitive tests link to domains of the Financial Competence Instrument (FCI). To date, they have established the following links:
- Trails A ( basic monetary skills; cash transactions)
  - Token Test (Basic monetary skills; Bank statement management)
  - Boston Naming: Conceptual knowledge; Financial judgement
  - DRS Attention: conceptual knowledge; checkbook management
  - WAIS similarities: bank statement management
  - DRS construction: bank statement management
- For further details: See Marson (2001) and Marson, Cody & Ingram (1995)
- <sup>91</sup> Royall, Cordes & Polk (1998)
- <sup>92</sup> Shulman (2000). Review of the research related to the diagnostic and screening use of the clock drawing test.
- <sup>93</sup> Royall & Gray (1992)
- <sup>94</sup> Some research supporting the use of EXIT25 includes Schillerstrom, Rickenbacker, Kaustubb, & Royall (2007) and Dymek, Atchinson & Harrell (2001)
- <sup>95</sup> Alison, Letts & Liu (2008)
- <sup>96</sup> Kertesz, Davidson, & Fox (1997)
- <sup>97</sup> Nasreddine, Phillips, Bedirian, Charbonneau, Whitehead, Collin, Cummings & Chertkow (2005)
- <sup>98</sup> Moore, Moseley & Palmer (2008)
- <sup>99</sup> Nolan (1984) as found in Stebnicki (1997).

- <sup>100</sup> Stebnicki, – citing others
- <sup>101</sup> Stebnicki (1997, p.35)
- <sup>102</sup> Moore, Palmer, Patterson & Jeste (2007)
- <sup>103</sup> Moore, Moseley & Palmer (2008)
- <sup>104</sup> Napier, Barret, Hart, Mullins, Schmerler & Kasckow (2007)
- <sup>105</sup> See for example Loewenstein, Arguelles, Bravo, Freeman, Arguelles, Acevedo & Eisdorfer (2001) and Wadley, Harrell & Marson (2003)
- <sup>106</sup> Moore, Moseley & Palmer (2008)
- <sup>107</sup> Moore et al. (2007)
- <sup>108</sup> Pickens, Naik, Burnett, Kelly, Gleason, & Dyer (2007)
- <sup>109</sup> Saunders and Simon (1987) developed this tool – the reference is found in Stebnicki, (1997)
- <sup>110</sup> For a more comprehensive review of functional screening tools used by occupational therapists see Alison, Letts & Liu (2008)
- <sup>111</sup> Loewenstein et al. (1989)
- <sup>112</sup> Loeb (1996)
- <sup>113</sup> Baird et al. (2001) .
- <sup>114</sup> Kohlman-Thomson, L (1992) Kohlman *evaluation of living skills* ( 3<sup>rd</sup> ed). Bethesda, MD: American Occupational Therapy Association. I was unable to access this and instead relied upon Pickens, Naik et al.(2007)
- <sup>115</sup> Pickens, Naik et al.(2007)
- <sup>116</sup> Zimnavoda, Weinblatt & Katz (2002). This article provides a published test of validity.
- <sup>117</sup> Pickens, Naik et al. (2007)
- <sup>118</sup> Lawton, M.P., & Brody, E.M. (1969)
- <sup>119</sup> Mausbach, Harvey, Goldman, Jeste, & Patterson (2007)
- <sup>120</sup> COTA (2001)
- <sup>121</sup> Sparrow et al (2005),cited in Moberg and Rick (2008)
- <sup>122</sup> Diel et al. (2005) cited in Moberg and Rick (2008)
- <sup>123</sup> Bruininks et al. (2004) cited in Moberg and Rick (2008)
- <sup>124</sup> Blessed, Tomlinson and Roth, 1968; Stern, Hesdorffer, Sano & Mayeux (1990)
- <sup>125</sup> Mahurin, DeBettignies & Pirozzolo (1991)
- <sup>126</sup> Willis, 1996
- <sup>127</sup> Reid, William & Gill (2003), cited in Naik et al. (2006)
- <sup>128</sup> See, for example, Shulman (2000) who provides a discussion of this in relation to the clock-drawing test.
- <sup>129</sup> For example, Dunn et al.'s (2006) review of tools for assessing consent to treatment recommend MacCAT-T as the best choice given it's comprehensiveness and supporting psychometric data.
- <sup>130</sup> Grisso & Applebaum (1997)
- <sup>131</sup> Dunn et al. (2006)
- <sup>132</sup> Breden & Vollman (2004)
- <sup>133</sup> Dunn et al. (2006)
- <sup>134</sup> Breden & Vollman (2004, p.277).
- <sup>135</sup> Ibid . See also O'Connor, Hall and Donnelly (2009) and Hulko and Stern (2009) for the development of this point from a conceptual perspective.
- <sup>136</sup> Okai et al. (2007) provide a good discussion of this point. Part of the issue, as identified by them, is that clinicians may be less likely to judge someone as incapable IF the person accepts treatment! The risk is that refusal will be equated with incapacity but acceptance will equal capacity.
- <sup>137</sup> Lai & Karlawish (2007)
- <sup>138</sup> Marson (2001)
- <sup>139</sup> Ibid; See also: Research:
- Wadley, Harrell, & Marson (2003) – compared to self and informant reports -
  - Kelly, Earnest et al. (in Marson, 2001) – examined in relation to AD and working memory
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- <sup>140</sup> Marson (2001)
- <sup>141</sup> Van Wielingen et al. (2004)
- <sup>142</sup> Kershaw & Webber (2008)

<sup>143</sup> Karlawish, J. & Lai, J. (2009) *Assessment of everyday decision-making (ACED)*. This manual is available through the authors and provides a step-by-step overview of how to use the tool.

<sup>144</sup> Ibid.

<sup>145</sup> See for example research by Marson et al. (2000)

<sup>146</sup> Folstein , Folstein & McHugh (1975)

<sup>147</sup> Tombaugh & McIntyre (1992, p. 922). This article provides an excellent review of this tool including summarizing the research done around establishing validity and reliability.

<sup>148</sup> See, for example, Dunn et al. (2006)

<sup>149</sup> Shulman (2000)

<sup>150</sup> As per research cited in Berger et al. (2008)



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