
Incapability Assessments: A Review of Assessment and Screening Tools

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Assessments: A review of Assessment and Screening Tools

Executive Summary

This report was commissioned by the British Columbia 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 in the process of exploring guardianship. The initial report was completed in April 2009 and it was then updated in March 2020 and again in September 2021.

The focus on assessing incapacity is a burgeoning area of research but still considered to be under-developed and under-conceptualized. Trends and common issues identified in this research include the following:

- A move toward understanding capacity as multi-dimensional and context-sensitive and which includes attention to culturally-laden values and beliefs;
- 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. This includes a growing body of work theorizing a relational foundation for understanding autonomy and capacity that has yet to be empirically grounded;
- A move toward a more functional approach for assessing; and
- The quest for a more transparent assessment process which includes a statement about the legal standards being utilized in order to help ground the assessor's opinions about capacity and improve comparability of findings between assessors.

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. 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.

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 (MacCAT – T) seems to be the gold standard. The second domain where there has also been a great deal of attention has been on developing financial decision-making tools - these have become increasingly sophisticated and better understood in the past ten years. In other domains, the research into standardized assessment tools is much less developed and attention to everyday decision-making and or decisions related to living independently are arguably, still in pioneering stage.

Decision-making tools provide useful information regarding *how* decisions are being made, usually drawing on standards of understanding, appreciation, reasoning and demonstration of choice. The

drawback here in relation to their practical use-ability as guides for forming an opinion on decision-making capacity, is that these tools may not be consistent with specific jurisdictional legal tests. This is rarely acknowledged or addressed in existing research-based literature and in fact, the use of these tools in day-to-day clinical practice is not well developed.

More commonly incorporated into the practice of assessing incapacity, is the use of standardized measures that have been developed for something other than assessing decision-making capacity – for example, evaluating functional, communication, or cognitive performance. These tools have the advantage that they are better understood by clinicians. Some of these tools can be used by a diverse range of clinicians, others require more extensive professional training and expertise to utilize appropriately. This review addresses two areas of screening tools: functional and cognitive - a third focused on communication tools is not addressed.

Key findings associated with the research around screening tests for cognitive functioning as related to assessments of incapacity include the following:

- Tools are often inappropriately interpreted, with inadequate evidence linking them to actual decisions about capacity.
- The Mini-Mental Status Examination (MMSE) has the most research supporting its use,
- There are however drawbacks to the use of the MMSE – in particular there are questions regarding the relationship between mid-range scores and 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. Finally, copyright issues are leading researchers and practitioners to consider other less costly options.
- Tests which assess executive functioning tend to be more relevant to understanding decision-making capacity.
- The Clock drawing tests (aka CLOX) may provide more insight into capacity issues than the MMSE as they are more sensitive to executive functioning. However, comparisons are limited because there are so many different ways of administering and scoring.
- Particularly within the BC context, the Montreal Cognitive Assessment (MoCA) is emerging as a tool of choice. It has many advantages over the MMSE, including better measurements of executive functioning, and increased sensitivity to mild cognitive impairment. However, although the link to decision-making seems intuitive, there is limited research correlating scoring to decision-making capacity.

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

- Increasingly, the importance of looking beyond cognitive aspects of decisional capacity to include performance – i.e. ability and history of carrying out decisions under question – is being recognized and built into tests of incapacity. (This is consistent with the guidelines for assessing financial capacity in BC under the *Adult Guardianship Act* Part 2.1 AGA 2.1).
- 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 instruments, those that integrate performance based assessments – as opposed to proxy measures and/or self report for example – 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 these standardized tools to (in) capacity.

Recommendations

- Standardized tools must be carefully scrutinized to insure that they are consistent with BC tests of incapacity under Adult Guardianship Legislation. Otherwise, they may provide important and useful information but interpretation of the results to make a determination about an adult's capacity must be done with extreme caution.
- There is a role for standardized instruments in the assessment of incapacity but in light of the state of uncertainty surrounding the value of most of these tools in relation to capacity, it will be important that these are not somehow given higher weighting than less standardized approaches - such as the 'gold standard' narrative clinical interview - to the assessment.
- A potentially more appropriate and effective way of insuring consistency across assessments will be to focus on insuring a common foundation for training and understanding.
- While the importance of understanding a person's values is identified as critical in an assessment, with few exceptions, most tools do not address this component except as an underlying part of the reasoning process. BC's *Adult Guardianship Act* Part 3 or Part 2.1 guidelines do not incorporate the reasoning standard which leaves questions as to how personal values can be integrated into the assessment of incapacity. This is an important area to be addressed.

Incapacity Assessments: A Review of Assessment and Screening Tools

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) capability provide one route for resolving this tension. Research suggests that the conduct of (in) capability assessments is a complex area of practice¹ where most professionals - including physicians (Skelton et al., 2010; Bjorksten et al., 2014) and psychiatrists (Seyfield et al., 2013) - often feel ill-prepared.

The purpose of this report is to provide some assistance to professionals who are responsible for conducting such assessments and making decisions about decision making capacity by examining the use of standardized tools that may be helpful for ensuring 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 decision-making 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 scoping review was conducted to identify what tools are being used to assess incapability. The first review included all publications until March 2009. 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. A second scoping review, conducted between November 2018 and March 2019 focused on identifying changes and developments in the ten years that had elapsed since the first report was written. This review was updated again in March 2020.

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 and/or supportive decision-making] and [instrument or tool or protocol or screen].¹ 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; long-term care planning, admission to a care facility and/or independent living decisions, and health care, and/or treatment]; specific tools; and special populations [culture*¹ 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:

¹ Use of an asterisk will draw search for any word which includes the root word. For example *capacity would also include incapacity and culture* should also include culture, cultural, cultures....

- a) What is the general state of knowledge regarding the assessment of incapability, particularly in terms of how these should be conducted?
- b) What tools have been developed directly to assess incapability? 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 decision-making capacity?

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

- Research related specifically to intellectual disability is not included in this review.
- After an initial first sweep of the literature, and in initial consultation with the Public Guardian and Trustee's(PGT's) office, I chose to focus attention primarily on two domains that are most pertinent to this project: financial decisions and personal care decisions (especially in relation to living independently). These correspond most closely to BC's Adult Guardianship Legislation - both current and anticipated. I address health care in less depth and do not address other domains such as driving, voting, or testamentary capacity.
- I did not conduct an in-depth 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) capability, 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 decision-making capacity; and (2) other screening tools that are commonly used to inform the assessment process.

Part III examines selected tools that seem particularly important/relevant to the BC context 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) Capability 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. The issues addressed below are:

- Assessment to do what?
- Models for conceptualizing capacity
- Connection to legislation
- Establishing a gold standard for assessments
- Clarifying language –definitions
- Standards for determining capability
- What constitutes a good capability assessment?
- Specialized populations

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”². This has led to a focus on domain specific capacity – BC’s 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, advance care planning, and vulnerability to undue influences have, to date, been more neglected.³

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

Models for conceptualizing capacity

Second, there has more recently been a call to expand assessments of capacity to include a more functional approach. Four models for conceptualizing capacity have been identified:⁴

- 1) Cognitive model (philosophical/legal): This model assumes that decision-making capacity is mediated through several cognitive abilities which include being able to express a choice/decision; understand the information relevant to the decision including pertinent risks and benefits; appreciate the reasonably foreseeable consequences of a decision and recognize that information relates to one’s self; and ability to reason. Based on the work of Grisso and Applebaum (1998) who initially articulated the standards, this approach is arguably the dominant lens for understanding decision-making capacity and underpins the development of

most, if not all, of the assessment tools. This approach has the most empirical research and is linked most closely to the assessment of decisional capacity and legal standards. However, it has serious limitations, especially when dealing with complex decisions about everyday living and care.⁵

- 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 Mini-Mental Status Examination (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.⁶
- 3) Functional model: 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 the decision. There is considerably less research using this approach but it is undoubtedly particularly pertinent when considering questions such as safety, independent living and financial management.
- 4) Relational autonomy model: Drawing on feminist relational ethics, this lens recognizes that both decision-making and autonomy can only be understood within a relational context. This lens reframes autonomy from a focus on independence to recognition of the self as relational. A relational analysis then concentrates on how relationships and social environment impact personal agency and decision-making. Second it begins to position capacity as fluid and dynamic, providing insights into how relational context can be used to foster, or challenge, decision-making capacity. Finally, it draws attention to the importance of understanding power dynamics and social positioning in relation to decision-making. The assumption underpinning a relational approach is that functional mental incapacity is inextricably linked with contextual and situational factors and may in fact, underpin a number of sequential cognitive processes.⁷

Connection to legislation

Thirdly, the degree to which these approaches are consistent with particular pieces of legislation is important to consider. Arguably in BC, Part 3 of the *Adult Guardianship Act* (AGA) incorporates a more cognitive approach where the test of incapability 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 not accepting the proposed plan. It is anticipated that this lens will also inform assessments under the care facility admission provisions of the *Health Care (Consent) and Care Facility (Admission) Act* now proclaimed.

In contrast, the *Mental Health Act* uses more of a medical model where the person must have a mental health diagnosis and be at 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 recently implemented *Adult Guardianship Act* Part 2.1 (AGA 2.1) standards for assessing incapacity where for example, the test of financial capacity 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.

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’ for assessments

The fourth issue is linked to the state of knowledge around best practice standards for conducting an assessment. Although there is growing interest in developing standardized instruments, the general consensus seems to be that the clinical interview remains the gold standard.⁸ 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.⁹ The very limited number of research studies conducted related to the assessment of incapacity for adult guardianship points to “suboptimal evaluations”¹⁰, unreliable use of clinical interviews¹¹, and a general agreement that more research is needed to establish the reliability and validity of tools.¹² 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 assessment practices.¹³

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 about the assessment results to the patient and the family in a way that they could better understand and accept¹⁴. 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 fifth issue is that discussions about incapacity cross several disciplinary thresholds and fields including the legal, clinical and ethical. One result of this has been that there is some 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 Capability?

One place where there is often confusion is around the use of the terms ‘capacity and ‘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 a 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).¹⁵ 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. The American Bar Association/American Psychological Association (ABA/APA) (2008) guidelines suggest “one approach to avoid confusion is to simply adapt the phrase “legal capacity” and “clinical capacity””.

Royall,¹⁶ 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.

Complicating this picture further is the often-interchangeable way that capacity and capability seem to be utilized. This seems to be largely linked to legislation. For example, in BC, the language of capability is used and reflecting the notion that people are presumed to be capable until the contrary is demonstrated, discussions may focus around capability, but the assessment is explicitly recognized as an assessment of *incapability*. 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 capability (or capacity) and not incapability or incapacity.

One step removed from the broader discussion of competence and capability/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 abilitiesⁱⁱ associated with decisional capacity: understanding basic facts surrounding a decision; appreciating the personal impact 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).

ⁱⁱ See following section for a more comprehensive discussion of this

b) Executive capacity: Increasingly it is being recognized that capacity is not just based on cognitive functioning. 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. BC’s Adult Guardianship Legislation reflects this trend as does the Yukon legislation. Naik et al.¹⁷ have operationalized this concept into three components: (1) ability of the person to develop a pre-determined plan; (2) ability to adapt this plan to changing or unexpected circumstances; and (3) 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 United Kingdom 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.¹⁸ *UK Mental Capacity Act* (MCA) 2005 and other legislation grounded in this approach - for example, Singapore’s *Mental Capacity Act* - focuses on mental capacity rather than mental health with the latter being 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.¹⁹ 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 capability or competence.

Standards for determining capability

A sixth issue centers on the use of standards. Within the literature, there are four standardsⁱⁱⁱ 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 presented²⁰. This set of standards initially came out of earlier work by Roth et al.,²¹ where there were initially seven criteria and is the result of a review of emergent case law literature in USA.²² This is important – it means that these standards were developed in relation to American legislation, not British Columbian. 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 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: this for example, is arguably the stance that BC’s *Adult Guardianship Act* (AGA) Part 3 takes where if the adult is not accepting the Support and Assistance Plan there is an assumption

ⁱⁱⁱ 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 incapacity try to address, and as abilities that are seen as important components of capacity.

that they are turning it down - and hence the test of incapability 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. Importantly, United Kingdom's *Mental Capacity Act* (MCA) includes a reasoning component that is not included in BC AGA Part 3 legislation - this is particularly important to keep in mind because a substantial amount of the literature focused on understanding capacity and decision-making comes out of UK or other countries who similarly assume a standard of reasoning.

Although there seems to be some agreement that these standards are relevant for understanding and determining capacity, beyond their questionable 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 treatment²³ 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.²⁴
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. The standard of appreciation appears to be particularly prone to misunderstanding.
3. There is some discussion 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). This however is controversial.
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 evidence of a choice. 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 adult guardianship legislation. Moreover, 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 seventh 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.²⁵ In particular, the importance of emotional and socio-cultural contextual variables for influencing decision-making has been identified as a critical component of an incapacity 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.²⁶ Modern emotion theory views emotions as containing basic values and goals which are important to making competent decisions.²⁷ Since values are culturally bounded and prescribed^{iv} 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.²⁸ 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.²⁹ Personal, social and environment-related factors are seen as making potentially important but, as yet, undetermined contributions³⁰ and further consideration of social and environmental factors that frame decision-making abilities is called for.³¹ 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 framework has now been integrated into the guidelines offered as best practice by the American Psychological Association³² This is an important step forward but the template has not been tested or validated as a prescribed protocol yet.

A further issue related to what constitutes a good assessment 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 approach³³ 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 among team members.

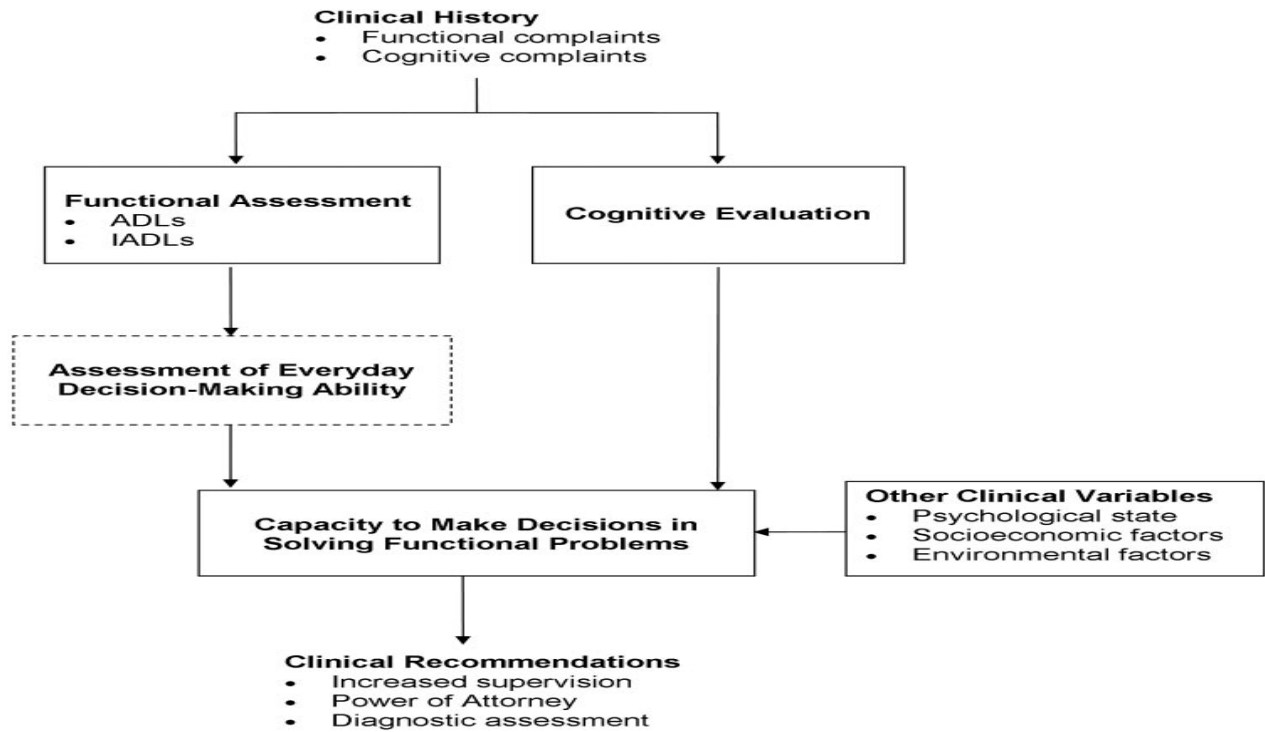
^{iv} Note, culture is being used broadly here to denote social positioning with broader communities including ethnic, familial, religious, gender, socio-economic location...

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.³⁴ 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 incapacity. Interesting, only one researcher³⁵ 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 capacity³⁶.

Lai and Karlawish³⁷ 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 (Instrumental Activities of Daily Living - IADL and Activities of Daily Living - 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 to clinical recommendations that might include delegation to a surrogate (or in BC, a substitute) decision-maker. Figure 1 depicts their process:

FIGURE 1: Model for Assessing the Capacity to Make Decisions^v

^v 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.



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 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.³⁸ 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.³⁹ 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 for 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 mental health conditions or diagnoses.

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, and Mild Cognitive Impairment or MCI. 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 mental health diagnoses 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.⁴⁰ 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.⁴¹ 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.⁴² This body of research however is sparse. Moreover, although the complexity related to assessing those with a brain injury, intellectual impairments, and addictions issue has been highlighted, these issues have been poorly addressed in terms of actual research. Moye et al (2013) suggest that most capacity instruments still lack fundamental normative data including studies of age differences and cultural biases, and that they have not been established using younger populations of people with developmental disabilities.

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.^{vi} 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.⁴³ 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.⁴⁴ 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 colleagues⁴⁵ attempt to address

^{vi} 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.

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, relational 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 incapacity assessment can be broken into two main categories: those developed specifically for assessing capacity in some area – referenced as decisional abilities or capacity assessment instruments (CAI) ⁴⁶ - 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 frequently referenced in the research as ‘capacity assessment instruments’ (CAI) 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 tools 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

| | Personal Care or Social Welfare/ Independent Living | Health Care | Financial/Property |
|--|--|--------------------------------------|--|
| Capacity Assessment Instruments | ACED, Dundrum Capacity Ladder | MacCAT-T, Dundrum Capacity Ladder | FCI, FAI, FDRS, Dundrum Capacity Ladder |
| Specific Screening Tools for Aspects of Assessment ^{vii} <ul style="list-style-type: none"> • Cognitive • Functional • Mental health | MMSE, MoCA, ILS, FBI, DRS | MMSE, MoCA, ILS, FBI | MMSE, MoCA, ILS, FBI |

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

Decisional Abilities Instruments (aka Capacity Assessment Tools)

In the last two decades, 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

^{vii} These tests INFORM the process by providing information that is relevant but do not actually EVALUATE or ASSESS capacity

treatments and/or research decisions. Since this is not the primary focus of this report, only a brief overview of the health-care decision-making tools will be provided, the bulk of this section will focus on everyday decision-making tools and tools focussed on financial decision-making.

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 facility⁴⁷), competence to give advance 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 in relation to health care have emerged⁴⁸ In one of the most comprehensive reviews, Kim, Karlawish and Caine⁴⁹ 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.⁵⁰ More recently, Lamont, Yeon & Chiarella (2013) identified nineteen different instruments for assessing capacity in relation to treatment issues and concluded that since only a few of these demonstrated both reliability and validity, there is need for further research to improve the validity of existing capacity assessment instruments.⁵¹

There are several trends emerging in this body of research. First, the developing tools have employed a number of approaches for assessing. These include:

- Structured interviews (i.e. Assessment of Capacity to Consent to Treatment (ACCT); Competency Interview Schedule; Hopkins Competency Assessment Test);
- Hypothetical vignettes with structured interview [for example, Competency to Consent to Treatment Instrument (CCTI); Assessment of Consent Capacity for Treatment (ACT); Hopemount Capacity Assessment Interview (HCAI)];
- Semi-structured interviewing (MacArthur Competency Assessment Tool for Treatment (MacCAT-T); Ontario Competency Questionnaire; Capacity Assessment Tool (CAT); Capacity Assessment Interview (CAI)).

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, 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).⁵² 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.⁵³

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).⁵⁴ It is now being described as the emerging gold standard and has the most research supporting it.⁵⁵ 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, and/or providing the structure and scoring guide for tools being developed in other areas. (See Part III of this report for a more detailed discussion of this tool).

Independent-living decision-making

This is an exciting area that is still in its developmental infancy. This is at least partially because of the complexity associated with understanding and assessing capacity in this area: it is simpler to make an assessment of capacity for a one-time procedure in a controlled situation versus assessment of executive abilities to make a series of decisions in unpredictable situations that cannot be controlled.⁵⁶ Moye et al, 2013 suggest that within the area of independent living, key skills have been identified but have not been placed as explicitly within a capacity framework as they have in health or financial decision-making⁵⁷ Others⁵⁸ identify the importance of examining both functional skills and executive capacity, which is defined by Naik et al (2008) as the “ability to implement and adapt plans, especially when faced with both predictable and unexpected challenges” (p. 130) Hence to be useful, a tool focused on assessing capacity for safe and independent living needs to recognize that capacity for independent living lies at the confluence of function, cognition and judgement.⁵⁹

While increasingly refined diagnostic tools are being developed, 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 (i.e. medical care, nutrition, safety, shelter...) and/or direct others to meet those needs.⁶⁰ Lai and Karlawish (2007) 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”.⁶¹

There are a number of research groups working in this area. The work of Naik and colleagues at Houston VA Medical Center has contributed to the development of a tool in this area in three ways. Early work articulated 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 including basic repair and maintenance; instrumental activities for daily living such as shopping, laundry and cooking; medical self-care such as medication monitoring; and basic financial management. 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.⁶²

A second focus by this group has been on developing the Capacity Assessment and Intervention (CAI) Model (Skelton et al., 2009). This model, based on the conceptual framework identified above, is intended to guide health and social care providers through a comprehensive capacity assessment. It includes a comprehensive geriatric assessment that integrates a variety of structured tools (for example, MMSE and CLOX, geriatric depression rating scale (GDS), the Kohlman evaluation of living skills (KELS) and a standardized assessments of ADL and IADL). This is then followed by a physician-conducted capacity interview exploring two aspects of capacity - decisional (capacity to make an informed decision) and executive (the capacity to implement one's decision) - in each of the five functional domains identified above. This interview is highly individualized and interactive, and hence, provides guidance but is not a structured assessment tool that has been validated.

A third contribution by this group is the development of a brief screening tool entitled, "Making and executing decisions for Safe and independent living" (MED-SAIL)⁶³ This is not a test of capacity per se, rather it is designed as a quick screen that allows community-based professionals to quickly determine whether an older adult has sufficient capacity to safely remain in their current environment or if a comprehensive capacity assessment is warranted. Seven scenarios related to safe independent living were developed through a series of focus groups with community-based health and social care professionals. They form the foundation for MED-SAIL and consist of the following:

1. The door to your home is locked and you do not have a key.
2. You run out of a medication that you take regularly.
3. You are at home and suddenly there is a fire in your kitchen.
4. You notice that the cut on your foot is not healing and has become infected.
5. Someone calls you saying you've won \$100,000 and all they need from you is your social security number to verify your identity.
6. You are driving to the grocery store and you get a flat tire.
7. Your heating unit [air conditioner] breaks down and it is very cold [hot] outside.

The community-based professional selects two of the most relevant scenarios to the adult being assessed and explores them with the adult through a series of questions that include prompting and probing. Both the structure and the scoring are based on the well-established MacArthur Competence Assessment Tool - Treatment (MacCATt-T) and are designed to assess the standards of understanding, expressing a choice, reasoning (problem solving/consequential reasoning and comparative reasoning) and generating consequences. The tool does *not* assess appreciation - operationalized as the ability to apply to one's own situation.

The advantages of the tool include an available on-line training program, useful guidelines for determining each of the standards of understanding, expressing a choice, reasoning and generating consequences, and preliminary research establishing validation against other tools such as the (Independent Living Scale (ILS) (r=0.574) and IADL (r=0.4440)).⁶⁴ It remains in early stages of

development however, has only limited validation, and similar to many other decision-making assessment tools, the standards may be more or less compliant with relevant legislation: For example, the standards and cut-offs in this tool represent a higher threshold than most of the BC AGA tests of incapability which don't include reasoning and generating consequence. A second limitation of this tool is that at this point, appreciation - or the ability to link materials to one's self - has not yet been operationalized and this is a standard that is used in BC legislation (albeit operationalized using the language of understanding as in 'understands that this applies to him/her').

A second group of researchers (Karliwash et al) has focused on developing the Assessment of Capacity for Everyday Decision-making (ACED). This is one of the first tools 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 living⁶⁵ - a focus that is directly relevant to BC AGA Part 3 Support and Assistance for Abused and Neglected Adults incapability assessment guidelines. This tool is geared toward older adults living in the community with cognitive impairment and focuses on three main domains: preparing meals, managing medications, and managing finances. 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 asked a prescribed series of questions. Questions pertain to the following standards: understanding (of the problem, the options for solving the problem, and the benefits and harms of the options); appreciating the benefits and harms of the options; expressing a choice; and comparative and consequential reasoning about the choice and its logical consistency⁶⁶. Responses are scored using a three point scale (0=inadequate, 1=marginal, 2=adequate). Performance is measured by summing the questions scores, with higher scores indicating better performance. (See Part III of this report for a more detailed description of this tool or contact Jason.karlawish@uphs.upenn.edu.)

This tool is one of the most relevant to BC's AGA Part 3 for assessing incapacity to not accept a support and assistance plan prepared to mitigate abuse, neglect and/or self-neglect, but little further development or validation of it seems to have occurred since 2009. Moreover, it employs the standard of reasoning, which is not included in BC's AGA.

Although literature around ACED itself is limited since it was proposed in 2009, ACED does provide the foundation for a new tool, Interview for Decisional Abilities (IDA) (Abrams et al., 2019). This tool is a semi-structured interview for gathering information on decisional abilities of Adult Protection Service (APS) clients experiencing abuse or neglect. According to the developers, it provides a standardized framework for protection workers to engage in a meaningful discussion with clients about risk and it is used as a component of a comprehensive APS assessment. The assessor begins by selecting from a list the risk that involves the most imminent danger to the client and then seeks to understand the clients understanding of the risk. Understanding is demonstrated if the client acknowledges the risk or problem exists or is assumed to exist by others and includes probes to determine the client's understanding of what could happen (consequences) as a result of the risk. Next, the client's insight (appreciation of the risk) as it applies to him or herself is established by asking the client to elaborate on the story of his involvement with the problem or risk. Step 3 assesses reasoning, which is operationalized as the client's ability to weigh the advantages and disadvantages of a plan to address the risk – the intent is to understand the client's

thinking, not the plan itself. The client's responses are scored as a yes/no/maybe for each of the three steps.

The tool is currently in early stages of development and reliability and validity have not been well established.

A strength of the tool is that it provides a structured template for exploring decision-making that can be individualized to the client and conducted within the context of a more relationally-oriented interview. Importantly, it documents the rationale for accepting or refusing services and could be adapted/utilized for an AGA Part 3 assessment of incapability. However, the tool is focused on assessing *ability to manage risk* which is not the focus of AGA Part 3 and it uses a standard of reasoning that is not consistent with BC AGA Part 3 legislation.

ACED (and indirectly IDA) appears to build upon work done by Anderer⁶⁷ who developed the Decision-making Instrument for Guardianship (DIG) as part of her unpublished 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. It is considered quite comprehensive (8 hypothetical problems related to domains such as hygiene, money management...) but the reliance upon hypothetical scenarios has two short-comings: 1) the 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 the 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.⁶⁸ This tool is routinely referenced but does not appear to be generally used.

The third group working on a tool in the area of independent living decision-making is a group of Irish researchers (Moynihan, O'Reilly, O'Connor, & Kennedy) who are developing a tool that they call the Dundrum Capacity Ladder⁶⁹. This tool claims to test functional capacity in relation to three domains: finances, decisions about health care, and welfare decisions related to independent living. The tool appears to be in infancy stage and has only been validated in relation to males with schizophrenia or schizoaffective disorder who are inpatients in a forensic unit. It is a vignette-based tool that the researchers claim provides a useful platform for structured decision-making that is easily adapted to the individual's context. It assesses understanding, appreciation, reasoning, and ability to communicate a choice. It is a very recent addition to the compilation of tools (2018) and has not been correlated to any other decision-making tools (for example, the MacCAT-T, or FCI) but one study has demonstrated some correlation to the Global Assessment of Functioning (GAF) and the MATRICS Consensus Cognitive Battery for cognitive deficiencies in schizophrenia.

There are two very apparent shortcomings with the Dundrum Capacity Ladder as an emerging tool. First, as noted above, the tool has only been applied to a very select group of subjects and it is unclear whether there is any applicability to other population groups. Second, the standards it is assessing are not consistent with BC legislation, which includes a focus on understanding and application to self but does not include ability to reason.

Pulling together the developmental work being done in the area of assessing capacity related to independent living then, three points emerge. First, much of this work is being carried out by three

main groups of researchers. Second, while all three groups have made important conceptual and instrumental contributions, the tools coming out of this research are still in very early stages of development and validation. Third, none are directly transferable to the BC context.

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 wrong⁷⁰. 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.’⁷¹ Declining financial abilities set individuals up for financial exploitation, 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.

There are a growing number of tools for assessing financial capacity, but recent systematic reviews have concluded that there is still no gold standard⁷² and a review of eight of the most commonly used instruments concluded that all eight instruments should be used with caution because all needed further empirical support for use as descriptive and/or evaluative instruments.⁷³ Hence, researchers continue to identify this area as under-developed conceptually and in need of systematic research.⁷⁴ Arguably however, it is a better-developed area than that focused on everyday decision-making or independent living, with particular growth in the past five years both conceptually,⁷⁵ and in relation to tool development and evaluation.⁷⁶

Tools for assessing financial capacity have emerged in two ways: as a component of a more general functional assessment instrument, and, as a stand-alone instrument for assessing financial capacity only. Lawton’s (1969) well-known tool for assessing Instrumental Activities of Daily Living (IADL) is the first tool to contain a set of questions related to ability to manage finances, but in the past 20 years it has become more common practice for functional tools evaluating independent living skills to include a set of questions addressing the financial domain. Generally, however, those instruments that are focused exclusively on financial capacity are preferred: A recent review⁷⁷ concludes that most screening tools that have a broader focus than just the financial domain do not have enough questions in the financial domain to fully assess financial capacity. With this in mind, this section will focus primarily on instruments that have been developed specifically to assess financial decision-making capacity.

The work of Daniel Marson and colleagues at the University of Alabama (Birmingham), has dominated the field of financial capacity assessments for over twenty years. This work has focused on both conceptualizing financial decision-making capacity and on tool development. Seminal work by them has 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).⁷⁸

Using this conceptualization, this group has led the development of a number of tools; the Financial Capacity Instrument (FCI) is perhaps the most widely used and recognized. 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.⁷⁹ At this point, it is the instrument with the strongest research support⁸⁰.

This structured questionnaire divides 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 (i.e. name coins) or complex (i.e. understand an investment option and make a choice). Except for the 8th 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.⁸¹ The test shows some ability to discriminate between people with dementia and a control group.⁸²

The administration time for the test is estimated at between 45 – 60 minutes. No research has been found which identifies the level of training required to administer the test but since it is publicly available there are no proprietary rights related to its use. A critique of this tool is that the decision-making scenarios are not particular to the adult being assessed.

See Part III of this report for a more comprehensive discussion of this tool.

While the work by Marson and the University of Alabama Birmingham team is perhaps best known, there are a number of other financial capacity assessment instruments that have been developed and have some research supporting their use. Table 2 identifies these and briefly highlights their respective strengths and limitations.

Of these tools, perhaps one of the most promising is a recent set of tools coming out of work by Lichtenberg and colleagues. This set of tools is unique in that they explicitly adopt a person-centered, contextual approach to addressing financial awareness, decision-making capacity, and vulnerability, including susceptibility to exploitation. The tools seek to integrate the four core abilities of the decision-making model (understanding, appreciation, reasoning and expressing a choice - considered intellectual factors in this model) with simultaneous consideration of various risks of financial exploitation (described as "contextual factors") and the individual's life-long financial values ("values"). According to its authors, the model seeks to evaluate integrity of financial decisional ability through a person-centered approach that considers, in the setting of a specific financial decision or transaction: (1) an individual's vulnerability to exploitation and undue influence (contextual factors), (2) his/her core decisional abilities (intellectual factors), and (3) his/her adherence to personal financial values. It has the advantage over many other tools in that it

uses a real single financial decision that the individual is considering rather than a hypothetical scenario⁸³.

This conceptual framework has been the foundation for three related tools: (a) the Lichtenberg Financial Decision-making Rating Scale (LFDRS); (b) the Lichtenberg Financial Decision-making Rating Scale - short version (LFDRS-SF); and (c) the Lichtenberg Financial Decision-making Screening Scale (LFDSS).

a) The Lichtenberg Financial Decision-making Rating Scale (LFDRS)

This scale was first published in 2015 and is the most comprehensive and time-consuming of the three tools. It is a 68 item rating scale (initially it had 77 items) that claims to help the clinician understand the personal context of the person making the decision. It consists of four subscales: Financial Situational Awareness, Psychological Vulnerability, Susceptibility to Undue Influence, and Intellectual Factors (i.e., decisional-ability factors). While the most exhaustive and insightful of their tools, the researchers acknowledge that it is time-consuming to administer and requires a high level of training, skills in advanced interviewing, rating techniques, and the ability to integrate the findings from the subscales into a clinical judgment. They recognize therefore, that this tool is likely only suitable for highly trained professionals.

b) The Lichtenberg Financial Decision-Making Rating Scale – Short Form - LFDRS-SF

Recognizing this restriction might limit its use, this team has developed an abbreviated version - or short form- of the LFDRS. The LFDRS-SF contains 34 items. While it does not provide as much context as the full version, preliminary results indicate that it is a valid and reliable tool for assessing financial capacity with findings that scores 19 or greater having excellent classification rates (91%), acceptable sensitivity (69%) and excellent negative predictive power (97%) but only 46% positive predictive power, while a cut-off score of 24 or greater yields high positive and negative predictive power and specificity but low sensitivity.⁸⁴ Based on these findings, the authors conclude that the LFDRS-SF is likely to be favoured over the full LFDRS, and because of this, they are using this shorter version as the available on-line scale. It can be accessed at, <https://olderadultnestegg.com> and includes access to a narrated training module for its use.

c) The Lichtenberg Financial Decision-Making Screening Scale - LFDSS

The third tool developed by this team of researchers is the Lichtenberg Financial Decision-Making Screening Scale (LFDSS). This screening tool was developed to be easily administered in the community by case managers, adult protection workers and other health and social care professionals. It is composed of 10 items taken from the LFDRS - 7 from the intellectual subscale (focused on decision-making) and 3 from the susceptibility to undue influence subscale. Although very short, it retains a person-centred philosophical foundation by focussing on assessing the older adult's understanding of the actual financial decision in question, with the requirement that the older adult communicate four important elements of his or her decision: choice, understanding, appreciation, and reasoning. It has the advantage of brevity, requires less training, and early findings suggest good validity. However, it does not assess any contextual factors and so gives limited information about understanding the financial decision-making process. It is intended to be used only as a screening tool to identify the need for further assessment.

Table 2: An Overview of Financial Capacity Assessment Instruments (FCAI) and Domain-Specific Financial Screening Tools

| Instrument | Description of Tool | Strengths | Limitations |
|---|--|---|--|
| Financial Capacity Instrument (FCI) ⁸⁵ | <ul style="list-style-type: none"> • 2nd stage development (FCI-8) • Evaluates 8 domains (areas) with 19 tasks | <ul style="list-style-type: none"> • Direct, standardized and quantified assessment • Global overview score • Multi-dimensional • Includes functional component • Clinically relevant and useful • Conceptually well-grounded • Most empirically well grounded | <ul style="list-style-type: none"> • Time-consuming to administer • Relevance is best established with cognitively impaired, community-dwelling elders • Focuses on neutral or hypothetical stimuli |
| Measure of Awareness of Financial Skills (MAFS) ⁸⁶ | <ul style="list-style-type: none"> • 32- item scale • Participant self-rating • Informant parallel questions • Performance on six financial tasks • 15 minutes administration | <ul style="list-style-type: none"> • Can compare self reports, informant reports and objective performance • Research-based | <ul style="list-style-type: none"> • Minimal research to date |
| Direct Assessment Functional Status Scale (DAFS) ⁸⁷ | <ul style="list-style-type: none"> • 7 domains including time orientation, communication, transportation, finances, shopping, grooming and eating. • Financial subscale has 21 items that measure five functional abilities: identifying currency; counting currency; writing a cheque; balancing a cheque-book; and making change • Each domain has a cut-off score indicating impairment: <ul style="list-style-type: none"> - Identifying currency <7; - counting <3; - writing a cheque <4 pts; - counting change < 2 pts Summary subscale score is obtained by adding the | <ul style="list-style-type: none"> • Good research to support use • High inter-rater and test-retest reliabilities⁸⁸ • Well validated among those with dementia and schizophrenia | <ul style="list-style-type: none"> • Not considered ‘gold standard’ because it does not assess important components of financial capacity including financial judgment and knowledge of important financial concepts |

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| | sum of correct performance for each domain. (Score <19 = overall impaired score.) | | |
| Self-Reported Financial Skills Scale ⁸⁹ | <ul style="list-style-type: none"> • 6-item scale that corresponds to 5 DAFS subscales • Self-rank each as independent/not independent • 1 overview item – do you manage own finances independently | <ul style="list-style-type: none"> • Very brief administration (5 min.) | <ul style="list-style-type: none"> • Developmental phase: Not validated, no data on reliability • Concerns with self-report scales |
| Prior Financial Capacity Form (PFCF) and Current Financial Capacity Form (CFCF) | <ul style="list-style-type: none"> • Provides comparison between premorbid (PFCF) and current (CFCF) financial capacity • Global judgment and judgment about functioning in 8 domains and 20 associated tasks • 3 level scoring: capable, marginally capable, incapable | <ul style="list-style-type: none"> • Functioning is appraised over time in everyday life settings • 10 – 15 min. administration • First tool to address relevance of premorbid functioning to current abilities | <ul style="list-style-type: none"> • Risk of bias and errors because information is obtained via collateral sources • In developmental stage but looks promising: High level of stability over 1 month period established⁹⁰ |
| Clinical Assessment Interview for Financial Capacity (CAIFC) ⁹¹ | <ul style="list-style-type: none"> • Interview format and specific test items • Examines competency in each of eight domains of the Marson conceptual model • Shares same domain organization as FCI but is entirely distinct and independent | <ul style="list-style-type: none"> • Combines the flexibility of an interview dialogue with many of the aspects of standardized testing | <ul style="list-style-type: none"> • Potential for considerable variability in outcomes related to clinician assessments of competency |
| Hopemount Capacity Assessment Interview (HCAI) – Financial Scale ⁹² | <ul style="list-style-type: none"> • Semi-structured interview • Scenario-based stimuli as basis for questioning | <ul style="list-style-type: none"> • Good inter-rater reliability reported • Designed to assess medical and financial decision-making among nursing home residents | <ul style="list-style-type: none"> • Rarely cited in research on financial capacity (more focus on medical decision-making component) • As with other standardized instruments, patients can find the scenario confusing and inapplicable, making it clinically difficult to use • Not well validated to other Capacity Assessment tools.⁹³ • Does not address actual performance |
| Financial Competency Assessment Inventory (FCAI) | <ul style="list-style-type: none"> • Structured interview format and observation of performance • 38 items (questions and tasks) | <ul style="list-style-type: none"> • Correlates well with ILS Money Management Scale and HCAI financial decision-making | <ul style="list-style-type: none"> • Administration skill and time not identified • In developmental stage • Useful guide to determine strengths and/or weaknesses |

| | | | |
|---|---|---|--|
| | <ul style="list-style-type: none"> • Six tasks: everyday financial abilities; financial judgement; estate management; cognitive functioning related to financial task; debt management; support resources • Tool can be recoded to assess understanding, appreciation, reasoning, and expressing a choice. | <ul style="list-style-type: none"> • Tested on 4 populations: ABI,^{viii} dementia, schizophrenia, ID • Well-correlated to other financial capacity instruments • Multi-dimensional approach • One of few tools to include support resources • Reliability and validity not strong but still one of better FCI | but does not provide a cut-off score ⁹⁴ |
| Independent Living Scales (ILS)⁹⁵ Money Management subscale | <ul style="list-style-type: none"> • One subscale of the ILS | <ul style="list-style-type: none"> • Provides feedback around money management • Reliability and validity of ILS is well-established • Next to FCI, strongest research base⁹⁶ | <ul style="list-style-type: none"> • Financial capacity is not developed as a multi-dimensional concept |
| <p>Lichtenberg Financial Decision Making Rating Scale (LFDRS)⁹⁷</p> <p>and</p> <p>Lichtenberg Financial Decision Making Rating Scale - Short Form (LFDRS-SF)</p> | <ul style="list-style-type: none"> • Seeks to evaluate “integrity of financial decisional ability” through a person-centered approach that considers, in the setting of a specific financial decision or transaction: (1) an individual’s vulnerability to exploitation and undue influence (contextual factors), (2) his/her core decisional abilities (intellectual factors), and (3) his/her adherence to personal financial values. • Longer (68-item) version is being replaced with a shorter (34) item version, both with 4 sub-scales. • Also a brief 10- item screening scale | <ul style="list-style-type: none"> • Person-centered, considers contextual factors (including undue influence and financial exploitation) and values^{ix} • More useful for decision-specific than domain specific questions of capacity | <ul style="list-style-type: none"> • New and largely untested • Uses 4 core standards which include reasoning - inconsistent with BC best practice guidelines for assessing financial capacity • Longer version is time-consuming and requires extensive training |

^{viii} ILS: Independent Living Scale; HCAI; Hopemount Capacity Assessment Interview; ABI = acquired brain injury (including alcohol-related); ID= persons with intellectual disabilities

^{ix} None of these tools specifically focus on undue influence, although the newly developed Lichtenberg Financial Decision Rating Scale (Lichtenberg, Stoltman, Ficker, Iris, & Mast, 2015) does include questions about undue influence:

- Have you had any conflicts with anyone about the way you spend money or to whom you give money?
- has anyone asked you to change your will?
- Has anyone recently told you to stop getting financial advice from someone?

A review of the data in this chart highlights that research into financial decision-making assessment tools is a burgeoning area, which has really begun to reach a new level in the past ten years. There are a number of tools from which to select, albeit most do not have strong research supporting their use at the point of writing. A key theme across these tools has been a focus 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. Recent developments in the assessment of financial incapacity show two particularly important trends: they 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 required⁹⁸ - and some attention is being given to individualizing these tools in order to promote relevance and person-centeredness.

Tools developed specific to assessing decision-making 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. Health treatment tools appear to be the best developed domain with the MacCAT-T being generally recognized as a ‘gold standard’ in relation to health care decision-making. It draws on a cognitive model that assesses capacity in relation to understanding, appreciation, reasoning and choice. The structure and scoring of this tool underpins many of the developing tools related to both independent living and financial management - both of these domains are less well developed in comparison to health care decision-making. This raises two points to consider. First, how important is it for a tool in these two areas to include a performance-based approach? An argument can be made that it may make much more sense to apply a cognitive model to a health care decision than to a more complex situation where both cognitive functioning and performance are inter-related.

Second, the need to consider the relevance of each tool to the specific legal tests being used to determine incapacity is increasingly being recognized. 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. Those tools that include reasoning components - such as the MacCAT-T and those derived from it - are not congruent with some legislative standards in BC AGA tests of (in) capability and are questionably congruent with BC’s care facility admission provisions of the Health Care (Consent) and Care Facility (Admission) Act (HCCFAA Part 3).

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. In particular, their use with people with intellectual impairments and substance-abuse issues has been poorly researched.

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.

Conclusion:

To conclude this section on decision-making assessment tools - in other words, tools that have been developed explicitly for the purpose of assessing decisional capacity in a particular area - there is growing interest in the development of standardized tools for assessing capacity related to specific areas of decision-making. These show promise because they provide structured ways of examining information that can lead to similar conclusions by different assessors⁹⁹. However, research into different tools is by and large, still in an early developmental phase - especially in some areas such as those focused on everyday decision-making or independent living - and there is limited information about the reliability and validity of most of these tools.¹⁰⁰ Moreover, the extent that these tools are being used outside of a research environment is unclear so how useable and useful they are in practice has not been well established.

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

While there has been considerable research focused on developing capacity assessment instruments (CAI), 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. When considered in relation to the assessment of incapacity, these types of tools can roughly be categorized into two broad categories: neuro-cognitive screening tools (including diagnostic screens and neuropsychological testing); and functional living skills assessment instruments. A third set of specialized screening and performance tools - those for example examining speech and communication - are recognized as contributing useful information to the assessment of capacity but are not reviewed in this report, nor are more specialized disciplinary-specific tests.

Neuro-Cognitive Screening Tools

There is clear recognition that neuro-cognitive processes play an important role in decision-making capacity. Marson (2012) for example notes that neuro-psychological evidence has substantial value by providing the clinician with explanatory links between the neurocognitive disorder (or other diagnostic condition) and identified impairments and should be incorporated into such assessments whenever possible - she is quick to caution however that neuro-psychological test results by themselves do not represent capacity findings.¹⁰¹ It is unsurprising then, that the most common way of incorporating standardized instruments into the assessment of incapacity is through the use of formal tools that have been designed to screen for neurocognitive functioning. 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.¹⁰² Hence, Marson's caution!

In terms of understanding the overall use of these types of 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* indeed 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, which 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. So while there is expectation that neuropsychological testing may improve validity and reliability of the capacity evaluations by providing a standardized elucidation of cognitive processes there is still much research to be done in terms of how these processes are linked to capacity and how they are being evaluated.¹⁰³ On this note, ABA-APA (2008) Handbook notes that clinicians should be aware that an assessment that focuses only on cognitive abilities may be particularly poor at predicting functioning and capacity to live independently. Moreover, findings from tools should always be recognized as proxy in that they are *not* measuring capacity.

With these caveats in mind, there are important results emerging in this research. Perhaps the most consistent is the importance of executive functioning (EF) on capacity¹⁰⁴. EF describes the ability to “orchestrate relatively simple ideas, movements or actions into complex, goal-directed behavior”.¹⁰⁵ In other words, it captures the ability to plan, organize and problem-solve. Classic research by Faden and Beauchamp¹⁰⁶ provides 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.¹⁰⁷

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. This means that identifying and selecting standardized tools that focus on executive functioning may have more relevance for providing insight into the assessment of incapacity than tools which are heavier focused on for example, memory or orientation to person, place or time.

Other aspects such as vocabulary comprehension - understood as ‘semantic knowledge’ or the ability to pair concepts with words - and working memory (especially verbal working memory) are also positively correlated with decision-making capacity.¹⁰⁸ How these influence capacity however is still under examination. For example, working memory seems to be important to understanding but not necessarily to reasoning. Hence, it becomes a question when interpreting results of a cognitive screen how much weighting should be given to memory components? Does poor short-term memory always translate to incapacity? And what structured tools should be considered as relevant? This is an important area of specialized knowledge in neuropsychology - well beyond the scope of this review - and there are many specialized tools that professionals trained in this area can

access. Particularly in more complex situations, a more in-depth neuropsychological assessment may be warranted which requires specialized knowledge to understand, administer and interpret the various tools.

In addition to considering what aspects are most important to assess in relationship to capacity, there is also considerable discussion about what kind of tools should be drawn upon. In particular, there is an emerging debate regarding the role of neuroscience in capacity assessments. Although still in its infancy, neurocognitive data is already revealing strong associations between structural and functional changes in the brain and decision-making capacity and these tests can highlight visually which areas of the brain are impaired.¹⁰⁹ There is however considerable controversy over the reliance on these tools - for example functional neuroimaging - since it would move away from the notion of capacity as decision or domain specific to a focus on cognitive functioning per se.

According to the ABA-APA (2008) there is no ‘core assessment battery’ for capacity assessment. Rather a flexible battery based on sound psychometric measures is required but “because capacity is an emerging practice area, there are a limited number of such tools available”. (p. 37). They provide an excellent overview of potential instruments, including the domain that the instrument assesses and its relevance to capacity, in the appendix of their on-line handbook [ABA/APA Assessment of Capacity in Older Adults](#). These will not be exhaustively reviewed here, but a few that are particularly common to clinical practice will be highlighted.

Unquestionably the Mini-Mental Status Examination (MMSE)¹¹⁰ is the most widely used tool both in practice and in research, internationally and nationally. It was originally created as a screening tool to quickly screen for cognitive impairment, provide a quantitative estimate of the severity of cognitive impairment and as a tool for documenting cognitive change over time.¹¹¹ It was never intended to be used on its own as a diagnostic tool nor was it developed as an assessment of capacity. Research has however established that it is a useful tool in relation to understanding (in) capacity, particularly on test scores below 17 and over 26.¹¹² 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 or for those with focal neurological illness,¹¹³ where a much larger battery of refined neurocognitive testing is recommended¹¹⁴. It has been validated in other cultures - for example there is a Chinese version of the MMSE (CMMSE) - but its cultural relevancy nevertheless remains suspect. Importantly, copyright issues are emerging which are already beginning to impact its use. (See Part III of this report for a more detailed description of this tool and the research that has been done linking it to capacity).

There is some belief that the Montreal Cognitive Assessment (MoCA)¹¹⁵ may be a better tool than the MMSE when seeking a quick cognitive screening tool. Initially developed to screen for MCI, it has now been validated on a number of different populations and has a strong research foundation supporting its use. It is a 30-item composite tool, which takes approximately fifteen minutes to administer. It includes several singular established tests - for example, Trails, Cube, Clock, Naming, Memory, Digit Span, Letter A, Serial 7, Sentence Repetition, Verbal Fluency F, Abstraction and Orientation - many of which are recognized as good measures of executive functioning. It is considered more sensitive than the MMSE in detecting mild cognitive impairment (MCI) and better assesses executive functioning. However its use in relation to the assessment of capacity is newer and less researched and support for the sensitivity and predictability of cut-off points is not as clear as it is with the MMSE. This means that it is not clearly defined how scoring correlates with incapacity (although correlation studies have found lower MoCA scores compared to the MMSE -

for example, one piece of research equated a MOCA score of 17 to an MMSE score of 24)¹¹⁶. It is anticipated that MoCA has the potential to become a more useful and used tool in the capacity assessment.

Aside from these two cognitive screening tools, there is a host of other potential screens. As noted above, a comprehensive review of all of the cognitive screening tools utilized in relation to understanding decision-making capacity is beyond the scope of this paper. Table 3 however does attempt to summarize some of the screening tools that have received the most interest in relation to decisions about capacity.

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

| Instrument | Description | Strengths | Limitations |
|---|--|---|--|
| Mini-Mental Status Examination (MMSE)¹¹⁷ | <ul style="list-style-type: none"> • 30 items which assess: orientation; registration; attention and calculation; recall; language; visual construction • Score 0 – 30 (higher score = higher performance) • 10-15 min. administration | <ul style="list-style-type: none"> • Most commonly used tool so high comparative value • Strong research base establishing reliability • Internationally recognized • Fast, easy to use • Research supports link to capacity for scores less than 19 and over 26 | <ul style="list-style-type: none"> • Erroneously used as a tool for measuring of decisional capacity • Limited focus on executive functioning so not considered the ‘best’ tool • Mid-range scores (18 – 24) lack accuracy in predicting capacity¹¹⁸ • ‘Blunt’ instrument’ for ascertaining capacity¹¹⁹ • Education, age and culture bias • Copyright issues are emerging that may restrict its future use |
| Modified Mini Mental Status Exam (3MS)¹²⁰ | <ul style="list-style-type: none"> • Basic MMSE format but content modified and new items added • Assesses: orientation, attention/concentration, immediate & delayed recall, word fluency, similarities; copy a pentagon • 15 – 20 min. administration • Score: 0 – 100 (higher number = higher function) | <ul style="list-style-type: none"> • Recommended over MMSE because considered to have higher validity and reliability than MMSE¹²¹ | <ul style="list-style-type: none"> • Less frequently used in capacity research • Takes longer to administer and mark |
| Montreal Cognitive Assessment (MoCA) | <ul style="list-style-type: none"> • 30 point cognitive screening test esp. useful for detecting MCI and dementia • 12 items which measure a wide range of cognitive functions • 10 min. administration | <ul style="list-style-type: none"> • A 7- item MoCA-LD version has been developed specifically for those with learning disabilities¹²² • Shows promise with patients with schizophrenia¹²³ • Widely used in clinical settings¹²⁴ • Easy to administer, effective and well- | <ul style="list-style-type: none"> • Link to capacity (i.e. cut-off scores) not found in the research |

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| | | <p>tolerated by those completing it¹²⁵</p> <ul style="list-style-type: none"> • Strong correlation with MMSE • Comparative research to other tools¹²⁶ • Considered a useful tool for identifying Parkinson’s Disease patients at risk of impaired capacity¹²⁷ | |
| Trails A and B ¹²⁸ | <ul style="list-style-type: none"> • These can be part of a battery of neuropsychological tests | <ul style="list-style-type: none"> • Assesses executive functioning • Simple, useful tool • Link to capacity is well-supported especially in relation to financial ability¹²⁹ • Good test of executive functioning | <ul style="list-style-type: none"> • Not well described in the research |
| Word Fluency | | <ul style="list-style-type: none"> • Research has linked it to measurement of incapability | <ul style="list-style-type: none"> • Not well described in the research |
| Wisconsin Card Sorting Test | | <ul style="list-style-type: none"> • Considered a ‘gold standard’ for assessing executive functioning | <ul style="list-style-type: none"> • Time-consuming to administer • Complex instructions • Requires more training |
| Clock Drawing Task (CDT) ¹³⁰ (CLOX) | <ul style="list-style-type: none"> • Described in literature as both CDT and CLOX • CLOX: Clox1 –clock drawing task (executive function); Clox2 – clock copying task (constructional praxis) • 10 min. administration • Assesses: comprehension (auditory), planning, visual memory and reconstruction in a graphic image, visuo-spatial abilities, motor programming and execution, numerical knowledge, abstract thinking, concentration and frustration tolerance¹³¹ | <ul style="list-style-type: none"> • Measures executive functioning aspects linked to capacity • Easy to administer • Good inter-rater and test/re-test reliability • Good sensitivity • Good concurrent validity • Culturally more friendly, validated in Asian populations | <ul style="list-style-type: none"> • Diverse methods for scoring • Recommended that it be used in conjunction with other screening tools • Diverse ways of administering • Difficulty comparing findings because of diverse scoring and ways of administering |
| Executive Interview (EXIT25) ¹³² | <ul style="list-style-type: none"> • 25-item multi-task assessment of executive function - a shorter version is available • Categories: perseveration, imitation behaviour, intrusions, frontal impulse control, spontaneity, disinhibition, utilization behaviour | <ul style="list-style-type: none"> • Solid body of research supporting link to measurement of capacity¹³³ • Assesses executive functioning • Bedside assessment | <ul style="list-style-type: none"> • Not commonly used in practice or research? • Requires further standardization of scoring and administration¹³⁶ |

| | | | |
|---|--|---|---|
| | <ul style="list-style-type: none"> • Score 0 – 50 (lower score = better performance) • 10 - 15 min. administration • a score of 15 or 16 discriminates normal older participants from those with dementia (higher score = greater impairment) | <ul style="list-style-type: none"> • Studies link scores to decision-making capacity ¹³⁴suggest scores can predict level of care, behaviour and IADL needs. • More responsive to change than MMSE • in contrast to MMSE, EXIT 25 (and CLOX1) may usefully predict non-recidivistic cases with Adult Protection Services in cases referred for a capacity assessment¹³⁵ | |
| Frontal Behavioral Inventory (FBI) ¹³⁷ | <ul style="list-style-type: none"> • 24-item inventory used to screen for frontal lobe dementia (FLD) | <ul style="list-style-type: none"> • FLD is associated with disturbances to executive functioning, so tool helps identify cases where this may be an issue | <ul style="list-style-type: none"> • Not a test of capacity; no research found linking it to assessments of capacity • Relies upon proxy report |
| Frontal Assessment Battery (FAB) ¹³⁸ | <ul style="list-style-type: none"> • 6 items to explore different aspects of frontal lobe functions • 6 items - similarities (conceptualization); lexical fluency (mental flexibility), motor series (programming), conflicting instructions (sensitivity to interference), go-no go (inhibitory control) and comprehension behaviour (environmental autonomy) | <ul style="list-style-type: none"> • No reference to the particular strengths of this tool could be found | <ul style="list-style-type: none"> • Not well researched in relationship to decision-making capacity |
| Mathias Dementia Rating Scale 2 (DRS-2) ¹³⁹ | <ul style="list-style-type: none"> • A commonly used global assessment tool for identifying cognitive impairment | <ul style="list-style-type: none"> • Commonly used • Easily administered | <ul style="list-style-type: none"> • Sensitive to executive impairments in Parkinson’s Disease (PD)¹⁴⁰ • No direct correlations to capacity found in the research |
| Everyday Cognitive Assessment (ECog) ¹⁴¹ | <ul style="list-style-type: none"> • Informant-based measure that assesses a participant’s ability to perform everyday tasks in the following areas: memory, language, visuospatial abilities, executive functioning/planning; executive function/organization; and executive function/divided attention. | <ul style="list-style-type: none"> • Strengths of this test are unclear | <ul style="list-style-type: none"> • Designed for people with MCI • Generally informant-based measures are less useful than performance-based • No link to capacity found in the literature review |

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| <p>St. Louis University Mental Status Examination (SLUMS)</p> | <ul style="list-style-type: none"> • 11-item screening questionnaire designed to test orientation, memory, attention, and executive function | <ul style="list-style-type: none"> • SLUMS is more sensitive than the MMSE in identifying a diagnosis of mild neurocognitive disorder | <ul style="list-style-type: none"> • Research linking SLUMS to a performance-based functional test (MED-SAIL) found no significant relationship between the two |
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Functional Living Skills Screening Tools

While cognitive screening tools provide helpful information, a particular area of interest is on establishing the “ecological validity of neuropsychological testing¹⁴² - that is, how well do these test scores actually reflect real world performance and capacity? 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.¹⁴³ It is the process of gathering information to develop insight into how the individual with a disability is currently functioning on a day-to-day basis within various environmental settings that they encounter.¹⁴⁴ The focus is on identifying: the overall level of adaptive functioning (i.e. Activities of Daily Living (ADL) and/or Instrumental Activities of Daily Living (IADL); the strengths and limitations in specific adaptive behaviours; the level and type of environmental demands where decisions must be made, and resources to assist in abilities for decision-making.¹⁴⁵ Increasingly, the importance of functional ability in relationship to assessments of incapacity is being recognized although there is also some agreement that standardized tests in this area are typically under-utilized in assessments.¹⁴⁶

There are a number of tools that have been developed and used extensively for the purpose of assessing functioning 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 perspective¹⁴⁷ and a clinical perspective.¹⁴⁸

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 ability and actual performance; this is important since research has identified discrepancies between self-report measures (for example ability to cognitively appraise a situation) and performance-based objective measures (i.e. actual performance).¹⁴⁹ 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.¹⁵⁰ 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, and 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 diagnoses 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.¹⁵¹
- 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.¹⁵²

Thus, the need for a performance-based, standardized tool to assist in the assessment of capacity is seen as advantageous – but not a panacea! An important area that requires further research and development is the link between specific performance tools and executive functioning since it is the latter that appears the most relevant for understanding decision-making capacity especially in relation to independent living. One promising approach is to attend more closely to those errors in functioning - also known as micro slips or micro-errors¹⁵³ - as these are identified as lending insight into executive or memory functions.

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, and 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 neglect¹⁵⁴ 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 service¹⁵⁵.

There is a plethora of instruments and a complete overview of these is beyond the scope of this report and several reviews are published.¹⁵⁶ Alison, Letts and Liu (2008) provide a comprehensive overview of these in relation to occupational therapy. More recently, a scoping review by Belchior and colleagues (2015) examines nine performance-based tools and provides useful guidance in identifying performance-based tools that are sensitive to subtle changes. While no recommendations are ultimately forthcoming as to ‘gold standards’, what they do provide is direction on the elements, which should be taken into consideration when choosing a tool. These include: the importance of an in-home performance-based test,¹⁵⁷; application of an error analysis during task performance - meaning pay attention to the errors not just the scores¹⁵⁸; the consideration of all operations related to executive functions; use of an unstructured approach; testing of complex IADL; and administered in a real-world setting. Interestingly, they found no tools that addressed all of these in their scoping review.

Below, some of the most common tools cited in the research related to the assessment of functional ability are identified and, where possible, their respective strengths and limitations in relation to the insights they provide around the assessment of capacity. These specific tools were selected based on either: a) their use in the literature; or b) recommendations or request for information about their usefulness vis-à-vis the capacity assessment from health and social care providers working in this area. It is recognized that this review of tools assessing performance is limited to relatively superficial overviews; a thorough evaluation of the tools would be useful but is beyond the scope of this report.

Table 4: Functional Assessment Tools Most Commonly Identified in the Research¹⁵⁹

| Instrument | Description of Tool | Strengths | Limitations |
|---|---|---|--|
| Direct Assessment of Functional Abilities (DAFS)¹⁶⁰ | <ul style="list-style-type: none"> • 7 subscales, 21 items • Areas assessed: communication, grooming eating, time, shopping, financial and transportation • 25-40 min. administration | <ul style="list-style-type: none"> • Multi-dimensional • Strong use in research • Reliability/validity established with both dementia and older adults • Assesses IADLs and ADLs | <ul style="list-style-type: none"> • Meal preparation not included • Clinic-based administration – not very portable |
| Independent Living Scales (ILS)¹⁶¹ | <ul style="list-style-type: none"> • 7 subscales, 68 items • Areas assessed: communication, time, safety, financial skills, shopping, transportation, medication, chores • Require examinee to solve problems, reveal knowledge and/or perform tasks • Includes sensory motor tasks (i.e. vision, reading hearing, speech, signature, writing and walking) • 45 min administration | <ul style="list-style-type: none"> • Multi-dimensional related to IADL • Assesses safety • Clinic-based but easily portable • Reliability established • Validated on wide sample base including older adults, adults with intellectual impairments; dementia and chronic psychiatric population • One of the functional assessments most linked to capacity in research, especially financial subscales¹⁶² • Standard scores, considering independent older adults, are provided not only for total score (M = 100; SD = 15) but also for the five subscales and two factors (T scores: M = 50; SD = 10) • Most empirical support linking it to capacity of all functional screening tools and scores have been correlated with actual judicial determinations of competence¹⁶³ | <ul style="list-style-type: none"> • Does not assess ADL • Some documentation is difficult to access • Use of ILS scores for determination of capacity is controversial¹⁶⁴ |

| | | | |
|---|--|--|---|
| <p>Kohlman Evaluation of Living Skills (KELS)¹⁶⁵</p> | <ul style="list-style-type: none"> • 5 subscales, 17 areas • Areas assessed: self-care, safety and health, money management, transportation and telephone, work and leisure • 20-30 min administration • 3 components: self-report, observation, performance • Score 0 – 16 (higher score means higher need; <5 = independent) | <ul style="list-style-type: none"> • Multi-dimensional • Clinic or community administered • Validated in relation to situations of self-neglect¹⁶⁶ • Assesses IADL and ADL • Good prognostic validity as a measure of safe and independent living in community¹⁶⁷ • Designed as a tool to assist with discharge planning • More predictive of functioning than MMSE¹⁶⁸ | <ul style="list-style-type: none"> • Data to support reliability and validity only available in unpublished sources • Links to executive abilities and/or decision-making capacity not well researched |
| <p>Instrumental Activities of Daily Living (IADL)¹⁶⁹</p> | <ul style="list-style-type: none"> • Self-report or proxy • 8 items • Score 0 – 8 (higher score means more dependent) | <ul style="list-style-type: none"> • Most commonly used in research? In practice? • Assesses IADL with a corresponding basic activities of daily living (ADL) | <ul style="list-style-type: none"> • Descriptive only – link to capacity not established • Proxy or direct observation |
| <p>University of California Performance-Based Skills Assessment (UPSA; and UPSA - Brief)¹⁷⁰</p> | <ul style="list-style-type: none"> • Five domains (subscales): finances, communication, planning/organization; travel; and household chores; <ul style="list-style-type: none"> • Brief: 2 subscales (communication and financial) • 10 – 15 min administration • Performance-based • Score = 0 - 100, sub-scales = 20) | <ul style="list-style-type: none"> • Validated with persons with schizophrenia, Parkinson’s and Alzheimer’s • High correlation with other areas of functioning • Support as a predictor of a person’s ability to live independently • Scores are sensitive to change via interventions • Very brief to administer | <ul style="list-style-type: none"> • While UPSA has strong research, support and development, this ‘Brief’ version is a very recent addition to the literature • Financial component limited to count change, read a bill and write a cheque • Requires several hours of formal training |
| <p>Management of Everyday Technology (META)</p> | <ul style="list-style-type: none"> • Assesses the ability to manage technology in everyday life • 10 items • Performance-based | <ul style="list-style-type: none"> • Structured but considers complex and difficult tasks so gives insight into some operations of executive functions | <ul style="list-style-type: none"> • Not yet translated into English |
| <p>Instrumental Activities of Daily Living Profile (IADL Profile) (</p> | <ul style="list-style-type: none"> • Simultaneous planning of a full series of embedded tasks necessary to attain the ultimate goal of hosting a meal for unexpected guests • relatively non-structured | <ul style="list-style-type: none"> • May be particularly sensitive to subtle change in functioning • ecological performance-based in person’s home and community environment • explicitly taps into executive functions | <ul style="list-style-type: none"> • Reliability not well-established • Further studies needed to validate • Seems gendered • No research establishing link to capacity |
| <p>Structured Assessment of Independent Living Skills (SAILS)¹⁷¹</p> | <ul style="list-style-type: none"> • 10 domains, 50 items • 60 min. administration • Performance-based in four main groups each with specific functional domains: motor, cognitive, | <ul style="list-style-type: none"> • No research found identifying particular strengths of this tool | <ul style="list-style-type: none"> • Link to capacity is not established |

| | | | |
|---|--|---|--|
| | <p>instrumental activities, and social interaction</p> <ul style="list-style-type: none"> • Money related evaluated by five items (counts money, makes change, understands monthly utility bill, writes cheque and understands check book) | | |
| Test of Everyday Functional Abilities (TEFA) | <ul style="list-style-type: none"> • Originally named the Texas Functional Living Scale • Cognitive based • Evaluates 5 subscales: (dressing (putting on a coat), time (telling time), money (writing a cheque), communication (dialling a telephone) and memory (i.e. remembering to take medication)) • Administration 15 - 20 min | <ul style="list-style-type: none"> • No research found identifying particular strengths of this tool in relation to performance • Money scale component - only assesses three financial abilities (count money, make change and write a cheque and is “clearly insufficient” (p. 221) | <ul style="list-style-type: none"> • No research was found linking it to decision-making and/or executive capacity around living independently • Some, but limited, research supporting reliability and correlation with MMSE |
| Barthel Index of Activities of Daily Living ¹⁷² | <ul style="list-style-type: none"> • Evaluation of functional independence in 10 ADLs (feeding, grooming, bathing, dressing, bowel and bladder care, toilet use, and mobility [ambulation, transfers, and stair climbing]) using a variety of response option formats (dichotomous or ordered polytomous) with different scoring weights • Various versions include different numbers of items | <ul style="list-style-type: none"> • Widely used with strokes and brain injury | <ul style="list-style-type: none"> • There are different versions and some have poor discrimination and should be used with caution • Seems to be referenced as both the BI of ADL and the BI for Assessment of stroke survivors • No research was found linking to decision-making • No research found linking performance scores or components to executive functioning or cognition |

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 tool¹⁷³
- Vineland Adaptive Behavior Interview¹⁷⁴
- Observed Tasks of Daily Living¹⁷⁵
- Scales of Independent Behavior – Revised¹⁷⁶
- *Blessed¹⁷⁷
- *Everyday Problems Test (EPT)¹⁷⁸
- Activities of Daily Living Efficacy Scale¹⁷⁹

These were not widely cited in the literature, nor were they linked to decisions about capacity and hence are not examined in further depth. A new test, Harvard Automated Phone Task (APT)¹⁸⁰ was uncovered that may be particularly useful for people with MCI. However, research around this tool still seems to be in pilot stage and no research was found linking it to the assessment of capacity.

It is recognized that administering functional tests is the expertise of occupational therapists who often have better training and understanding in administering these tools. In complex situations where understanding of actual performance is unclear, it would be important to include someone with this expertise.

Summary and considerations related to using existing standardized tools to inform the assessment of incapacity

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 - for example where errors are occurring - that is highly relevant to the assessment which unfortunately, is not always considered or documented.¹⁸¹

In terms of examining standardized functional tools, no clear 'winner' emerges. Rather the importance of familiarity with the particular tool - including knowing what subject group the tool has been validated with - will help dictate selection. There are however some guidelines for evaluating preferred tools. These include: Is the tool performance-based, ideally using real world situations that are relevant to the adult being assessed? Does the tool address executive functioning in any way? What is the balance between sensitivity and administration time?

Similarly, in relationship to the use of cognitive screening tools there is no 'one' tool that can be used. However, tools that offer more insights linked to executive functioning, working memory, and possibly verbal comprehension appear to have more support underpinning any attempts to link results to tests of incapacity. This is an area where specialized knowledge related to neurocognitive testing may benefit the assessment, especially in complex situations.

Importantly, these tools are not actually assessments of capacity and for most - especially those examining functioning - the link to decisions about incapacity is not well established.

Part III: Overview of Selected Tools

In Part II, 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:

1. The instrument is identified in the academic literature as a ‘gold standard’ tool (for example, the MacCAT-T).
2. 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. Even if not used in their entirety, they provide interesting guidelines for structuring a comprehensive assessment. A new tool, the Lichtenberg Decision--Making Capacity Assessment Scale is particularly pertinent to BC given its person-centered foundation and the inclusion of susceptibility to financial exploitation.
3. 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 Instruments)

- The MacArthur Competence Assessment Tool for Treatment (MacCAT-T)
- Financial Capacity Instrument (FCI)
- Financial Competence Assessment Inventory (FCAI)
- Lichtenberg Decision-making Rating (and Screening) Scales (LFDRS)
- Assessment of Everyday Decision-making (ACED)

Cognitive Assessment Screening Instruments

- Mini-Mental Status Examination (MMSE)
- The Executive Clock Drawing Task (CLOX)
- Montreal Cognitive Assessment (MoCA)

Decision-Making Abilities Tools (Capability Assessment Instruments)

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/health care decision making.¹⁸² 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 of treatment options; 2) appreciation of the diagnosis and its treatment (requires insight into how these will affect the patient individually); 3) reasoning, which examines why and how a health care decision was made and the potential to compare consequences; and 4) ability to express a choice.¹⁸³

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.¹⁸⁴ 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’ tool¹⁸⁵ 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 establishing validity and reliability compared to all other tools assessing capacity to consent to treatment.

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 appreciation and reasoning subscales.¹⁸⁶
- 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”¹⁸⁷ 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”.¹⁸⁸
- One result of the above is that there may be some tendency that the reliance on a tool such as the MacCAT-T is more likely to result in a person being declared incompetent than through the use of clinician assessment using a clinical interview.¹⁸⁹

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 instrument’s 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 understanding 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 who will be declared incapable.

- 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 fell 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 as well as the capacity to perform several executive tasks related to financial transactions. Specifically, it assesses financial knowledge (declarative), the ability to perform financial activities (procedural), and judgment in performing relevant monetary transactions (judgemental).¹⁹⁰ It comes out of the work of Marson and colleagues at the University of Alabama Birmingham (UAB), and appears to be emerging as the instrument with the strongest research support¹⁹¹.

This structured questionnaire divides 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 (i.e. Name coins) or complex (i.e. understand an investment option and make a choice).

Table 1. Description of FCI Domains and Tasks.^x

| FCI Domain | Task Description | Core Knowledge |
|--|--|--|
| Domain 1: Basic Monetary Skills <ul style="list-style-type: none"> • Naming coins/currency • Valuing coins/currency • Counting coins/currency | 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"> • Define financial concepts • Apply financial concepts | 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"> • 1- item grocery transaction • 3- item grocery transaction • Vending machine transaction • 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"> • Understanding checkbook • Using checkbook | Identify and explain parts of a cheque and cheque register Enter into stimulated transaction – pay by cheque | Declarative Procedural |

^x 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"> • Understanding bank statement • Using bank statement | <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"> • Detect mail fraud risk • Investment decision • Detect telephone fraud risk | <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"> • Understanding bills • Identifying and prioritizing bills • Preparing bills for mailing | <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 8th domain – personal financial knowledge - 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.¹⁹² The test shows some ability to discriminate between people with dementia and a control group.¹⁹³

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.¹⁹⁴
- 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 disability 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.¹⁹⁵

- While it has the largest volume of measurement property evidence compared to other financial management tools, the amount and methodological quality of this evidence is still considered to be insufficient.¹⁹⁶

Financial Competence Assessment Inventory (FCAI)197

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, the 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, support resources (SR) 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 Hopemount Capacity Assessment Interview (HCAI) and Independent Living Scale (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 led 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.

Lichtenberg Financial Decision-Making Suite

This set of tools is unique in that they explicitly adopt a person-centered, contextual approach to addressing financial awareness, decision-making capacity, and vulnerability, including susceptibility to exploitation. The tools seek to integrate the four core abilities of the decision-making model (understanding, appreciation, reasoning and expressing a choice - considered intellectual factors in this model) with simultaneous consideration of various risks of financial exploitation (described as “contextual factors”) and the individual’s life-long financial values (“values”). According to its authors, the model seeks to evaluate the integrity of financial decisional ability through a person-centered approach that considers, in the setting of a specific financial decision or transaction: (1) an individual’s vulnerability to exploitation and undue influence (contextual factors), (2) his/her core decisional abilities (intellectual factors), and (3) his/her adherence to personal financial values. It has the advantage over many other tools in that it uses a real single financial decision that the individual is considering rather than a hypothetical scenario¹⁹⁸.

This conceptual framework has been the foundation for three related tools: the Lichtenberg Financial Decision-Making Rating Scale (LFDRS); the Lichtenberg Financial Decision-Making Rating Scale - short version (LFDRS-SF); and the Lichtenberg Financial Decision-Making Screening Scale (LFDSS).

The Lichtenberg Financial Decision-making Rating Scale (LFDRS) was first published in 2015 and is the most comprehensive and time-consuming of the three tools. It is a 68-item rating scale (initially it had 77 items) that claims to help the clinician understand the personal context of the person making the decision. It consists of four subscales: Financial Situational Awareness, Psychological Vulnerability, Susceptibility to Undue Influence, and Intellectual Factors (i.e., decisional-ability factors). While the most exhaustive and insightful of their tools, the researchers acknowledge that it is time-consuming to administer and requires a high level of training, skills in advanced interviewing and rating techniques, and the ability to integrate the findings from the subscales into a clinical judgment. They recognize therefore that this tool is likely only suitable for highly trained professionals.

An abbreviated version - or short form- of the LFDRS has also been developed. The LFDRS-SF contains 34 items. While it does not provide as much context as the full version, preliminary results indicate that it is a valid and reliable tool for assessing financial capacity with findings that scores 19 or greater have excellent classification rates (91%), acceptable sensitivity (69%) and excellent negative predictive power (97%) but only 46% positive predictive power, while a cut-off score of 24 or greater yields high positive and negative predictive power and specificity but low sensitivity.¹⁹⁹ Based on these findings, the authors conclude that the LFDRS-SF is likely to be favoured over the full LFDRS, and because of this, they are using this shorter version as the available on-line scale. It can be accessed at <https://olderadultnestegg.com> and includes access to a narrated training module for its use.

The third tool developed by this team of researchers is the Lichtenberg Financial Decision-Making Screening Scale (LFDSS). This screening tool was developed to be easily administered in the community by case managers, adult protection workers and other health and social care professionals. It is composed of 10 items taken from the LFDRS - 7 from the intellectual subscale (focused on decision-making) and 3 from the susceptibility to undue influence subscale.

Although very short, it retains a person-centred philosophical foundation by focussing on assessing the older adult's understanding of the actual financial decision in question, with the requirement that the older adult communicate four important elements of his or her decision: choice, understanding, appreciation, and reasoning. It has the advantage of brevity, requires less training, and early findings suggest good validity. However, it does not assess any contextual factors and so gives limited information in understanding the financial decision-making process. It is intended to be used only as a screening tool to identify the need for further assessment.

Assessment of Everyday Decision-making (ACED)

Description

The Assessment of Everyday Decision-making (ACED) ²⁰⁰ is the first tool available with data supporting its reliability and validity to address everyday decision-making ability related to ability to live independently. ^{201xi} 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 principles 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 for addressing the problem and potential benefits and downsides of each option, continuously asking the person to paraphrase in his/her own words the information being provided.
- The interviewer scores responses using a 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 is assessed in relation to: understanding, appreciation, reasoning, expressing a choice, 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

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 a patient is facing. As long as

^{xi} Note, the work being done by Naik et al. shares members with the work being done to develop ACED (Lai and Karlawish).

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.²⁰²
- 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 copy of the ACED instrument and scoring criteria are available upon request (jason.karlawish@uphs.upenn.edu). Additionally, 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 Adult Guardianship Act, 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 the 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, and reasoning) but does not assess the ability to carry out decisions.
- Test performance is very heavily based upon memory for the 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.
- There does not appear to be any recent research on this tool since 2009.

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/health care decision making.
- 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.

Cognitive Assessment Screening Instruments

Mini-Mental Status Examination (MMSE)

Description:

Although a number of screening tools exist, the Mini-Mental Status Examination (MMSE)²⁰³ is unquestionably the most widely used tool both in practice and in research. It was originally created to screen for cognitive impairment, to provide a quantitative estimate of the severity of cognitive impairment and for documenting cognitive change over time.²⁰⁴ 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 32 different research studies. They found that research varied 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 scale 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 ensuring 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.²⁰⁵
- Too often the MMSE is treated as though it is 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 Alzheimer’s Disease 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 incapacity 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 were relatively good at identifying competence, and scores 16-20 and below correctly predicted incompetence. 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 the 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 Direct Assessment Functional Status Scale (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 Financial Capacity Instrument (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 - Financial Capacity Assessment Instrument (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.
- Tariq et al (2006) concluded that the MMSE is not as sensitive in identifying and diagnosing MCI compared to the St. Louis University Mental Status Examination (SLUMS) which is an 11 item screening tool designed to test orientation, memory, attention, and executive functioning.
- Pachet, Astner & Brown, (2010) examined the relationship between cognitive deficits, as measured by the MMSE and decision-making capacity to determine whether the sensitivity and specificity of the MMSE varied based upon the patient population being assessed. Using a sample size of 152 patients and varying cutoff scores, the MMSE demonstrated extremely poor sensitivity. In contrast, the MMSE had excellent specificity when scores of 19 or less were obtained. In their sample, not one patient, regardless of diagnosis, was deemed to have capacity if their MMSE score was below 20. However, reliance on the MMSE for scores above 19 would too frequently lead to misclassification and incorrect assumptions about a patient's decision-making abilities. They concluded that although a score below 20 consistently yielded findings

of incapability in their sample, it remains their opinion that the MMSE should not be used as a stand-alone tool to make determinations related to capacity, especially when considering the complexities associated with capacity evaluations and the vital areas, such as executive functioning and individual values and beliefs, which are omitted by the MMSE.

- Giannouli et al., (2018) - attempted to develop a financial incapacity assessment tool in Greece. One of the measures they used included the MMSE which is apparently widely used in Greece - they found it to be a good predictor of financial incompetence with a cut-off score of 27.
- American Bar Association/American Psychological Association (ABA/APA) (2008) suggest that the MMSE provides a ballpark estimate of level of functioning but it is limited in its ability to predict capacity because of its lack of sensitivity to executive functioning.
- Saczynki et al., 2015 - examined comparisons of MoCA and MMSE scores and concluded that the two can be associated with lower MoCA scores equating to higher MMSE scores (i.e. an MMSE cut-off of 27/ 30 is associated with a score of 23/30 for MCI. This means the MoCA is likely more sensitive to very mild changes than the MMSE.
- Sessums et al, (2011): concluded in their review related to health care decision-making that r “although not designed to assess incapacity, Mini-Mental State Examination (MMSE) scores less than 20 increased the likelihood of incapacity (LR, 6.3; 95% CI, 3.7-11), scores of 20 to 24 had no effect (LR, 0.87; 95% CI, 0.53-1.2), and scores greater than 24 significantly lowered the likelihood of incapacity (LR, 0.14; 95% CI, 0.06-0.34) “.

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 and is a particularly poor indicator with scores above 20.

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. CLOX 1 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.
- The 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.²⁰⁶

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 setting 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 a global screening tool, there is some lack of sensitivity in cases where very mild²⁰⁷ dementia is reported but well correlated with other dementia scales including the MMSE, Blessed Dementia Scale, Global Deterioration Scale, and Cambridge Cognitive Examination.²⁰⁸

Montreal Cognitive Assessment (MoCA)

Montreal Cognitive Assessment (MoCA)²⁰⁹ may be a better tool than the MMSE when seeking a quick cognitive screening tool. Initially developed to screen for MCI, it has now been validated with a number of different populations and has strong research foundation supporting its use as a screening tool. It is a 30-item composite tool, which takes approximately fifteen minutes to administer. It includes several singular established tests - for example, Trails, Cube, Clock, Naming, Memory, Digit Span, Letter A, Serial 7, Sentence Repetition, Verbal Fluency F, Abstraction and Orientation - many of which are recognized as good measures of executive functioning. It is considered more sensitive than the MMSE in detecting mild cognitive impairment (MCI) and better assesses executive functioning.

Its use in relation to the assessment of capacity is newer and less researched and support for the sensitivity and predictability of cut-off points is not as clear as it is with the MMSE. Specifically, it is not clearly defined how scoring correlates with incapacity. However, there are some trends that correlation studies have found lower MoCA scores compared to MMSE – for example, one piece of research equated a MoCA score of 17 to an MMSE score of 24)²¹⁰.

The MoCA has been translated and validated in a number of different languages (i.e. Spanish, Portuguese, and Chinese) and applied to different populations (brain injury, kidney disease, different types of dementia, schizophrenia).

Some selected research on the use of MoCA

Brenkel et al., (2017) sought to identify an online cognitive screening tool for assessing mental capacity through the measurement of executive function. Methods: A mixed elderly sample of 45 individuals, aged 65 years and older, were screened with the Montreal Cognitive Assessment (MoCA) and the modified Cambridge Brain Sciences Battery. Results: Two computerized tests from the Cambridge Brain Sciences Battery were shown to provide information over and above that obtained with a standard cognitive screening tool, correctly sorting the majority of individuals with borderline MoCA scores. Conclusions: The brief computerized battery should be used in conjunction with standard tests such as the MoCA in order to differentiate cognitively intact from cognitively impaired older adults.

Yang et al, (2018) validated the MoCA with people with schizophrenia - study not linked explicitly to capacity.

Tiffin-Richards et al, (2014) - compared the MoCA to the MMSE with patients with chronic kidney disease undergoing hemodialysis. They found that the MoCA discriminated better than the MMSE on executive functioning elements. This study is not linked explicitly to capacity.

Moirand et al, (2018) compared pre-and post Electroconvulsive Therapy (ECT) scores and found that the MoCA detected a higher number of patients with cognitive deficits than the MMSE. After ECT, the MoCA and MMSE total scores were comparable, but the MoCA detected more impairments than did the MMSE for visuo-executive, memory and language sub scores. ECT significantly decreased the language capacities but improved the visuo-executive and abstraction performances measured by MoCA. In remitters, the MoCA total score and visuo-executive and

abstraction performances were significantly improved, while other cognitive functions remained unchanged. They concluded that the MoCA is a useful screening tool for monitoring cognitive functioning during an ECT course.

Saczynki et al., (2015) considered the link between scores on the MoCA and MMSE. They concluded that lower MoCA scores equate to higher MMSE scores. For example, MMSE cut-off for no MCI or dementia is 27 compared to 23 on the MoCA and an MMSE score of 23 (considered impaired is comparable to a MoCA score of 17. This study doesn't link to capacity.

Karliawash (2013) found that both the MMSE and MoCA could detect the likelihood of impaired capacity with people with Parkinson's disease, but the MoCA demonstrated greater sensitivity.

Gluhm et al., 2013 found the MoCA at least as good as the MMSE in screening for executive dysfunction in people with Huntington's disease.

Hollis et al., (2015) found that for those diagnosed with MCI, the MoCA was a better predictor of how a person would do on a driving test than the MMSE.

Athilingam et al., (2011) compared MMSE and MoCA in patients with heart failure and found the MoCA to be more sensitive.

Part IV – For Further Reading

Recommended readings and resources

American Bar Association/American Psychological Association (ABA/APA) Assessment of Capacity of Older Adults Project Working Group. (2008) *Assessment of Older Adults with Diminished Capacity, A Handbook for Psychologists*. American Bar Association Commission on Law and Aging - American Psychological Association

- The American Bar Association (ABA) and the American Psychological Association (APA) collaborated on a series of capacity assessment handbooks for attorneys, judges, and psychologists (ABA Commission on Aging & APA, 2005, 2006, 2008) that are available for free download at <https://www.apa.org/pi/aging/programs/assessment/index>. The ABA–APA capacity assessment handbooks represent an important collaboration between the legal and psychological disciplines to promote sound conceptual understanding and skilled clinical assessment of civil capacities in older adults.

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.

Engel, L., Chui, A., Beaton, D., Green, R., & Dawson, D. (2018) Systematic Review of Measurement Property Evidence for 8 Financial Management Instruments in Populations with Acquired Cognitive Impairment. *Archives of Physical Medicine and Rehabilitation* 99, 1848 – 75.

- This article reports on a systematic review and meta-analysis of the following financial management tools: Cognitive Competency Test (CCT); Everyday Functioning Battery/Functional Impact Assessment (EFB/FIA); Financial Capacity Instrument (FCI); Financial Competency Assessment Inventory (FCAI); Independent Living Scales (ILS); Kohlman Evaluation of Living Skills (KELS); Measurement for Awareness of Financial Skills (MAFS); and Semi-structured Clinical Interview of Financial Capacity (SCIFC)

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 (i.e. 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. This is a 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.

Marson, D. (2016) Conceptual Models and Guidelines for Clinical Assessment of Financial Capacity *Archives of Clinical Neuropsychology* 31 (2016) 541–553.

- Marson, a pioneer in the development of understanding related to financial capacity identifies six concepts that have been used to try to conceptualize financial capacity and links these to applicable financial capacity assessment instruments. He concludes with a set of guidelines for conducting financial capacity assessments.

McSwiggan, S., Meares, S., & Porter, M. (2016) Decision-making capacity evaluation in adult guardianship: a systematic review. *International Psychogeriatrics* 28(3) 373-384

- A systematic review was undertaken to appraise the design and methodological quality of the published literature on health professionals' written reports of decision-making capacity and to describe the content of these reports. Very interesting report which documents some of the common practices when conducting and writing up an assessment report that weaken the report.

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 of incapability 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 of the Adult Guardianship Act.

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

- 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 health care decision making 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.

Gilbert, T., Bosquet, A., Thomas-Anterion, C., Bonnefoy, M. & Le Saux, O (2017) Assessing capacity to consent for research in cognitively impaired older patients. *Clinical Interventions in Aging. 12, 1553 - 1563.*

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.

Lamont, S., Jeon, Y., & Chiarella, M. (2013) Assessing patient capacity to consent to treatment: an integrative review of instruments and tools. *J. of Clinical Nursing, 22, 2387- 2403.*

- Reviews 19 instruments used to assess patient capacity related to health care decision making/treatment decisions. Concludes that only a few demonstrate both reliability and validity and there is need for more research in this area. This review provides a narrative synthesis of literature on 19 instruments or tools developed to aid assessment of patient capacity to make health care decisions in the general hospital setting. The questions they considered include:
 - What instruments, tools or guidelines are available and what criteria do they use to aid assessment of patient capacity to consent?
 - What are the psychometric properties of the known instruments for assessing patient capacity to consent?
 - What is known about the implementation of these instruments and the patient populations they assess?
 - How do instruments compare with clinician judgements of patient capacity?

Authors conclude that few tools have established sufficient reliability and validity suggesting the need for further research in this area.

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.

Sessums, L., Zembrzuska, H. & Jackson, J. (2011) Does this patient have medical decision-making capacity? *JAMA 306*(4), 420 - 427.

- Examined high-quality prospective studies (n=43) of instruments that evaluated health care decision-making capacity

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.

Belchoir, P & Holmes, M. (2015) Performance-based tools for assessing functional performance in individuals with mild cognitive impairment. *The Open Journal of Occupational Therapy, 3*(3).

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 strengths 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

¹ For example, Moynihan et al. (2018) describe it as “the most ethically complex task which clinicians are called upon to perform on a routine basis” (p.2); Ratliff et al., 2016 describe it as the “most conceptually and ethically challenging areas of clinical practice” and Marshall & Sprung, 2017 concluded in their review of the literature around assessing capacity that that “health professionals lack the knowledge, confidence and understanding to accurately assess mental capacity

² Jeste, D. & Saks, E. (2006, p. 611)

³ 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

⁴ Calcedo-Barba, Garcia-Solano, Fraguas & Chapela (2007)

⁵ See Perkins, Naik et al.(2007) for a good discussion of this

⁶ For a fuller discussion of this point, see for example: Jeste, D. & Saks, E. (2006)

⁷ C. Kong in her 2017 book entitled, *Mental Capacity in Relationship* (Cambridge, University Press) examines the need for, and the construction of, a relational approach for a to understanding capacity; Also, Moynihan et al, 2018, O’Connor, 2011,

⁸ See for example, Moynihan et al., (2018) and, Lamont et al., (2013)

⁹ 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 clinicians tended to find fewer patients lacking mental capacity than did researchers.

¹⁰ Moye, Wood et al. (2007)

¹¹ See Moye, Karel et al. (2004, p. 166) for a list of citations finding this

¹² (ibid) See also, Lamont et al., 2013;

¹³ 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.

¹⁴ Reference required for this point

¹⁵ Moye, Dymek & Karlawish (2001).

¹⁶ Royall (2002)

¹⁷ Naik et al. (2008)

¹⁸ Okai, et al. (2007)

¹⁹ Okai et al. (2007 p. 291) do a nice job outlining the differences between these two approaches - mental capacity approach and mental health approach.

²⁰ Grisso & Appelbaum (1998).

²¹ Roth et al, 1977

²² Grisso et al. (1997)

²³ , Dunn, Nowrangi, Palmer, Jeste & Saks (2006, p.1331)

²⁴ 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.

²⁵ Sources: Moye, Wood et al. (2007 p. 605); Moye et al., (2013) ABA-APA Capacity Assessments of Older Adults Working group (2007). 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).

²⁶ White, B.C. (1994) *Competence to Consent*. Washington, DC: Georgetown University Press.

²⁷ Buchanen & Brock (1999); Vellinga et al. (2004)

- ²⁸ 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
- ²⁹ Kim et al. (2002)
- ³⁰ Jeste & Saks (2006); see also Moye et al. (2007)
- ³¹ 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)
- ³² ABA - APA Guidelines (2009)
- ³³ Pachet, Newberry & Erskine (2007, p.175) provide a useful review related to who and how the assessment is carried out.
- ³⁴ 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.
- ³⁵ Moberg & Rick (2008) make explicit the importance of articulating the legal standards being used when conducting an assessment of incapacity.
- ³⁶ The ABA/APA 2008 handbook for psychologists: guidelines for assessing incapacity draw attention to the importance of articulating legislative standards.
- ³⁷ Lai & Karlawish (2007)
- ³⁸ See Kim et al.
- ³⁹ See for example, Manthorpe (2009); Boyle (2008); O'Connor, Purves & Downs (2009)
- ⁴⁰ Kim et al
- ⁴¹ For a comprehensive review of the research comparing different diagnostic groups, see Jeste and Saks (2006).
- ⁴² Breden and Vollman et al. (2003)
- ⁴³ See Okai et al. (2007) for a review of this research
- ⁴⁴ See for example, Tsai (2009)
- ⁴⁵ Moye et al.(2007)
- ⁴⁶ 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'.
- ⁴⁷ I was unable to find any studies that examined the decision to go into long term care as a 'treatment' decision, nor did I find any studies which examined capacity specifically in relation to the decision to go into (or to turn down) long term care. When this decision was considered, it was within the context of safe and independent living decisions-making (aka everyday decision-making) capacity assessment instruments.
- ⁴⁸ 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); Sessums, Zembrzuska & Jackson, 201. Several of these have developed excellent comparison charts.
- ⁴⁹ Kim, Karlawish and Caine (2002)
- ⁵⁰ Kim, Karlawish and Caine- See page 153 – 158 for a discussion of each of the various tools found in this literature review.
- ⁵¹ Dunn et al. (2006), Lamont, Jeon and Chiarella, 2013
- ⁵² Vellinga et al. (2004), review the tools related to how they have operationalized these standards
- ⁵³ Sturman (2005) and
- ⁵⁴ Grisso and Appelbaum, 1998
- ⁵⁵ Vellinga et al. (2004); Sturman (2005); Dunn et al. (2006); Raymont, Buchanan et al. (2007)
- ⁵⁶ Clionsky et al., 2016
- ⁵⁷ Moye et al 2013
- ⁵⁸ Clionsky 35 al., 2016; Naik et al., 2008
- ⁵⁹ Mills, Regev, Kunik, Wilson, Moye, McCullough & Naik (2014)
- ⁶⁰ Cooney et al. (2004) provide an excellent discussion about this
- ⁶¹ Lai and Karlawish (2007, p.102).
- ⁶² Naik, Lai, Kunik & Dyer (2008) p. 27 provide an excellent discussion of this.
- ⁶³ Mills, Regev, Hunik, Wilson, Moye, McCullough & Naik (2014)

- ⁶⁴ Mills, Regev, Hunik, Wilson, Moye, McCullough & Naik (2014)
- ⁶⁵ Karlawish & Lai (2008)
- ⁶⁶ Ibid, page 694
- ⁶⁷ Anderer (1997) Unpublished doctoral dissertation. Allegheny University of the Health Sciences.
- ⁶⁸ See Lai & Karlawish (2007) for a good discussion of this tool
- ⁶⁹ Moynihan, O'Reilly, O'Connor, & Kennedy (2018)
- ⁷⁰ Marson, D. C. (2001)
- ⁷¹ Marson, D. C., Sawrie, S.M., Snyder, S., McInturff, B., Stalvey, T. Boothe, A., Aldridge, T. Chatterjee, A. & Harrell, L. (2000). See also, Marson (2017)
- ⁷² Napier, Barret et al. (2007), Marson, 2017
- ⁷³ Engel et al (2018)
- ⁷⁴ Marson (2016)
- ⁷⁵ See for example Marson, 2016 for a comprehensive overview of the different ways that financial capacity has been conceptualized. He identifies six clinical models of financial capacity:(1) the early gerontological IADL model of Lawton, (2) the clinical skills model linking financial skills to living independently; (3) a related cognitive psychological model developed by Marson and colleagues, (4) financial decision-making model adapting earlier decisional capacity work of Appelbaum and Grisso, (5) person-centered model of financial decision-making developed by Lichtenberg and colleagues, and (6) a recent model of financial capacity in the real world developed through the Institute of Medicine. He suggests that there is currently not a model of financial capacity that currently unifies clinical and forensic perspectives.
- ⁷⁶ Recent reviews evaluating financial assessment instruments include: Sousa et al, 2014; Engel, 2018;
- ⁷⁷ Sousa et al., 2014
- ⁷⁸ Kelly, Earnst et al. (2003) provide an overview of these three abilities
- ⁷⁹ Lai & Karlawish (2007)
- ⁸⁰ Engel, Chui, Beaton, Green, & Dawson, D. (2018)
- ⁸¹ Marson (2001)
- ⁸² Ibid; See also the following research: Wadley, Harrell, & Marson (2003) – compared to self and informant reports; Kelly, Earnst 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.
- ⁸³ See Lichtenberg, Stolman, Ficker, Iris & Mast, 2015; Lichtenberg, Gross & Ficker, 2018 for a discussion of the development and testing of the Lichtenberg Financial Decision-making Rating Scale (LRFMS)
- ⁸⁴ Lichtenberg et al., 2018
- ⁸⁵ Marson (2001)
- ⁸⁶ Cramer, K., Tuokko, H.A., Mateer, C.A. & Hultsch, D.F. (2004) Note: this tool is developed in BC (University of Victoria)
- ⁸⁷ Loewenstein et al. (1989)
- ⁸⁸ See Napier et al. (2007, p.317) for a list of research
- ⁸⁹ Napier et al. (2007)
- ⁹⁰ Wadley et al. (2003)
- ⁹¹ Marson, Sawrie, Snyder, McInturff, Stalvey, Boothe, (2000). Team
- ⁹² 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. Edelstein (2000) describes the process of developing this tool;
- ⁹³ Sessum et al (2011)
- ⁹⁴ Sousa et al., 2011
- ⁹⁵ Anderton Loeb, P. (1996)
- ⁹⁶ Sousa et al., 2014
- ⁹⁷ Lichtenberg et al., 2015
- ⁹⁸ Lichtenberg et al, 2015
- ⁹⁹ 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.
- ¹⁰⁰ Moye, Karel et al. (2004)

¹⁰¹ Marson et al (2012) for example note that neuro-psychological evidence has substantial value by providing the clinician with explanatory links between the neurocognitive disorder (or other diagnostic condition) and identified impairments. Although neuropsychological test results by themselves do not represent capacity findings, they play a very valuable role in capacity evaluations and should be incorporated into such assessments wherever possible Marson et al., 2012).

¹⁰² Vellinga et al. (2004a); they also cite Fitten et al. (1990) and Kitamura & Kitamura (2000), American Bar Association/American Psychological Association (ABA/APA) Assessment of Capacity of Older Adults Project Working Group (2008)

¹⁰³ Mullaly, E., Kinsella, G., Berberovic, N., Cohen, Y., Dedda, K., Froud, B., et al. (2007)

¹⁰⁴ See for example, Palmar & Salva, 2007, Okonkwo, Griffith, Belue, Lanza, Zamrini, Harrell, Brockington, Clark, Raman & Marsons, 2008; Peterson 2018

¹⁰⁵ Royall, D. R. & Gray, K. F. (1992)

¹⁰⁶ 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.

¹⁰⁷ See Cooney et al. (2004) for a discussion of this.

¹⁰⁸ See Peterson (2018) for a review of some of this research

¹⁰⁹ Ibid

¹¹⁰ Folstein, Folstein & McHugh (1975)

¹¹¹ Tombaugh & McIntyre (1992, p. 922). This article provides an excellent review of this tool including summarizing the research done around establishing validity and reliability.

¹¹² In a recent review, Sessum et al found that the MMSE scores below 19 were 'good' predictors of capacity, those, below 16 were much better and those between 20 and 24 not a good indicator

¹¹³ Kirshner, 2013

¹¹⁴ See a classic article by Alexander 1988 who suggests that the determination of competency in patients with focal deficits requires the analysis of 7 cognitive domains: attention, memory, language, spatial/perceptual, reasoning, emotional/affective aspects, and miscellaneous specific cognitive functions, including calculation ability, ability to understand pragmatics or the emotional, metaphoric/idiomatic, or humorous/sarcastic aspects of spoken language (these types of communication deficits are often seen in patients with right hemisphere disorders, who do not have traditional language deficits, or aphasia). He does not suggest a specific battery of tests however, rather highlights the importance of individualizing each assessment.

¹¹⁵ Nasreddine, Phillips, Bedirian, Charbonneau, Whitehead, Collin, Cummings & Chertkow (2005)

¹¹⁶ See for example: Ogurel, 2015 ; Trzepacz, Hochstetler, Wan, Walker and Saykin, 2015; Saczynski, Inouye, Guess, Jones, Fong, Nemeth, Hodara, Ngo, Marcantonio, 2015;

¹¹⁷ Folstein, Folstein, & McHugh (1975)

¹¹⁸ Kim, Karlawish, & Caine (2002). They provide a good overview of the research linking MMSE scores to capacity.

¹¹⁹ Conclusion made by Sturman, (2005) based on his review of the research linking MMSE to capacity.

¹²⁰ Teng & Chiu (1987)

¹²¹ Tombaugh & McIntyre (1992)

¹²² Edge, Oyefeso, Evans & Evans (2015) Cognitive Assessment as a mental capacity assessment tool for patients with a learning disability;

¹²³ Yang et al., 2018

¹²⁴ Yang, Rashid et al., 2018

¹²⁵ Zahinoor et al., 2013 found in Edge et al., 2016)

¹²⁶ Hendershott et al (2019) found MoCa to be more sensitive to memory impairment and visio-spatial impairments but the Mattis Dementia Rating Scale 2 was sensitive to executive impairments with people with Parkinson's Disease;

¹²⁷ Karlawash, Cary et al, 2013

¹²⁸ Bassett (1999)

¹²⁹ 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)

¹³⁰ Royall, Cordes & Polk (1998)

¹³¹ Shulman (2000). Review of the research related to the diagnostic and screening use of the clock drawing test.

¹³² Royall & Gray (1992)

¹³³ Some research supporting the use of EXIT25 includes Schillerstrom, Rickenbacker, Kaustubb, & Royall (2007) and Dymek, Atchinson & Harrell (2001)

¹³⁴ For example, Shillerstrom et al., 2007;

¹³⁵ Terracina et al., 2015 found that only measures of executive functioning - as measured by EXIT 25 and CLOX distinguished which cases would be re-referred to Adult Protection Services.

¹³⁶ Alison, Letts & Liu (2008)

¹³⁷ Kertesz, Davidson, & Fox (1997)

¹³⁸ Dubois et al., 2000

¹³⁹ Jurica & Leitten, 2001,

¹⁴⁰ Hendershott, Zhu, Llanes, et al., 2019;

¹⁴¹ Farias et al., 2008)

¹⁴² See for example, Moberg and Rick (2008) and Peterson (2018) for a more comprehensive discussion of this issue.

¹⁴³ Nolan (1984) as found in Stebnicki (1997).

¹⁴⁴ Stebnicki, – citing others

¹⁴⁵ Stebnicki (1997, p.35)

¹⁴⁶ Moore, Moseley & Palmer (2008)

¹⁴⁷ Moore, Palmer, Patterson & Jeste (2007)

¹⁴⁸ Moore, Moseley & Palmer (2008)

¹⁴⁹ Napier, Barret, Hart, Mullins, Schmerler & Kasckow (2007)

¹⁵⁰ See for example Loewenstein, Arguelles, Bravo, Freeman, Arguelles, Acevedo & Eisdorfer (2001) and Wadley, Harrell & Marson (2003)

¹⁵¹ Moore, Moseley & Palmer (2008)

¹⁵² Moore et al. (2007)

¹⁵³ Seligman, S. C., Giovannetti, T., Sestito, J., & Libon, D. J. (2013). A new approach to the characterization of subtle errors in everyday action: Implications for mild cognitive impairment. *The Clinical Neuropsychologist*, 28(1), 97–115

¹⁵⁴ Pickens, Naik, Burnett, Kelly, Gleason, & Dyer (2007)

¹⁵⁵ Saunders and Simon (1987) developed this tool – the reference is found in Stebnicki, (1997)

¹⁵⁶ See for example: Alison, Letts and Liu (2008) provide a comprehensive overview of these in relation to the occupational therapy, Moore, Palmer, Patterson and Jeste (2007) review performance-based measures of functional living skills; and

¹⁵⁷ See also Provencher, V., Demers, L., Gagnon, L., & Gélinas, I. (2012). For a discussion on the importance of in-home testing over clinic testing.

¹⁵⁸ This reference the need to examine what errors are made rather than just scores or what is done correctly. See also Albert et al., 2011 and Seligman, Giovannetti, Sestito, & Libon, D. (2013) for a discussion of this.

¹⁵⁹ For a more comprehensive review of functional screening tools used by occupational therapists see Alison, Letts & Liu (2008)

¹⁶⁰ Loewenstein et al. (1989)

¹⁶¹ Loeb (1996)

¹⁶² Sousa et al., 2014

¹⁶³ Quickel and Dumakas, 2013 examined how ILS correlated with actual judicial determination of competency in older adults and found that there was a strong correlation between TMT-B which suggests that differences in executive functioning contribute to differences in functional aspects of daily living. There is also research correlating this scale to the DRS, MMSE, Geriatric Depression Scale and Boston Naming Test

¹⁶⁴ Baird et al. (2001).

¹⁶⁵ Kohlman-Thomson, L (1992) Kohlman *evaluation of living skills* (3rd ed). Bethesda, MD: American Occupational Therapy Association. I was unable to access this and instead relied upon Pickens, Naik et al.(2007)

¹⁶⁶ Pickens, Naik et al.(2007)

¹⁶⁷ Zimnavoda, Weinblatt & Katz (2002). This article provides a published test of validity.

¹⁶⁸ Pickens, Naik et al. (2007)

¹⁶⁹ Lawton, M.P., & Brody, E.M. (1969)

¹⁷⁰ Mausbach, Harvey, Goldman, Jeste, & Patterson (2007)

- ¹⁷¹ Mahurin, DeBettignies & Pirozzolo (1991)
- ¹⁷² Mahoney & Barthel, 1965)
- ¹⁷³ COTA (2001)
- ¹⁷⁴ Sparrow et al (2005) cited in Moberg and Rick (2008)
- ¹⁷⁵ Diel et al. (2005) cited in Moberg and Rick (2008)
- ¹⁷⁶ Bruininks et al. (2004) cited in Moberg and Rick (2008)
- ¹⁷⁷ Blessed, Tomlinson and Roth, 1968; Stern, Hesdorffer, Sano & Mayeux (1990)
- ¹⁷⁸ Willis, 1996
- ¹⁷⁹ Reid, William & Gill (2003), cited in Naik et al. (2006)
- ¹⁸⁰ See Marshall, Aghjayan, Dekhtyar, Locascio, Jethwani, Amarigkio et al., 2019 for a brief description of this tool and results of preliminary pilot research linking the tool to other functional tools.
- ¹⁸¹ See, for example, Shulman (2000) who provides a discussion of this in relation to the clock-drawing test.
- ¹⁸² 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.
- ¹⁸³ Grisso & Applebaum (1997)
- ¹⁸⁴ Dunn et al. (2006)
- ¹⁸⁵ Breden & Vollman (2004)
- ¹⁸⁶ Dunn et al. (2006)
- ¹⁸⁷ Breden & Vollman (2004, p.277).
- ¹⁸⁸ Ibid .See also O'Connor, Hall and Donnelly (2009) and Hulko and Stern (2009) for the development of this point from a conceptual perspective.
- ¹⁸⁹ 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.
- ¹⁹⁰ Lai & Karlawish (2007)
- ¹⁹¹ Engel et al 2018
- ¹⁹² Marson (2001)
- ¹⁹³ Ibid; See also: 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.
- ¹⁹⁴ Marson (2001)
- ¹⁹⁵ Van Wielingen et al. (2004)
- ¹⁹⁶ Engel et al. 2018 - a systematic review of 8 of the most common tools
- ¹⁹⁷ Kershaw & Webber (2008)
- ¹⁹⁸ See Lichtenberg, Stolman, Ficker, Iris & Mast, 2015; Lichtenberg, Gross & Ficker, 2018 for a discussion of the development and testing of the Lichtenberg Financial Decision-making Rating Scale (LRFRS)
- ¹⁹⁹ Lichtenberg et al., 2018
- ²⁰⁰ 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.
- ²⁰¹ Ibid.
- ²⁰² See for example research by Marson et al. (2000)
- ²⁰³ Folstein , Folstein & McHugh (1975)
- ²⁰⁴ Tombaugh & McIntyre (1992, p. 922). This article provides an excellent review of this tool including summarizing the research done around establishing validity and reliability.
- ²⁰⁵ See, for example, Dunn et al. (2006)
- ²⁰⁶ Shulman (2000)
- ²⁰⁷ Matsuoko et al, 2014 - Japanese version validation and comparison with J-EXIT25
- ²⁰⁸ As per research cited in Berger et al. (2008)
- ²⁰⁹ Nasreddine, Phillips, Bedirian, Charbonneau, Whitehead, Collin, Cummings & Chertkow (2005)
- ²¹⁰ See for example: Ogurel, 2015 ; Trzepacz, Hochstetler, Wan, Walker and Saykin, 2015; Saczynski, Inouye, Guess, Jones, Fong, Nemeth, Hodara, Ngo, Marcantonio, 2015;

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