CHAPTER 6: Incapacity

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6.1 Incapacity and Adult Guardianship

A guardian may not be appointed for an adult unless the adult has been adjudicated to be incapacitated or "incompetent" pursuant to G.S. Ch. 35A, Art. 1. *In re Efird*, 114 N.C. App. 638 (1994).

The question of the respondent's "incapacity" or "incompetency," therefore, is a necessary issue and must be determined in any proceeding seeking the appointment of a guardian for the respondent.

6.2 Defining Incapacity

A. Purpose

The legal definition of "incapacity" or "incompetency" is important because it defines the circumstances under which the State may restrict an adult's decision-making authority by appointing a guardian to make personal or financial decisions for him or her.

B. History

Although the concept of mental incapacity or incompetency has always been central in connection with adult guardianship proceedings, there is no, and never has been any, uniform definition of "incapacity" or "incompetency."

Before 1977, North Carolina's guardianship laws, like those of other states, defined "incapacity" or "incompetency" primarily through general, and usually undefined, terms regarding an individual's status, mental incapacity, or condition, including "lunatic," "idiot," "inebriate," "imbecile," "feeble-minded," "mentally deficient," and "insane."

Over the past forty years, however, the national trend generally has been to abandon definitions that rely on pejorative labels (such as "idiot" and "lunatic") in favor of definitions that focus on an individual's mental or physical condition and cognitive and functional impairments.

Historically, legal definitions of "incapacity" or "incompetency" in adult guardianship proceedings have focused on an individual's "global" or general capacity to make decisions or manage his or her property and personal affairs, rather than a person's mental capacity to make decisions with respect to particular transactions or matters, such as marrying, entering into a contract, making a will, standing trial in a criminal proceeding, etc. *See Hagins v. Greensboro Redevelopment Comm*'n, 275 N.C. 90 (1969). More importantly, "incapacity" or "incompetency" in the context of adult guardianship proceedings generally was considered to be "all or nothing." A person either was, or was not, "incapacitated" or "incompetent" and a judicial determination of "incapacity" or "incompetency" generally resulted in a comprehensive, if not almost total, loss of an "incompetent" person's legal rights.

Today, "capacity" and "incapacity" generally are seen to be the two ends of a continuum that includes varying degrees of capacity and incapacity rather than a clearly-differentiated dichotomy—concepts that are more "gray" than "black or white." As a result, many state guardianship laws expressly or implicitly incorporate the concepts of "partial incapacity" and "limited guardianship" into their definitions of "incapacity" or "incompetency."

C. Contemporary Definitional Components

Today, most state adult guardianship laws define "incapacity" or "incompetency" through a combination of two or more of the following components:

- a "medical" component that requires that the respondent's incapacity be caused by a diagnosed medical condition or identified mental or physical impairment, such as mental illness, developmental disability, or chronic intoxication;
- a "functional" component that requires that the respondent's incapacity limit his or her ability to manage his or her own affairs or property or to care for his or her essential personal needs such as medical care, food, clothing, shelter, and safety;
- a "cognitive" component that requires that the respondent's incapacity involve a mental or physical condition that limits his or her ability to make or communicate "rational" decisions;
- a "necessity" component that requires that the respondent's incapacity endanger the respondent's person or property to such an extent that appointment of a guardian, as opposed to some other "less restrictive" alternative, is necessary and in the respondent's best interest.

The 1997 Uniform Guardianship and Protective Proceedings Act, for example, employs the second, third, and fourth components (but not the first component) of "incapacity" in defining an "incapacitated person" as a person "who, for reasons other than being a minor, is unable to receive and evaluate information or make or communicate decisions to such an extent that [he or she] lacks the ability to meet [his or her essential needs with respect to] physical health, safety, or self-care, even with appropriate technological assistance."

6.3 Statutory Definition of Incapacity

G.S. 35A-1101(7) defines an "incompetent adult" as an adult or emancipated minor who

- lacks sufficient capacity to manage his or her own affairs or to make or communicate important decisions concerning his or her person, family, or property,
- due to mental illness, mental retardation, epilepsy, cerebral palsy, autism, inebriety, senility, disease, injury, or similar cause or condition.

Similarly, G.S. 35A-1101(8) defines an "incompetent child" as an unemancipated minor who is at least 17½ years old and, for reasons other than his or her minority, lacks sufficient capacity to manage his or her own affairs or to make or communicate important decisions concerning his or her person, family, or property due to mental illness, mental retardation, epilepsy, cerebral palsy, autism, inebriety, senility, disease, injury, or similar cause or condition.

6.4 Analyzing and Interpreting the Statutory Definition of Incapacity

A. Definitional Components or Elements

North Carolina's definition of incapacity consists of two separate, but related, components or elements:

- a functional or cognitive element; and
- a medical component.

Functional or cognitive element. The functional or cognitive element of the definition refers to an individual's inability to manage his or her affairs or to make or communicate important decisions regarding his or her person, family, or property.

Medical component. The medical component of incapacity refers to the mental or physical condition that is the cause of the individual's inability to make or communicate important decisions or manage his or her affairs.

Relationship between the components or elements. Both components or elements of the definition are necessary in determining the issue of a respondent's incapacity, but neither is sufficient standing alone. The mere fact that a respondent is "mentally ill," for example, is not sufficient, in and of itself, to support a judicial determination that he or she is incapacitated or "incompetent." Instead, the petitioner must prove and the court must find that

- a respondent is mentally ill (or suffers from another mental or physical condition) and
- he or she lacks sufficient capacity to manage his or her own affairs or property or to make or communicate important decisions concerning his or her person, family, or property.

In addition, the two components or elements of North Carolina's definition of incapacity are causally related. A respondent's functional or cognitive incapacity must be caused by his or her mental illness, mental retardation, epilepsy, cerebral palsy, autism, inebriety, senility, disease, injury, or similar cause or condition.

B. Minimal or Sufficient vs. Optimal Capacity

It is important to note that North Carolina's definition of incapacity uses the term "sufficient capacity." This strongly suggests that even if a respondent suffers from a cognitive impairment that limits his or her ability to make or communicate important decisions or manage his or her affairs or property, he or she should not be determined to be "incompetent" unless he or she lacks the understanding or mental capacity that is *minimally* required to manage his or her affairs or property. Proof that a respondent's decision-making ability is not optimal or perfect, therefore, is insufficient to support a judicial determination of incapacity under G.S. Ch. 35A, Art. 1. Or, phrased differently, a judicial determination of incapacity requires proof that a respondent's decision-making capacity is *significantly* impaired.

C. Partial Incapacity and Limited Guardianship

It is also important to note that North Carolina's definition of incapacity implicitly incorporates the concepts of "partial incapacity" and "limited guardianship." G.S. 35A-1212 and G.S. 35A-1215 authorize the Clerk to make findings regarding the "nature and extent" of a respondent's incapacity and to create a limited guardianship if a limited guardianship is warranted by the nature and extent of the ward's incapacity. Moreover, G.S. 35A-1201(a)(5) recognizes that, in at least some instances, an "incompetent" ward may retain sufficient capacity to exercise certain rights or make or participate in certain decisions.

D. Temporary and Permanent Incapacity

North Carolina's guardianship law, like that of other states, does not require that a respondent's incapacity be permanent rather than temporary, curable, or reversible. The Clerk's authority, under G.S. 35A-1212 and G.S. 35A-1215, to make findings regarding the "nature and extent" of a respondent's incapacity clearly includes the authority to make findings regarding the probable duration of the respondent's incapacity or prognosis for improvement. If the ward's condition improves, the Clerk may modify the guardianship order and create a limited guardianship if a limited guardianship is warranted given the nature and extent of the ward's incapacity. *See* G.S. 35A-1207. And if the ward's condition improves to the extent that he or she is no longer incompetent, the Clerk is required, upon motion by the ward, the guardian, or an interested party, to enter an order restoring the ward's competency. G.S. 35A-1130.

E. The "Necessity" Component

Although North Carolina's definition of incapacity does not expressly incorporate a "necessity" component, G.S. 35A-1201(a)(4) may implicitly do so by providing that the Clerk should not appoint a guardian for an incompetent respondent unless it is clear that appointing a guardian for the respondent will give the respondent a fuller capacity for exercising his or her rights.

6.5 The Medical Component of Incapacity

The medical component of incapacity refers to a diagnosed medical condition or identified mental or physical condition that is the cause of a respondent's cognitive impairment or functional incapacity.

A. Purpose

The purpose of the medical component of incapacity is to limit the State's authority by providing an objective, medical standard that differentiates between individuals who lack the mental capacity required to act in their own interest and those who are mentally competent but *choose* to act in eccentric, unreasonable, irrational, foolish, crazy, or even self-destructive ways.

Whether definitions of incapacity that require proof of a disabling medical condition or physical or mental impairment actually accomplish this purpose is open to question, especially in light of the fact that at least sixteen states, including North Carolina, have adopted "catch-all" provisions that include the category "other cause" in addition to specified conditions such as "mental illness" and "developmental disability." At least one commentator, therefore, has suggested that the medical component of incapacity "has become superfluous as a definitional standard in the law of guardianship," that it should be abandoned because it has provided only "an aura of objectivity without substance," and that it should be replaced by definitional standards that focus on the cognitive capacity and functional impairments of respondents. *See* Charles P. Sabatino and Suzanna L. Basinger, *Competency: Reforming Our Legal Fictions*, 6 J. MENTAL HEALTH & AGING 119 (2000).

B. History

The medical component of North Carolina's definition of incapacity was first adopted in 1977, was made generally applicable to all adult guardianship proceedings in 1987, and remains a part of the current statutory definition of incapacity under G.S. 35A-1101(7).

C. Definitions

North Carolina's guardianship statute defines several of the medical diagnoses or mental or physical conditions that comprise the medical component of North Carolina's definition of incapacity.

- "Mental illness" is, and has been since 1945, defined as any "illness that so lessens the capacity of a person to use self-control, judgment, and discretion in the conduct of the person's affairs and social relations as to make it necessary or advisable for the person to be under treatment, care, supervision, guidance, or control." G.S. 35A-1101(12). Mental illnesses or disorders that *may* affect capacity include bipolar disorder or manic depression, major depression, and schizophrenia.
- "Mental retardation" or developmental disability is defined as "significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested before age 22." G.S. 35A-1101(13).
- "Inebriety" is defined as "the habitual use of alcohol or drugs rendering a person incompetent to transact ordinary business concerning the person's estate, dangerous to person or property, cruel and intolerable to family, or unable to provide for family." G.S. 35A-1101(11).
- "Autism" is defined as "a physical disorder of the brain which causes disturbances in the developmental rate of physical, social, and language skills; abnormal responses to sensations; absence of or delay in speech or language; or abnormal ways of relating to people, objects, and events." G.S. 35A-1101(1).
- "Cerebral palsy" is defined as "a muscle dysfunction, characterized by impairment of movement, often combined with speech impairment, and caused by abnormality of or damage to the brain." G.S. 35A-1101(2).

• "Epilepsy" is defined as a neurological condition characterized by abnormal electricalchemical discharges in the brain manifested in seizures or other physical activities that range from momentary lapses of consciousness to convulsive movements. G.S. 35A-1101(5).

It is important to note that the statutory definitions of mental illness, mental retardation (developmental disability), inebriety, autism, cerebral palsy, and epilepsy either differ from the definitions of mental disorders contained in, or are not defined in, the *Diagnostic and Statistical Manual of Mental Disorders-IV* (DSM-IV).

It is also important to note that the statutory definitions of mental illness and inebriety focus on the cognitive or functional impairments resulting from an individual's mental illness or inebriety and not solely on the person's mental or physical condition. This is also true with respect to some, though not all, of the diagnoses of mental disorders contained in the *Diagnostic and Statistical Manual of Mental Disorders-IV* (DSM-IV).

Senility. G.S. 35A-1101 does not define "senility." The term "senility" is outdated, imprecise, and inaccurate, and generally has been replaced by the term "dementia." "Dementia" has many different causes and is characterized by a decline in memory in association with a decline in other cognitive abilities, such as judgment or abstract thinking, or changes in personality. Dementia occurs disproportionately among senior citizens. "Old age," however, is not a sufficient basis, standing alone, to find a respondent incapacitated. *See Goodson v. Lehmon*, 224 N.C. 616 (1944).

Other mental or physical conditions. Although the medical component of North Carolina's definition of incapacity includes any "disease, injury, or . . . condition" similar to the particular mental and physical disorders listed in G.S. 35A-1101(7), these "other" diseases, injuries, or conditions must be such that they are proximately related to the respondent's inability to make or communicate important decisions regarding his or her person, family, or property or to manage his or her own affairs and property. Other diseases, injuries, or conditions that *may* affect capacity include alcoholic dementia, Alzheimer's disease, coma or persistent vegetative state, delirium, frontal or frototemporal dementia, Jacob-Creutzfeldt disease, diffuse Lewy body dementia, Parkinson's disease, stroke or cerebral vascular accident, traumatic brain injury, vascular dementia, and dementia resulting from AIDS, Huntington's disease, or amyotrophic lateral sclerosis (Lou Gehrig's disease).

D. Incapacity and Physical Impairments

Physical disorders, disease, and conditions that result in physical impairments or limit an individual's physical ability to care for himself or herself or perform normal activities of daily living are *not* sufficient to prove that a respondent is incapacitated unless they also result in the respondent's inability to make or communicate important decisions regarding his or her person, family, or property or significantly limit the respondent's *mental or cognitive capacity* to manage his or her own affairs or property. *See Goodson v. Lehmon*, 224 N.C. 616 (1944); *Cox v. Jefferson-Pilot Fire & Casualty Co.*, 80 N.C. App. 122 (1986). For example, the noted English physicist, Stephen Hawking, suffers from amyotrophic lateral sclerosis (Lou Gehrig's disease), is unable to walk, is unable to speak (except through the use of a keypad

and voice synthesizer), has almost no use of his extremities, and cannot feed, dress, toilet, or bathe himself. There is no question that he is physically disabled and functionally impaired with respect to most activities of daily living and instrumental activities of daily living. But it is equally clear that, so far, his medical condition has not limited his general mental or cognitive capacity, has not significantly limited his mental or cognitive capacity to manage his own affairs and property or to make important decisions regarding his person, family, or property, and has not resulted in his being unable to communicate his decisions to others.

E. Proof of Medical Condition

The medical component of incapacity generally must be proved by the testimony of a medical expert who has examined the respondent or the respondent's medical records or other information regarding the respondent's condition, or by information from the respondent's medical records indicating that the respondent has been diagnosed as suffering from mental illness or another mental or physical disorder, disease, or condition.

Proof that a respondent is mentally ill, is developmentally disabled (mentally retarded), is an inebriate, an alcoholic or drug addict or substance abuser, is autistic, suffers from cerebral palsy or epilepsy, is senile or suffers from dementia, or has any other mental or physical disorder, disease, or condition, is not sufficient, in and of itself, to prove that the respondent is incapacitated.

6.6 The Functional and Cognitive Elements of Incapacity

A. Statutory Definition

The functional and cognitive elements of incapacity refer to

- the respondent's mental or cognitive ability to manage his or her own affairs and property, and
- the respondent's mental, cognitive, or physical ability to make or communicate important decisions regarding his or her person, family, or property.

Although functional and cognitive elements of incapacity could be viewed as two separate and distinct "tests" of incapacity, the "division between the functional . . . [and cognitive aspects of incapacity] is somewhat artificial, since functional capacity depends in part on . . . [mental or cognitive] capacity." *See* Stephen J. Anderer, *Determining Competency in Guardianship Proceedings* (Washington, DC: American Bar Association, 1990), 27. The truth, therefore, is that the functional and cognitive aspects of incapacity are more accurately viewed as two related and complementary elements of incapacity, both of which focus primarily on a respondent's ability to perform particular functions—managing his or her own affairs and making important decisions regarding his or her person, family, or property—that require some degree of mental or cognitive capacity.

B. Nature and Purpose

The functional or cognitive element of incapacity is much more important than the medical component of incapacity. A respondent's functional or cognitive impairment, therefore, should be the primary focus of a proceeding to appoint a guardian for an allegedly incapacitated adult. Nonetheless, proof that a respondent is cognitively or functionally impaired is insufficient to establish a respondent's incapacity without evidence that the respondent's incapacity results from an identified mental or physical impairment, disease, injury, or condition.

It is important to note, again, that the standard for determining whether a respondent is incapacitated focuses on whether the respondent lacks *sufficient* capacity to manage his or her own affairs or property or to make or communicate important decisions regarding his or her person, family, or property. The issue, therefore, is not whether the respondent's mental or cognitive capacity is optimal or unimpaired, but rather whether his or her mental or cognitive capacity is *minimally adequate* to enable him or her to function, make decisions, and care for his or her personal needs and financial affairs at the level that is necessary to ensure his or her own well-being, protection, and safety. Nor is it sufficient to prove that another person might manage a respondent's affairs or property more wisely or efficiently than the respondent. *See Hagins v. Greensboro Redevelopment Comm'n*, 275 N.C. 90 (1969).

And, finally, because the functional and cognitive elements of incapacity focus primarily on the respondent's *mental or cognitive* capacity or incapacity, it is important to note that a respondent's *physical* capacity or incapacity is irrelevant in determining the respondent's incapacity *unless* it significantly affects his or her ability to make or communicate important decisions regarding his or her person, family, or property. *See Goodson v. Lehmon*, 224 N.C. 616 (1944). For this reason, proof that a respondent is unable, due to a physical impairment, disease, injury, or condition, to perform some or all of the activities of daily living (ADLs) or even some or all of the instrumental activities of daily living (IADLs)—is insufficient to prove that the respondent is incapacitated.

C. Capacity to Manage One's Affairs

The first prong of the functional element of incapacity (which dates back at least to 1883) focuses on the respondent's capacity to manage his or her own affairs. It is, nominally at least, an objective standard that focuses on the respondent's actual and potential functioning—the respondent's behavior and actions with respect to his or her person, family, and property. It focuses more on the *outcome* of the respondent's decisions than on the respondent's decisions themselves or the *process* by which the respondent makes decisions.

The functional element of incapacity theoretically distinguishes "clinical incapacity" from "legal incapacity." See Charles P. Sabatino and Suzanna L. Basinger, *Competency: Reforming Our Legal Fictions*, 6 J. MENTAL HEALTH & AGING 119 (2000). Requiring proof that a respondent is functionally impaired in the sense of being unable to adequately manage his or her affairs or property is intended to ensure that the State intervenes only when necessary to protect a substantial personal or property interest of the respondent that is threatened due to the respondent's condition. See Stephen J. Anderer, *Determining Competency in Guardianship*

Proceedings (Washington, DC: American Bar Association, 1990), 10. The functional element of incapacity also may implicitly incorporate the element of "necessity" by requiring objective proof that a respondent's property, health, safety, or welfare will be harmed as a result of his or her impairment.

Functional definitions of incapacity, however, are often vague and imprecise and, too often, are applied subjectively by concluding that a respondent who behaves or acts in an "unreasonable" or "irrational" manner must be mentally incompetent.

G.S. 35A-1101 does not define the phrase "lacks sufficient capacity to manage . . . [his or her] own affairs." Nor is there an abundance of case law that interprets this aspect of the statutory definition of incapacity.

A 1969 decision by the North Carolina Supreme Court, however, suggests that a person lacks sufficient capacity to manage his or her own affairs if his or her mental or cognitive impairment is such that he or she is incapable of

- transacting the ordinary business involved in taking care of his or her property, health, or personal safety or welfare,
- exercising rational judgment, and
- weighing the consequences of his or her acts upon himself or herself, his or her family, or his or her property and estate.

See Hagins v. Greensboro Redevelopment Comm'n, 275 N.C. 90 (1969).

Conversely, a person does not lack sufficient capacity to manage his or her own affairs if he or she

- understands what is necessarily required for the management of his or her ordinary personal and business affairs,
- is able to perform those acts with reasonable continuity,
- comprehends the effect of what he or she does, and
- can exercise his or her own will.

See Hagins v. Greensboro Redevelopment Comm'n, 275 N.C. 90 (1969). See also Cox v. Jefferson-Pilot Fire & Casualty Co., 80 N.C. App. 122 (1986); Soderlund v. N.C. School of the Arts, 125 N.C. App. 386 (1997); State Farm Fire & Casualty Co. v. Darsie, 161 N.C. App. 542 (2003).

A person's "affairs" encompass all of an individual's personal, business, and financial affairs. *See Hagins v. Greensboro Redevelopment Comm'n*, 275 N.C. 90 (1969). More specifically, a person's "affairs" include matters relating to his or her

- health care,
- personal safety,
- residence,
- nutrition,

- clothing,
- personal hygiene,
- family relationships,
- personal relationships,
- finances,
- business, and
- property.

D. Capacity to Make and Communicate Important Decisions

The second prong of the functional or cognitive element of incapacity, which was first added to North Carolina's guardianship statute in 1977 and was made generally applicable in all adult guardianship proceedings in 1987, focuses directly on deficiencies in a respondent's cognitive functioning by examining the respondent's mental or cognitive capacity to make or communicate important decisions regarding his or her person, family, or property.

The cognitive element of incapacity focuses directly on deficiencies in a respondent's cognitive functioning. In theory, the cognitive element of incapacity provides an objective standard that allows individuals who have at least a minimally adequate level of mental and cognitive capacity to make "unreasonable," "irrational," "unwise," "ill-advised," "foolish," "stupid," or even self-destructive decisions as long as they do so through the use of a "rational" decision-making process.

It is important to note that the cognitive element of incapacity focuses on an individual's decision-making *capacity*, rather than the behaviors or actions that may result from the individual's decisions or inability to make a decision. Stated differently, this "test" of incapacity focuses on the respondent's ability to make "rational" decisions or the *process* through which the respondent makes decisions, rather than the *content* of the respondent's decisions or inability to make "rational" decisions or the behaviors, actions, or consequences that result from the respondent's decisions or inability to make "rational" decisions. The issue, therefore, is not whether a respondent's decisions appear, to a reasonable or rational observer, to be unreasonable, irrational, unwise, ill-advised, stupid, or even self-destructive, but rather whether some mental or physical impairment renders the respondent incapable of making rational decisions or significantly limits the respondent's ability to do so.

At a minimum, assessments of a respondent's cognitive functioning should focus on the respondent's

- awareness,
- perception,
- orientation to reality,
- concentration,
- memory,

- comprehension,
- insight,
- reasoning,
- deliberation,
- appreciation of consequences, and
- choice.

A respondent may lack sufficient capacity to make important decisions concerning his or her person, family, or property if he or she

- cannot understand or appreciate the facts that are relevant in connection with a particular decision or situation;
- is unable to express a choice or preference with respect to a particular decision or situation;
- is unable to understand the risks, benefits, and alternatives with respect to a particular decision or situation;
- is unable to appreciate the consequences of a particular decision or situation; or
- is unable to weigh, in a rational manner and consistent with his or her values, the relative risks, benefits, and consequences involved in a particular decision or situation.

Although G.S. 35A-1101 does not define the phrase "important decisions concerning . . . [the respondent's] person, family, or property," it clearly includes decisions regarding the respondent's health, safety, welfare, personal and family affairs, and business and financial affairs.

6.7 Clinical Assessment of Cognitive and Functional Incapacity

Medical or clinical assessments of capacity or incapacity are different from legal determinations of capacity or incapacity. Clinical assessments of an individual's mental, cognitive, or functional capacity, however, are relevant in determining whether, in the context of a legal proceeding to appoint a guardian for that individual, he or she is "incompetent" or incapacitated.

A. General Mental Capacity

Clinical evaluations of an individual's *general* mental capacity or incapacity assess the extent to which the individual's cognitive functioning is *minimally adequate* in the areas of

- word knowledge,
- recent and remote memory,
- perceptual accuracy or reality testing,
- insight,

- abstraction, and
- executive functioning and judgment in both the personal and social spheres.

B. Specific Cognitive and Functional Capacity

In most cases, a clinical evaluation of an individual's capacity or incapacity also should focus more particularly on an individual's specific capacity with respect to one or more cognitive or functional "domains" (areas of cognitive or functional behavior), such as consenting to medical treatment, engaging in financial transactions, or caring for oneself in an independent living situation.

C. Clinical Evaluation of Incapacity

Clinical evaluations of an individual's capacity or incapacity should be based on a thorough professional assessment of the individual's

- cognitive capacity,
- medical or mental diagnosis and condition,
- functional capacity, and
- environment, context, and situation.

Cognitive capacity. An individual's cognitive capacity refers to his or her general mental capacity or ability in the areas of attention, concentration, perception, memory, understanding, comprehension, deliberation, reasoning, and judgment. Clinicians assess an individual's cognitive capacity through clinical interviews and cognitive testing. *See* Appendix 6-8, Cognition and Cognitive Testing and Appendix 6-9, Brief Guide to Psychological and Neuropsychological Instruments. Some instruments, such as the Folstein Mini Mental Status Examination (MMSE), which is a short test that assesses an individual's awareness of time, place, and orientation, comprehension and production of language, short-term memory, and ability to attend and concentrate, may be used as an initial screening device to determine whether an individual *may* be cognitively impaired but are not determinative with respect to whether an individual is or isn't cognitively impaired.

Medical diagnosis. An accurate medical diagnosis of an individual's mental and physical condition is important in determining whether the individual is cognitively impaired, the cause of the individual's impairment, the likely extent of the individual's impairment, whether the individual's impairment is permanent or temporary, whether the individual's condition will improve or get worse, whether treatment may improve the individual's condition, and what treatment might help improve the individual's condition. Cognitive impairments may be caused by cognitive disorders such as dementia, by psychiatric disorders such as schizophrenia, by other medical conditions, such as stroke or traumatic brain injury, or by other factors such as substance abuse. Diagnoses of mental impairments are listed and described in the *Diagnostic and Statistical Manual of Mental Disorders-IV* (DSM-IV). *See also* Appendix 6-2, Medical Conditions Affecting Capacity; Appendix 6-3, Dementia Overview; Appendix 6-4, Temporary and Reversible Causes of Confusion; Appendix 6-5, Medications That May Commonly Cause Confusion; and Appendix 6-6, Distinguishing Delirium from

Dementia. A diagnosis that an individual suffers from a mental illness, developmental disability, or other medical condition, however, is not, in and of itself, sufficient to support a conclusion that the individual lacks mental capacity.

Functional capacity. An individual's functional capacity refers to the mental capacity required to perform particular functions or activities, such as making decisions regarding medical treatment, financial transactions, or personal care. For example, mental capacity to consent to or refuse medical treatment generally is understood to require

- the capacity or ability to understand or comprehend information regarding one's medical diagnosis and the potential risks and benefits of medical treatments;
- the ability to appreciate the significance or applicability of that information to one's own situation;
- the ability to make a reasoned choice by rationally evaluating the benefits and risks of medical treatment in light of one's own life and values; and
- the ability to communicate a definite and consistent decision regarding medical treatment.

Similarly, assessments of functional capacity in the domain of financial matters examine an individual's knowledge (ability to describe facts, concepts, and events related to financial activities); skills (the ability to make change, write checks, or perform other activities related to financial activities); and judgment (the ability to make rational or reasonably sound financial decisions). The concepts of functional and cognitive impairment are related to the extent that an individual's cognitive impairment may impair his or her ability to perform certain functions. Functional capacity, however, must be assessed separately from an individual's general cognitive capacity because the fact that an individual has a cognitive impairment does not necessarily mean that his or her cognitive impairment limits his or her ability to perform a particular function. Clinicians assess functional capacity through direct observation, reports from family members, performance-based testing, and functional instruments. See Appendix 6-10, Everyday Functioning and Functional Assessment; Appendix 6-11, Activities of Daily Living; and Appendix 6-12, Instrumental Activities of Daily Living. A respondent's ability to perform instrumental activities of daily living (IADLs) *may* be relevant to the issue of the respondent's mental or cognitive capacity. Assessments of a respondent's ability to perform normal activities of daily living (ADLs) generally are not relevant to the issue of the respondent's mental or cognitive capacity, but may be useful in determining the needs of an incapacitated ward or developing a guardianship plan for an incapacitated ward.

Environmental assessment. Assessment of an individual's environment, context, and situation examines the degree to which an individual's personal, social, and physical environments affect his or her capacity, the personal, physical, psychosocial, and situational demands that are placed on the individual, the individual's personal history, values, and preferences, the personal, social, and other resources that are available to the individual, and the situational risks to the individual. Clinicians assess an individual's environment, context, and situation through direct questioning of the individual or through information obtained from the individual's family or other sources.

6.8 Multidisciplinary Evaluations of Incapacity

A. Statutory Definition

A multidisciplinary evaluation (MDE) is a court-ordered evaluation of a respondent's incapacity conducted in connection with an adult guardianship proceeding. *See* G.S. 35A-1101(14).

B. Obtaining an MDE

The procedures for requesting and obtaining an MDE are discussed in detail in Chapter 5 of this manual.

C. Preparing an MDE

A multidisciplinary evaluation must be conducted, prepared, coordinated, or assembled by a state or local social service, public health, mental health, vocational rehabilitation, diagnostic evaluation, or human service agency designated in the Clerk's order directing the evaluation. *See* G.S. 35A-1111(b); G.S. 35A-1101(4). When a state or local human services agency is the petitioner in a pending guardianship proceeding, that agency should not be designated to conduct, prepare, coordinate, or assemble a multidisciplinary evaluation of the respondent. An agency that has been designated to perform a multidisciplinary evaluation may perform the multidisciplinary evaluation itself (if its staff includes a doctor, psychologist, and social worker), request other state or local human services agencies to conduct all or part of the evaluation, or contract with doctors, psychologists, and social workers who are not employed by state or local human services agencies to conduct all or part of the evaluation.

D. Purpose of the MDE

The purposes of a multidisciplinary evaluation are to assist the Clerk in determining whether the respondent is incapacitated, the nature and extent of a respondent's incapacity, and the needs of the respondent that should be addressed in a guardianship plan. *See* G.S. 35A-1111(a).

E. Nature and Scope of the MDE

A multidisciplinary evaluation must contain current medical, psychological, and social work evaluations of the respondent. An evaluation is considered to be "current" if it has been done within the year immediately preceding a guardianship hearing. In ordering a multidisciplinary evaluation, the Clerk may direct that these evaluations address specific issues or questions regarding the respondent's alleged incapacity. The Clerk also may order the respondent to attend a multidisciplinary evaluation for the purpose of being evaluated. G.S. 35A-1111(d).

Medical component. The medical component of a multidisciplinary evaluation should be completed by a licensed physician or other qualified medical professional who has examined

the respondent or reviewed the respondent's medical records. The physician who completes the medical component of a multidisciplinary evaluation need not be a psychiatrist. At a minimum, the medical component of a multidisciplinary evaluation should provide current information regarding the respondent's physical and neurological status, relevant medical history, diagnoses of physical and mental disorders, conditions, or impairments, etiology of and prognosis for the respondent's impairments and condition, current and recommended medical treatment (including medications), results of pertinent tests, and clinical impressions of the respondent's medical condition.

Psychological component. The psychological component of a multidisciplinary evaluation should be conducted by a licensed clinical psychologist or other qualified mental health professional (such as a psychiatrist or licensed clinical social worker) who has examined the respondent or reviewed the respondent's medical and mental health records and other relevant information. At a minimum, the psychological component of a multidisciplinary evaluation should provide current information regarding the respondent's mental health, intellectual functioning, emotional status, and adaptive behavior, diagnoses of mental disorders, conditions, or impairments, etiology of and prognosis for the respondent's impairments and condition, current and recommended treatment (including medications), results of pertinent tests, and clinical impressions of the respondent's mental condition.

Social work component. The social work component of a multidisciplinary evaluation should be conducted by a qualified social worker who has examined the respondent or obtained reliable information regarding the respondent's situation. At a minimum, the social work component of a multidisciplinary evaluation should provide current information regarding the personal, family, social, and environmental aspects of the respondent's life, including a description and assessment of the respondent's living situation, family and interpersonal relationships, available family and community support and resources, employment, transportation, performance of activities of daily living, and performance of instrumental activities of daily living, as well as clinical impressions of the respondent's personal, family, and social condition.

Other assessments. Multidisciplinary evaluations also may include current evaluations by professionals in the areas of education, vocational rehabilitation, occupational therapy, vocational therapy, psychiatry, speech and hearing, and communications disorders.

Summary and report of assessment. A multidisciplinary evaluation should include a summary, prepared by the designated agency or one or more of the professionals who evaluated the respondent, that assesses whether the respondent is or may be "incompetent" or incapacitated, and, if so, assesses the nature and extent of the respondent's incapacity. If a respondent has the capacity to make particular decisions or perform certain activities, the summary should indicate the areas in which the respondent retains sufficient capacity to make particular decisions of a limited guardianship. The agency's or professionals' report also may make recommendations with respect to a guardianship plan that will meet the respondent's needs, the ways in which a guardian should assist or care for the respondent, the persons or agencies that are most qualified or suitable to serve as the

respondent's guardian or guardians, and the manner in which the respondent's guardianship should be monitored, reviewed, or reassessed.

6.9 Judicial Determination of Incapacity

A. Determination by Clerk, Judge, or Jury

Determinations of mental incapacity or "incompetency" under G.S. Ch. 35A, Art. 1 are made by the Clerk of Superior Court, by a jury if a jury trial has been properly demanded or ordered pursuant to G.S. 35A-1110, or by a Superior Court Judge (or jury) if an order adjudicating a respondent's incapacity is appealed to the Superior Court pursuant to G.S. 35A-1115.

B. Statutory Elements

To find a respondent incapacitated, the Clerk (or jury or judge) must find that

- the respondent lacks sufficient capacity to manage his or her affairs or to make or communicate important decisions regarding his or her person, family, or property, *and*
- the respondent's lack of capacity is due to mental illness, mental retardation, epilepsy, cerebral palsy, autism, inebriety, senility, disease, injury, or similar cause or condition.

C. Determinations of Fact and Law

The issue of incapacity, for purposes of appointing a guardian to manage the personal or financial affairs of an adult, involves a *legal*, rather than a medical or social, determination of the adult's capacity to make decisions and manage his or her personal or financial affairs.

D. Evidence of Incapacity

In determining whether a respondent is incapacitated, the Clerk (or jury or judge) should consider evidence regarding

- the respondent's medical condition;
- the respondent's cognition;
- the respondent's everyday functioning;
- the respondent's values and preferences;
- the risk of harm to the respondent or the respondent's property resulting from the respondent's incapacity and the level of supervision needed to protect the respondent or the respondent's property; and
- the means that may be available to enhance the respondent's capacity.

If the Clerk (or jury or judge) determines that the respondent is not incapacitated, the Clerk (or judge) must enter an order dismissing the proceeding.

E. Standard of Proof

In order to find a respondent incapacitated, the Clerk's (or jury's or judge's) findings must be based on clear, cogent, and convincing evidence. G.S. 35A-1112(d); *In re Efird*, 114 N.C. App. 635 (1994).

F. Finding Regarding Incapacity

An order appointing a guardian for an incapacitated respondent should include findings regarding the nature and extent of the respondent's incapacity. *See* G.S. 35A-1112(d). If the Clerk orders a limited guardianship, the Clerk's order must include findings regarding the nature and extent of the respondent's incapacity as they relate to the respondent's need for a guardian. G.S. 35A-1215(b).

G. The Judicial Decision-Making Process

When the Clerk adjudicates the issue of incapacity and appoints a guardian for an incapacitated respondent, the Clerk's order should

- appropriately balance the respondent's well-being and rights;
- promote the respondent's rights to autonomy and self-determination to the greatest extent possible;
- identify and take advantage of less restrictive alternatives to guardianship whenever possible;
- provide appropriate guidance to guardians and establish procedures for monitoring guardianship; and
- limit the scope of guardianship when a limited guardianship is appropriate.

H. Limited Guardianship Orders

When the Clerk orders a limited guardianship, the Clerk's order should specify the legal rights that will be retained by the ward and the limits that are imposed with respect to the guardian's powers and duties. G.S. 35A-1215(b).

Appendix 6-1 Clinical Professionals

Reprinted by permission of the American Bar Association and the American Psychological Association from *Judicial Determination of Capacity of Older Adults in Guardianship Proceedings*.

Note: The information provided in this appendix is meant to highlight some of the strengths that varied professionals may bring to the capacity evaluation practice. It is not meant to define or limit the absolute, necessary, or full scope of practice for these professionals, but rather to highlight some potential strengths each discipline may bring to the capacity evaluation process.

A clinician is a general term for a healthcare professional who works with patients. A wide range of clinicians may bring expertise to the capacity evaluation process.

Geriatricians, geriatric psychiatrists, or geropsychologists are practitioners with specialized training in aging. They are experienced in considering the multiple medical, social, and psychological factors that may impact an older adult's functioning. A geriatric assessment team is comprised of multiple disciplines, each with advanced training in syndromes of aging.

Neurologists are medical doctors (M.D.) with specialized training in brain function. They may address how specific neurological conditions (e.g., dementia) are affecting the individual and his or her capacity.

Neuropsychologists are psychologists with specialized training in cognitive testing. They may address relationships between neurological conditions, cognitive tests results, and an individual's functional abilities.

Nurses have medical expertise and some, such as visiting nurses in Area Agencies on Aging, may have in-depth information on how a person's medical condition is impacting functioning in the home. Geriatric nurse practitioners are advanced practice nurses with additional credentials to assess and treat the medical problems of aging.

Occupational therapists are professionals with advanced degrees specializing in the assessment of an individual's functioning on everyday tasks, such as eating, meal preparation, bill paying, cleaning, and shopping.

Physicians are medical doctors (M.D.). Physicians who are primary care clinicians or internists can provide a summary of the individual's major medical conditions. In some cases, the physician may have provided care to the individual over many years and can provide a historical perspective on the individual's functioning (although this cannot be assumed).

Psychiatrists are medical doctors (M.D.) with specialized training in mental health. They may address how specific psychiatric conditions (e.g., schizophrenia) and related emotional and mental systems may be affecting the individual and his or her capacity. Geropsychiatrists receive additional training in problems of aging; forensic psychiatrists receive additional training in mental health and the law.

Psychologists are clinicians with advanced training in behavioral health. They may utilize standardized testing and in-depth assessment, which is useful when the judge wants detailed information about areas of cognitive or behavioral strengths or weaknesses. Geropsychologists receive additional training in problems of aging; forensic psychologists receive additional training in mental health and the law.

Social workers are trained to consider the multiple determinants on an individual's social functioning, and are often knowledgeable about a wide range of social and community services that may assist the individual.

Appendix 6-2 Medical Conditions Affecting Capacity

Reprinted by permission of the American Bar Association and the American Psychological Association from *Judicial Determination of Capacity of Older Adults in Guardianship Proceedings*.

Dementia is a general term for a medical condition characterized by a loss of memory and functioning. Primary degenerative dementias are those with disease processes that result in a deteriorating course, including Alzheimer's disease, Lewy Body Dementia, and Frontal Dementia (each associated with a type of abnormal brain cell).

Condition	Source	Symptoms	Treatability
Alcoholic Dementia	A fairly common form of dementia, caused by long-term abuse of alcohol, usually for 20 years or more. Alcohol is a neurotoxin that passes the blood- brain barrier.	Memory loss, problem solving difficulty, and impairments in visuospatial function are commonly found in patients with alcohol dementia.	Alcohol dementia is partially reversible, if there is long term sobriety—cessation of use. There is evidence to suggest that some damaged brain tissue may regenerate following extended sobriety, leading to modest improvements in thinking and function.
Alzheimer's disease ("AD")	Most common type of dementia, caused by a progressive brain disease involving protein deposits in brain and disruption of neurotransmitter systems.	Initial short-term memory loss, followed by problems in language and communication, orientation to time and place, everyday problem solving, and eventually recognition of people and everyday objects. In the early stages, an individual may retain some decisional and functional abilities.	Progressive and irreversible, resulting ultimately in a terminal state. Medications may improve symptoms and cause a temporary brightening of function in the earlier stages.
Bipolar Disorder or Manic Depression	A psychiatric illness characterized by alternating periods of mania and depression.	Affects functional and decisional abilities in the manic stage or when the depressed stage is severe.	Can be treated with medications, but requires a strong commitment to treatment on the part of the individual. Varies over time; periodic re-evaluation is needed.

Condition	Source	Symptoms	Treatability
Coma	A state of temporary or permanent unconsciousness.	Minimally responsive or unresponsive, unable to communicate decisions and needs a substitute decision maker.	Often temporary; regular re- evaluation required.
Delirium	A temporary confusional state with a wide variety of causes, such as dehydration, poor nutrition, multiple medication use, medication reaction, anesthesia, metabolic imbalances, and infections.	Substantially impaired attention and significant decisional and functional impairments across many domains. May be difficult to distinguish from the confusion and inattention characteristic of dementia.	Often temporary and reversible. If untreated may proceed to a dementia. It is important to rule out delirium before diagnosing dementia. To do so, a good understanding of the history and course of functional decline, as well as a full medical work-up, are necessary.
Frontal or Frontotemporal Dementia (Pick's disease is one example)	Broad category of dementia caused by brain diseases or small strokes that affect the frontal lobes of the brain.	Problems with personality and behavior are often the first changes, followed by problems in organization, judgment, insight, motivation, and the ability to engage in goal-oriented behavior.	Early in their disease, patients may have areas of retained functional ability, but as disease progresses they can rapidly lose all decisional capacity.
Jacob-Creutzfeldt Disease	A rare type of progressive dementia affecting humans that is related to 'mad cow' disease.	The disease usually has a rapid course, with death occurring within two years of initial symptoms. These include fatigue, mental slowing, depression, bizarre ideations, confusion, and motor disturbances, including muscular jerking, leading finally to a vegetative state and death.	There is no treatment currently and the disease is relentlessly progressive.

Condition	Source	Symptoms	Treatability
Diffuse Lewy Body Dementia (DLB)	A type of dementia on the Parkinson disease spectrum.	DLB involves mental changes that precede or co-occur with motor changes. Visual hallucinations are common, as are fluctuations in mental capacity.	This disease is progressive and there are no known treatments. Parkinson medications are often of limited use.
Major Depression	A very common psychiatric illness.	Sad or disinterested mood, poor appetite, energy, sleep, and concentration, feelings of hopelessness, helplessness, and suicidality. In severe cases, very poor hygiene, hallucinations, delusions, and impaired decisional and functional abilities.	Treatable and reversible, although in some resistant cases electroconvulsive therapy (ECT) is needed.
Developmental Disorders ("DD") including Mental Retardation ("MR")	Brain-related conditions that begin at birth or childhood (before age 18) and continue throughout adult life. MR concerns low- level intellectual functioning with functional deficits that can be found across many kinds of DD, including autism, Down syndrome, and cerebral palsy.	Functioning tends to be stable over time but lower than normal peers. MR is most commonly mild. Some conditions such as Downs syndrome may develop a supervening dementia later in life, causing decline in already limited decisional and functional abilities.	Not reversible, but everyday functioning can be improved with a wide range of supports, interventions, and less restrictive alternatives. Individuals with DD have a wide range of decisional and functional abilities and, thus, require careful assessment by skilled clinicians.
Parkinson's Disease (PD)	Progressive brain disease that initially affects motor function, but in many cases proceeds to dementia.	PD presents initially with problems with tremors and physical movement, followed by problems with expression and thinking, and leading sometimes to dementia after a number of years.	PD is progressive, but motor symptoms can be treated for many years. Eventually, medications become ineffective and most physical and mental capacities are lost. Evaluation of capacity must avoid confusion of physical for cognitive impairment.

Condition	Source	Symptoms	Treatability
Persistent Vegetative State (PSV)	A state of minimal or no responsiveness following emergence from coma.	Patient is mute and immobile with an absence of all higher mental activity. Cannot communicate decisions and requires a substitute decision maker for all areas.	Cases of PSV usually lead to death within a year's time.
Schizophrenia	A chronic brain- based psychiatric illness	Hallucinations and delusions; poor judgment, insight, planning, personal hygiene, and interpersonal skills. May range from mild to severe, and impact on functional and decisional abilities, are likewise variable.	Many symptoms can be successfully treated with medication. Capacity loss often occurs when patients go off their medications.
Stroke or Cerebral Vascular Accident ("CVA")	A significant bleeding in the brain, or a blockage of oxygen to the brain.	May affect just one part of the brain, so individuals should be carefully assessed to determine their functional and decisional abilities.	Some level of recovery and improved function over the first year; thus a temporary guardianship might be considered if the stroke is recent.
Traumatic Brain Injury ("TBI")	A blow to the head that usually involves loss of consciousness.	Individuals with mild and moderate TBI may appear superficially the same as before the accident, but have persisting problems with motivation, judgment, and organization. Those with severe TBI may have profound problems with everyday functioning.	Usually show recovery of thinking and functional abilities over the first year; thus a temporary guardianship should be considered if the injury is recent.
Vascular Dementia ("VaD")	Multiple strokes that accumulate and cause dementia.	Decisional and functional strengths and weaknesses may vary, depending on the extent and location of the strokes.	May remain stable over time if underlying cerebrovascular or heart disease is successfully managed.

Appendix 6-3 Dementia Overview

Reprinted by permission of the American Bar Association and the American Psychological Association from *Assessment of Older Adults with Diminished Capacity*.¹

What is dementia?

Dementia is a syndrome characterized by decline in memory in association with either decline in other cognitive abilities, e.g., judgment and abstract thinking, or personality change. The resulting impairment must be severe enough to interfere with work or usual social activities or relationships. The requirement for decline distinguishes dementia from life-long mental retardation, although a person with mental retardation can develop dementia if his or her cognitive abilities decline from a previous level. The requirement also means that a person with high previous intelligence can have dementia if his or her cognitive abilities decline interferes with work or usual social activities or relationships. Outdated terms: terms that were used in the past, such as *senility, chronic brain syndrome*, and *hardening of the arteries*, are rarely used now because they are imprecise and inaccurate.

What causes dementia?

Dementia can be caused by more than 70 diseases and conditions. The most common cause is Alzheimer's disease, which is present in 60 percent to 75 percent of dementia cases in the United States. The second most common cause is vascular or multi-infarct disease, which is present in 10 percent to 20 percent of cases.

Alzheimer's disease and multi-infarct disease often coexist in a condition referred to as *mixed dementia*. Other diseases and conditions that can cause dementia include Lewy body disease, fronto-temporal disease (including Pick's disease), Creutzfeld-Jacob disease, Parkinson's disease, Huntington's disease, amyotrophic lateral sclerosis (Lou Gehrig's disease), and AIDS.

Reversible dementia. In a small minority of people with dementia, the condition may be partially or completely reversible with treatment of underlying causes, such as chronic infections, thyroid disease, and normal pressure hydrocephalus. Unfortunately, these situations are rare.

How common is dementia?

The total number of people with dementia in the United States is not known. That is because most people with dementia do not have a diagnosis, and no study with a nationally representative sample and procedures for diagnosing dementia has been completed.

^{1.} Prepared by Katie Maslow, M.S.W., of the Alzheimer's Association, Washington, D.C. [references omitted]. *Assessment of Older Adults with Diminished Capacity* is available on-line at: www.apa.org/pi/aging/diminished_capacity.pdf.

Estimates of the number of people with Alzheimer's disease come from studies of smaller community samples. Results of two widely cited studies indicate that 2 percent of people age 65 to 74 have Alzheimer's disease, with the proportion increasing to 8 percent to 19 percent of people age 75 to 84, and 29 percent to 42 percent of people age 85 and over. Combining these proportions and U.S. Census data indicates that 2.6 million to 4.5 million people age 65 and over (7 percent to 13 percent of all people age 65 and over) had Alzheimer's disease in 2000. Since prevalence rises rapidly with age, the total number of people with Alzheimer's disease will increase greatly as the age groups 75 to 84 and 85+ grow in coming decades. Alzheimer's disease occurs in a small proportion (probably less than one percent) of people under age 65. That proportion may increase in the future as the disease is recognized earlier. Assuming that Alzheimer's disease is present in 60 percent to 75 percent of all cases of dementia in the U.S. and that it affected 2.6 to 4.5 million people age 65 and over in 2000, one could estimate that 3.4 to 7.5 million people age 65 and over had dementia in 2000. Preliminary data from the Health and Retirement Survey indicate that there may be 400,000 people under age 65 with dementia, for a total of 3.9 to 8 million people with dementia in all age groups in 2000.

What are the symptoms of dementia?

As noted above, dementia is characterized by decline in memory associated with decline in other cognitive abilities or personality change. Many descriptions of the symptoms of dementia focus primarily on symptoms of Alzheimer's disease. Symptoms of other dementing diseases and conditions are often described only as they differ from the symptoms of Alzheimer's disease.

Alzheimer's disease generally begins gradually. Its causes are not known, but much has been learned in recent years about the risk factors, biology, and course of the disease.

The earliest symptoms of Alzheimer's disease are usually memory problems, especially problems with learning and recall of new information. Other early symptoms include difficulty with language (e.g., word-finding) and disturbances in visuospatial skills that can result in getting lost in a familiar setting. Deficits in executive functions (e.g., planning, organization, and judgment) are also common. These cognitive changes limit the person's ability to work and carry out activities that are needed for independent living, e.g., driving, shopping, cooking, and managing finances. The person may or may not be aware of, and be disturbed by, these changes. Alzheimer's disease is progressive.

Over time, the person's cognitive deficits worsen, and other kinds of symptoms appear. Many people with Alzheimer's disease are depressed. Some become withdrawn, apathetic, and/or irritable. Agitation is common, and some people with Alzheimer's disease develop psychiatric and behavioral symptoms, e.g., delusions, aggression, wandering, and inappropriate sexual behaviors. Most people with the disease require 24-hour supervision at least in the middle stage of their illness. Eventually, they become unable to bathe, dress, toilet, and feed themselves. Gait and swallowing difficulties are also common in the late stage of the disease. Death usually occurs sooner than would be predicted on the basis of population data. Vascular or multi-infarct dementia differs from Alzheimer's dementia in that it generally begins more abruptly and exhibits a step-wise progression of symptoms. This is because the condition is usually caused by a stroke, multiple small strokes, or changes in blood supply to the brain that result in specific brain lesions. A person's cognitive and other symptoms depend on the type, location, and extent of these lesions; thus, symptoms vary greatly from one person to another.

Lewy body disease differs from Alzheimer's disease in that it usually progresses more rapidly. Visual hallucinations, fluctuating cognitive abilities, changing attention and alertness, and motor signs of parkinsonism are also more common.

Fronto-temporal disease (including Pick's disease) differs from Alzheimer's disease in that learning ability and visuospatial skills are often less affected, and noncognitive symptoms are more common. Patients frequently exhibit profound apathy, distractability, and impulsivity.

Can stages of dementia be identified?

Various staging systems have been developed for dementia. These systems are useful because they provide a conceptual framework that often helps families, care providers, and others understand where their relative or client is in the course of his or her illness and, therefore, think about and plan for the person's current and future care. Some relatively simple staging systems identify only 3 stages (mild, moderate, and severe) and define the stages in very general terms. Other staging systems are more complex and precise. An example of the latter type is the Global Deterioration Scale, a 7-stage system based on the severity of a person's cognitive and self-care deficits and psychiatric and behavioral symptoms.

Despite the usefulness of this and other staging systems, it is important to remember that the progression of dementing diseases and conditions and the timing of particular symptoms vary greatly from one person to another. Thus few patients progress through the stages exactly as they are defined in any system.

How can cognitive changes that are common in normal aging be distinguished from dementia?

It is often very difficult to distinguish memory problems and other cognitive changes that are common in normal aging from the early symptoms of dementia, in part because cognitive changes in normal aging are not well understood.

In its dementia guideline, the American Medical Association points out that a person with dementia will eventually become unable to maintain independent functioning, whereas independent functioning is preserved in normal aging. To distinguish dementia and normal aging without waiting to see whether the person's functioning worsens, the guideline suggests several comparisons: for example, in dementia, the person's family is likely to be more concerned about his or her forgetfulness, whereas in normal aging, the person may be more concerned; similarly, in dementia, there is likely to be notable decline in memory for recent events and ability to converse, whereas in normal aging, the person remembers important events and maintains the ability to converse. These and other comparisons are helpful but not definitive in distinguishing the two conditions. Mild Cognitive Impairment is a condition that is receiving increasing attention as researchers attempt to understand the causes of Alzheimer's disease and find ways to prevent and treat it. For research purposes, it is efficient to study people who are at high risk for the disease, and many elderly people are now enrolled as subjects in observational studies and clinical trials where they are diagnosed as having mild cognitive impairment. An unknown number of elderly people are also being diagnosed with mild cognitive impairment outside of research settings. Many researchers and clinicians believe that all people with mild cognitive impairment will eventually transition to Alzheimer's disease. Reported rates of transition range from 6 percent to 25 percent per year in individuals age 66 to 81 at the start of the study. Some clinicians and advocates question the wisdom of diagnosing mild cognitive impairment in people who are quite old at time of diagnosis, may be upset by the diagnosis, may not transition for four or more years, and may be denied insurance and/or admission to certain residential care facilities if the diagnosis is known.

Why is it important to diagnose dementia and the underlying cause of the dementia?

Some physicians are reluctant to diagnose dementia or its underlying cause because they think the conditions are hopeless and are hesitant to call attention to them unless asked by the family. Over the past decade, dementia and its causes are being diagnosed more often, primarily because of the availability of medications for Alzheimer's disease and greater general awareness of Alzheimer's and dementia. Still many people with dementia have not been diagnosed. Physicians may be aware of a patient's cognitive deficits even if they have not conducted a formal evaluation, but even when a formal diagnosis is made, the patient and family may not be told, and the diagnosis may not be entered into his or her medical record.

Diagnosis of dementia is important because it allows the person, and perhaps more so his or her family, to understand what is happening to the person and increases the likelihood that they will access available information and supportive services. It also increases the likelihood that physicians will initiate treatments and be alert to limitations in the person's ability to report symptoms accurately, manage medications safely, and understand and comply with other recommendations. Early diagnosis is important because it gives the person and family time to make financial, legal, and medical decisions while the person is capable.

How can dementia be diagnosed?

Dementia and Alzheimer's disease can be diagnosed with high accuracy (90 percent or higher) when standardized diagnostic criteria are used. Diagnosis of vascular or multi-infarct disease, Lewy body disease, and fronto-temporal disease is often more difficult because many people with these conditions have atypical or nonspecific symptoms.

The first steps in diagnosis are a focused history and physical, mental status testing, and discussions with the family, if any. Laboratory tests are often used, primarily to rule out reversible or partially reversible causes of dementia. There is disagreement about the value of neuroimaging procedures, but virtually all experts agree that these procedures are useful for younger patients and patients with unusual symptoms.

Delirium and depression can present with symptoms similar to dementia. Recognition and differential diagnosis of these three conditions is important. Delirium is an acute condition that can and should be treated quickly. Depression is also treatable in older people. In addition, however, people with dementia are at increased risk of developing delirium, and many people with dementia also have depression; thus, the three conditions often coexist. Effective treatment of coexisting delirium and/or depression may improve cognitive functioning in a person with dementia, although research suggests that treatment for depression often does not have as much effect as expected on the person's cognitive functioning.

Treatment of dementia

Many medical associations and other groups have developed guidelines and consensus statements about treatment of dementia. These documents differ in length, primary focus, and intended audience, but their recommendations are similar. While acknowledging that the effects of available medications for Alzheimer's disease are often modest, the documents generally recommend an initial trial of the medications.

Aggressive treatment of cardiovascular conditions is recommended since these conditions can cause vascular dementia and hasten onset of symptom development in people with Alzheimer's disease. The guidelines and consensus statements recommend careful evaluation of mood and behavioral symptoms and efforts to manage these symptoms nonpharmacologically, if possible. They also recommend treatment of depression, attention to safety issues (e.g., driving, wandering, and firearms), referrals to community services, and involvement and support of family caregivers.

Coexisting medical conditions in people with dementia

Many people with dementia also have other serious medical conditions. Medicare fee-forservice claims for 1999 show, for example, that 30 percent of beneficiaries with dementia also had coronary heart disease, 28 percent also had congestive heart failure, 21 percent also had diabetes, and 16 percent also had thyroid disease. These medical conditions and the medications and other procedures that are used to treat the conditions can worsen cognitive and other symptoms in a person with dementia. At the same time, dementia clearly complicates the treatment of the other conditions. Families and other informal and paid caregivers of people with dementia and co-existing medical conditions are often coping with extremely difficult care situations.

Where do people with dementia live?

No precise information is available about where people with dementia live, but available data suggest that at any one time, about 20 percent of all people with dementia are in nursing homes; about 10 percent are in assisted living or other residential care facilities; and the remaining 70 percent are at home alone or with a family member or other informal caregiver.

People with dementia who live alone. Studies indicate that about 20 percent of people with dementia live alone. About half of these people have a relative or friend who functions as a

caregiver, but the other half have no one. Some of these individuals have mild dementia, but many have moderate to severe dementia. They may come to the attention of attorneys when a landlord, neighbor, or law enforcement official realizes they are unable to care for themselves and may create safety problems for others. Lack of an available surrogate decisionmaker may make them difficult clients.

Appendix 6-4 Temporary and Reversible Causes of Confusion

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Causes of Delirium

If any of these are present:

Common Medical Causes

- Provide appropriate treatment or accommodations.
- Re-assess capacity after treatment or accommodation.

Did the evaluator consider how long the pro- and vitals done?	blem has been going on? Were standard lab tests
Drugs	More than 6 meds or more than 3 new meds or use of drugs that cause confusion?
Electrolytes	Low sodium, blood sugar, calcium, etc?
Lack of Drugs, Water, Food	Pain, malnutrition, dehydration?
Infection or Intoxification	Sepsis, urinary track infection, pneumonia; alcohol, metals, solvents?
Reduced Sensory Input	Impaired vision, hearing, nerve conduction?
Intracranial Causes	Subdural hematoma, meningitis, seizure, brain tumor?
Urinary Retention or Fecal Impaction	Drugs, constipation?
Myocardial	Heart attack, heart failure, arrhythmia?
Other Causes of Confusion: Liver or kidney disease Vitamin deficiency Post surgical state	Hepatitis, diabetes, renal failure? Folate, nicotinic acid, thiamine, vitamin B12? Anesthesia, pain?

The Delirium mnemonic is adapted from a chapter by JL Rudolph and ER Marcantonio.

Common Psychosocial Causes

Was a careful case history taken?

Transfer trauma (a recent move that has the individual disoriented)?

Recent death of a spouse or loved one?

Recent stressful event?

Depression and anxiety?

Insomnia?

Common Miscommunication Problems

Did the evaluator assess whether the person could see, hear, and understand questions?

Difficulty understanding English?

Decisions impacted by religious, cultural, or ethnic background?

Low educational or reading level; illiterate?

Difficulty hearing or seeing?

Appendix 6-5 Medications That May Commonly Cause Confusion

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Class	Uses	Examples of More Problematic Medicines
Anticholinergic	Block the action of the neurotransmitter acetylcholine	Atropine, Scopolamine, and many Antihistamines such as Chlorpheniramin, Cyproheptadine, Dexchlorpheniramine, Diphenhydramine, Hydroxyzine, Promethazine
Antidepressants	Depression	Amitriptyline, Doxepin
AntiParkinson drugs	Parkinson's disease symptoms	Levodopa (L-dopa or Sinemet), Bromocriptine
Antipsychotics	Hallucinations, Delusions	Chlorpromazine, Haloperidol, Thioridazine, Thiothixene
Barbiturates	Sleep and Anxiety	Phenobarbital, Secobarbital

Class	Uses	Examples of More Problematic Medicines
Benzodiazepines	Sleep and Anxiety	Chlordiazepoxide, Diazepam, Flurazepam, Nitrazepam
Histamine-2 (H2) Blockers	Block the action of gastric acid secretion	Cimetidine, Famotidine, Nizatidine, Ranitidine
Nonsteroidal antinflam- matory drugs (NSAIDs)	Pain	Ibuprofen, Indomethacin
Opioids	Pain	Morphine, Propoxyphene, Meperidine
Steroids	Inflammation, Pulmonary disease	Predisone, Dexamethasone, Methylprednisolone

Appendix 6-6 Distinguishing Delirium from Dementia

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Characteristics	Delirium	Dementia
Onset	Acute	Insidious
Course	Fluctuating	Stable and deteriorating
Duration	Hours to weeks, sometimes longer	Months to years
Attention	Poor	Usually normal
Perception	Hallucinations and misperceptions	Usually normal
Consciousness and orientation	Clouded; disoriented	Clear until late stages
Memory	Poor memory after 1 minute or more	Poor memory after 15 minutes or more, but may be okay in shorter time periods

Note: The most critical factors in distinguishing a temporary cause of impairment from dementia are:

- comes on rather suddenly,
- fluctuates between good and bad,
- problems with attention.

Appendix 6-7 Cognition and Cognitive Testing

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Cognitive Screening

Cognitive screening tests are useful for giving a general level of overall cognitive impairment. They may be used as an overall screening to determine whether additional testing is needed. They may also be used for individuals with more severe levels of impairment who cannot complete other tests.

Acronym	Screening Test Name	Screening Test Description
BIMC	Blessed Information Memory Concentration Test	33-point scale with subtests of orientation, personal information, current events, recall, and concentration. There is a short version with six items.
Cognistat	The Neurobehavioral Cognitive Status Examination	This screening test examines language, memory, arithmetic, attention, judgment, and reasoning.
MMSE	Mini Mental State Examination	30-point screening instrument that assesses orientation, immediate registration of three words, attention and calculation, short-term recall of three words, language, and visual construction.
MSQ	Mental Status Questionnaire	10-item, 10-point scale assessing orientation to place, time, person, and current events. It has low to modest sensitivity for detecting neurological illness.
7MS	The Seven Minute Screen	This screening instrument combines four tests, each with separate scores of various ranges: recall, verbal fluency, orientation, and clock drawing.
SPMSQ	Short Portable Mental Status Questionnaire	10-point scale scored as a sum of errors on subtests of orientation, location, personal information, current events, and counting backwards. High scores (8–10) equals severe impairment. Race and age corrections to scores are available.

Appendix 6-8 Neuropsychological Assessment and Testing

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Neuropsychological Testing

A neuropsychological evaluation typically assesses various areas called "domains" with neuroanatomic correlates (see table below). Some of these areas are assessed through observation of the client's presentation and communication during a clinical interview. Most are assessed through tests that have standard instructions, standard scoring, and are referenced to adults of similar age and education to provide performance range that is "normreferenced."

Domain	Description	Relevance to Capacity	Methods of Assessment
Appearance	√ Grooming, weight, interaction with others	√ Appearance, orientation, and interaction indicate general mental condition and may reveal problems with judgment	√ Observation
Sensory Acuity	√ Ability to hear, see, smell, touch	 √ Sensory deficits impact functioning in the environment. √ Sensory deficits may make performance on neuropsychological tests worse and, therefore, should be considered in interpreting scores 	√ Observation √ Structured hearing tests √ Structured vision tests
Motor Activity	 √ Motor activity (active, agitated, slowed) √ Motor skills (gross and fine) detection of visual, auditory, tactile stimuli 	 ✓ Motor deficits impact functioning in the environment. ✓ Motor deficits may make performance on neuropsychological tests worse and therefore should be considered in interpreting scores 	 √ Observation √ Finger Tapping √ Grooved Pegboard √ Finger Oscillation Test √ Tactual Performance Test

Domain	Description	Relevance to Capacity	Methods of Assessment
Attention	√ Attend to a stimulus √ Concentrate on a stimulus over brief time periods	√ Basic function necessary for processing information	 √ Digit Span Forward and Backward √ Working Memory (from the WMS-III) √ Paced Auditory Serial Attention Test (PASAT) √ Visual Search and Attention Test (VSAT) √ Visual Attention (from the Dementia Rating Scale (DRS)) √ Trails A of the Trail Making Test √ Continuous Performance Test
Memory	 √ Working memory: attend to verbal or visual material over short time periods; hold two ideas in mind √ Short-term or recent memory and learning: ability to encode, store, and retrieve information √ Long-term memory: remember information from the past 	 √ Some memory is important for all decision making. √ Although memory aids can be used, individuals must be able to hold ideas in mind ("working memory") √ Memory is especially important for functioning at home and remembering to perform critical activities (like take medications) and be safe (like turn off stove) 	 √ Memory Assessment Batteries (from the WMS-III or the Memory Assessment Scales (MAS)) √ Auditory Verbal Learning Test √ Recognition (from the DRS) √ Fuld Object Memory Evaluation √ California Verbal Learning Test (CVLT) √ Hopkins Verbal Learning Test (HVLT) √ Rey Auditory Verbal Learning Test

Domain	Description	Relevance to Capacity	Methods of Assessment
Communication (also called expressive language)	√ Express self in words or writing √ State choices	√ Basic function necessary to convey choices in decision making	 √ Communication during testing √ Controlled Oral Word Association Test (commonly called the verbal fluency) √ Boston Diagnostic Aphasia Examination (BDAE) √ Multilingual Aphasia Examination √ Boston Naming Test (BNT)
Understanding (also called receptive language)	√ Understand written, spoken, or visual information	√ Important when making decisions, especially regarding new problems or new treatments √ Critical to understanding the options	√ Understanding during testing √ Boston Diagnostic Aphasia Examination (BDAE) √ Multilingual Aphasia Examination
Arithmetic or Mathematical Skills	√ Understand basic quantities √ Make simple calculations	√ Important for financial decision making √ Important for day to day financial tasks	√ Arithmetic subtest of WAIS-III
Reasoning	√ Compare two choices √ Reason logically about outcomes	√ Critical in almost all decision making	$\sqrt{Verbal subtests}$ from the WAIS-III, such as Similarities, Comprehension $\sqrt{Proverbs}$

Domain	Description	Relevance to Capacity	Methods of Assessment
Visual-Spatial and Visuo-Constructional Reasoning	√ Visual-spatial perception √ Visual problem solving	√ Important for functioning in the home and community √ Essential for driving	 √ Performance subtests from WAIS-III, such as Block Design, Object Assembly, Matrix Reasoning √ Hooper Visual Organization Test √ Visual Form Discrimination Test √ Visual Form Discrimination Test √ Clock Drawing √ Rey-Osterrieth Complex Figure √ Line Bisection √ Bender Visual Motor Gestalt Test √ Tactual Performance Test
Executive Functioning	√ Plan for the future √ Demonstrate judgment √ Inhibit inappropriate responses	√ Essential for most decision making √ Important to avoid undue influence	 √ Similarities (from the WAIS-III) √ Trails B of the Trail Making Test (TMT) √ Wisconsin Card Sorting Test √ Stroop Color Word Test √ Delis-Kaplan Executive Function System (DKEFS) √ Mazes √ Tower of London
Insight	 √ Acknowledge deficits √ Acknowledge the potential benefit of intervention √ Accept help √ Often considered a part of "executive function" 	$\sqrt{\text{Critical to the use}}$ of less restrictive alternatives $\sqrt{\text{An individual needs}}$ to be able to recognize they have a deficit and be willing to accept help in order to use home services	√ Interview √ Comparing observed deficits with the individual's reports of deficits √ Informant reports

Appendix 6-9 Brief Guide to Psychological and Neuropsychological Instruments

Reprinted by permission of the American Bar Association and the American Psychological Association from *Assessment of Older Adults with Diminished Capacity*.

For the purposes of this fact sheet, psychological tests are described in four categories: (1) tests used to evaluate and document symptoms of cognitive impairment; (2) tests used to rate the type and severity of emotional or personality disorder; (3) tests used to detect unusual response styles, or the validity of test taking; and (4) tests used to evaluate specific functional capacities or abilities. A brief guide to cognitive screening instruments is provided at the end of this appendix.

This listing is not meant as an exhaustive or definitive list, but provides an overview of some of the more commonly assessed domains and tests. The number of tests can be somewhat overwhelming; added to this is that evaluators may refer to tests by shortened names or abbreviations. For more information on specific tests, please refer to the reference books noted at the end of this chapter.

A. Tests for Evaluating Cognitive Impairment

A comprehensive psychological or neuropsychological evaluation would typically assess the domains of appearance and motor activity, mood, level of consciousness, attention, memory, language, visual-spatial or constructional ability, reasoning, fund of information, and calculations. Some of these areas are assessed through observation of the client's presentation and communication during a clinical interview. Other areas can be assessed through standardized, norm-referenced tests.

1. Appearance, Orientation, and Motor Activity

Definition: Although typically assessed through observation, not testing, an important part of a comprehensive evaluation is examination of appearance, grooming, weight, motor activity (active, agitated, slowed), and orientation to person, place, time, and current events.

2. Level of consciousness

Definition: Although also typically assessed through observation, not testing, the evaluator will also observe the degree of alertness and general mental confusion, rating as alert, lethargic, or stupor. Additional assessment with basic measure of attention may be necessary.

3. Attention

Definition: Attention concerns the basic ability to attend to a stimulus; also the ability to sustain attention over time, as well as freedom from distractibility.

Tests:

• Digit Span Forward/Digit Span Backward from the Wechsler Adult Intelligence Scale-III (WAIS-III) or the Wechsler Memory Scale-III (WMS-III)

- Working Memory (from the WMS-III)
- Paced Auditory Serial Attention Test (PASAT)
- Visual Search and Attention Test (VSAT)
- Visual Attention (from the Dementia Rating Scale (DRS))
- Trails A of the Trail Making Test

4. Memory and Learning

Definition: Memory assessment involves evaluation of the system by which individuals register, store, retain, and retrieve information in verbal and visual domains.

Tests:

- Memory Assessment Batteries (from the WMS-III or the Memory Assessment Scales (MAS))
- Auditory Verbal Learning Test
- Recall and Recognition (from the DRS)
- Fuld Object Memory Evaluation
- California Verbal Learning Test (CVLT)
- Hopkins Verbal Learning Test (HVLT)

5. Language

Definition: Language includes a number of abilities such as spontaneous speech, the fluency of speech, repetition of speech, naming or word finding, reading, writing, comprehension. The presence of aphasia (difficulty receiving or expressing speech) and thought disordered speech is also noted.

Tests:

- Boston Naming Test (BNT)
- Controlled Oral Word Association Test (commonly called the "FAS")
- Boston Diagnostic Aphasia Examination (BDAE)
- Token Test

6. Executive Function

Definition: The assessment of executive functions concern planning, judgment, purposeful and effective action, concept formation, and volition. This area is often an extremely important aspect of capacity.

Tests:

- Similarities (from the WAIS-III)
- Trails B of the Trail Making Test (TMT)
- Wisconsin Card Sorting Test

- Stroop Color Word Test
- Delis-Kaplan Executive Function System (DKEFS)
- Malloy
- Mazes

7. Visual-Spatial and Visuo-Constructional Reasoning and Abilities

Definition: Visual spatial assessment involves evaluation of visual-spatial perception, problem solving, reasoning, and construction or motor performance involving visual-spatial skills.

Tests:

- Performance subtests from WAIS-III, such as Block Design, Object Assembly, Matrix Reasoning
- Hooper Visual Organization Test
- Visual Form Discrimination Test
- Clock Drawing
- Rey-Osterrieth Complex Figure
- Line Bisection

8. Verbal Reasoning and Abilities

Definition: The assessment of verbal reasoning involves evaluation of logical thinking, practical judgments, and comprehension of relationships. Related abilities are fund of knowledge, which is the extent of information known and retained, and calculation concerning arithmetic skills.

Tests:

- Verbal subtests from the WAIS-III, such as Similarities, Comprehension, Information, Arithmetic
- Proverbs

9. Motor Functions

Definition: Tests of motor function provide basic ability about praxis or motor skills in each hand, which are important for distinguishing observed deficits on tasks involving motor performance from primary (motor) or secondary (central nervous system) deficits.

Tests:

- Finger Tapping
- Grooved Pegboard

B. Tests for Emotional and Personality Functioning

Tests of emotional and personality functioning can provide a more objective means to assess the range and severity of emotional or personal dysfunction.

1. Mood and Symptoms of Depression, Anxiety, and Psychoses

Definition: These scales assess the individual's degree of depressed or anxious mood, and associated symptoms such as insomnia, fatigue, low energy, low appetite, loss of interest or pleasure, irritability, feelings of helplessness, worthlessness, hopelessness, or suicidal ideation. Some scales will also assess the degree of hallucinations, delusions, suspicious or hostile thought processes.

Tests:

- Geriatric Depression Scale (GDS)
- Cornell Scale for Depression in Dementia
- Dementia Mood Assessment Scale (DMAS)
- Beck Depression Inventory (BDI)
- Beck Anxiety Inventory (BAI)
- Brief Symptom Inventory (BSI)

2. Personality

Definition: Personality inventories are occasionally used in capacity assessment to explore unusual ways of interacting with others and looking at reality that may be impacting sound decision-making. Projective personality tests are relatively less structured and allow the patient open-ended responses. Objective tests in contrast typically provide a question and ask the patient to choose one answer (e.g., "yes" or "no").

Tests:

- Rorschach
- Minnesota Multiphasic Personality Inventory-2 (MMPI)
- Profile of Mood States (POMS)

C. Tests of Effort, Motivation, or Response Style

These measures, also referred to as validity tests, are structured in such a way to detect inconsistent or unlikely response patterns indicative of attempts to exaggerate cognitive problems. They serve as one type of evidence permitting the clinician to judge the validity of the overall cognitive testing. Generally they detect test-taking response patterns that deviate from chance responding or from norms for established cognitively impaired clinical populations like AD. If the tests are positive, they suggest an intentional (or in some cases subconscious) test-taking approach to exaggerate deficits. It remains a clinical judgment as to how to interpret the clinical meaning of the test-taking bias/exaggeration. In some cases, they may reflect malingering for monetary secondary gain, whereas in others they may indicate a factitious disorder or sometimes a somatoform disorder.

Tests of validity may be used when the examiner is concerned that the individual has a reason to gain from "faking bad" on the test, such as in disability claims. Older adults who are receiving capacity evaluation are most likely to be giving maximal effort to perform at their highest level, in which case formal tests of validity are probably not indicated.

1. Validity

Definition: Validity tests are structured in such a way to detect inconsistent or unlikely response patterns indicative of attempts to exaggerate cognitive dysfunction.

Tests:

- Test of Memory Malingering (TOMM)
- 21 Item Test
- 15 Item Test
- CVLT-II Forced Choice

D. Tests for Evaluating Specific Capacities or Abilities

When capacity or competency is specifically in question, a comprehensive evaluation would include direct assessment of the area in question. We include here instruments designed for clinical (not research) use. As these tests are more recently developed, we include a more detailed description of the instruments. Specific information on reliability and validity relevant to the Daubert standard of scientific admissibility can be found in the test manuals.

1. Adult Functional Adaptive Behavior Scale (AFABS)

Primary Reference: P.S. Pierce, Adult Functional Adaptive Behavior Scale: Manual of Directions (1989).

Area Assessed: Functional Abilities for Independent Living

Description: The Adult Functional Adaptive Behavior Scale (AFABS) was developed to assist in the assessment of ADL and IADL functions in the elderly to evaluate their capacity for personal responsibility and the matching of a client to a placement setting. The AFABS consists of 14 items. Six items rate ADLs: eating, ambulation, toileting, dressing, grooming, and managing (keeping clean) personal area. Two items tap IADLs: managing money and managing health needs. Six items tap cognitive and social functioning: socialization, environmental orientation (ranging from able to locate room up through able to travel independently in the community), reality orientation (aware of person, place, time, and current events), receptive speech communication, expressive communication, and memory. Items are rated on four levels: 0.0 representing a lack of the capacity, 0.5 representing some capacity with assistance, 1.0 representing some capacity without assistance, and 1.5 representing independent functioning in that area. Individual scores are summed to receive a total score in adaptive functioning.

The AFABS assesses adaptive functioning through interviewing an informant wellacquainted with the functioning of the individual in question. The informant data is combined with the examiner's observation of and interaction with the client to arrive at final ratings. The AFABS is designed for relatively easy and brief administration (approximately 15 minutes). The author recommends it be administered only by professionals experienced in psychological and functional assessment, specifically a psychologist, occupational therapist, or psychometrician, although research with the AFABS has also utilized psychiatric nurses and social workers trained in its administration.

2. Aid to Capacity Evaluation (ACE)

Primary Reference: Edward Etchells et al., Assessment of Patients Capacity to Consent to Treatment, 14 J. Gen. Internal Med. 27–34 (1990).

Area Assessed: Medical Decision-Making

Description: The ACE is a semi-structured assessment interview that addresses seven facets of capacity for an actual medical decision (not a standardized vignette): the ability to understand (1) the medical problem, (2) the treatment, (3) the alternatives to treatment, and (4) the option of refusing treatment; (5) the ability to perceive consequences of (6a) accepting treatment and (6b) refusing treatment; and (7) the ability to make a decision not substantially based on hallucinations, delusions, or depression. These reflect legal standards in Ontario, Canada but also correspond to U.S. legal standards.

3. Capacity Assessment Tool (CAT)

Primary Reference: M.T. Carney et al., The Development and Piloting of a Capacity Assessment Tool, 12 J. Clinical Ethics 17–23 (2001).

Area Assessed: Medical Decision-Making

Description: The CAT proposes to evaluate capacity based on six abilities: communication, understanding choices, comprehension of risks and benefits, insight, decision/choice process, and judgment. It uses a structured interview format to assess capacity to choose between two options in an actual treatment situation; as such, it does not use a hypothetical vignette.

4. Capacity to Consent to Treatment Interview (CCTI)

Primary Reference: Daniel C. Marson et al., Assessing the Competency of Patients with Alzheimer's Disease Under Different Legal Standards, 52 Arch. Neurol. 949–954 (1995).

Area Assessed: Medical Decision-Making

Description: The CCTI is based on two clinical vignettes; a neoplasm condition and a cardiac condition. Information about each condition and related treatment alternatives is presented at a fifth to sixth grade reading level with low syntactic complexity. Vignettes are presented orally and in writing; participants are then presented questions to assess their decisional abilities in terms of understanding, appreciation, reasoning, and expression of choice.

5. Competency Interview Schedule (CIS)

Primary Reference: G. Bean et al., The Assessment of Competence to Make a Treatment Decision: An Empirical Approach, 41 Can. J. Psych. 85–92 (1996).

Area Assessed: Medical Decision-Making

Description: The CIS is a 15-item interview designed to assess consent capacity for electro-convulsive therapy (ECT). Patients referred for ECT receive information about their

diagnosis and treatment alternatives by the treating clinician, and the CIS then assesses decisional abilities based on responses to the 15 items.

6. Decision Assessment Measure

Primary Reference: J.G. Wong et al., The Capacity of People with a "Mental Disability" to Make a Health Care Decision, 30 Psych. Med. 295–306 (2000).

Area Assessed: Medical Decision-Making

Description: Wong et al., working in England, developed a measure that references incapacity criteria in England and Wales (understanding, reasoning, and communicating a choice), based on methodology by Thomas Grisso et al. (*The MacArthur Treatment Competence Study: II. Measures of Abilities Related to Competence to Consent to Treatment*, 19(2) L. & Human Behavior 127–148 (1995)). Their instrument also assesses the ability to retain material because it is one of the legal standards for capacity in England and Wales (though not in the United States).

A standardized vignette regarding blood drawing is used to assess paraphrased recall, recognition, and non-verbal demonstration of understanding (pointing to the correct information on a sheet with both correct information and distracter/incorrect information).

7. Decision-Making Instrument for Guardianship (DIG)

Primary Reference: S.J. Anderer, Developing An Instrument to Evaluate the Capacity of Elderly Persons to Make Personal Care and Financial Decisions (1997) (Unpubl. doctoral dissertation, Allegheny Univ. of Health Sciences).

Area Assessed: Self Care, Home Care, Financial, (Guardianship)

Description: The Decision-Making Instrument for Guardianship (DIG) was developed to evaluate the abilities of individuals to make decisions in everyday situations often the subject of guardianship proceedings. The instrument consists of eight vignettes describing situations involving problems in eight areas: hygiene, nutrition, health care, residence, property acquisition, routine money management in property acquisition, major expenses in property acquisition, and property disposition. Examinees are read a brief vignette describing these situations in the second person. Detailed scoring criteria are used to assign points for aspects of problem solving including defining the problem, generating alternatives, consequential thinking, and complex/comparative thinking. The DIG is carefully standardized. Standard instructions, vignettes, questions, and prompts are provided in the manual. In addition, detailed scoring criteria are provided. Sheets with simplified lists of salient points of each vignette, provided in large type, help to standardize vignette administration and emphasize the assessment of problem solving and not reading comprehension or memory. Vignettes are kept simple, easy to understand, and are brief.

8. Direct Assessment of Functional Status (DAFS)

Primary Reference: David A. Loewenstein et al., A New Scale for the Assessment of Functional Status in Alzheimer's Disease and Related Disorders, 44 J. Gerontology: Psych. Sci. 114–121 (1989).

Area Assessed: Functional Abilities for Independent Living

Description: The Direct Assessment of Functional Status (DAFS) was designed to assess functional abilities in individuals with dementing illnesses. The scale assesses seven areas: time orientation (16 points), communication abilities (including telephone and mail; 17 points), transportation (requiring reading of road signs; 13 points), financial skills (including identifying and counting currency, writing a check and balancing a checkbook; 21 points), shopping skills (involving grocery shopping; 16 points), eating skills (10 points), dressing and grooming skills (13 points). The composite functional score has a maximum of 93 points, exclusive of the driving subscale, which is considered optional. The DAFS requires that the patient attempt to actually perform each item (e.g., is given a telephone and asked to dial the operator). The entire assessment is estimated to require 30–35 minutes to complete. Any psychometrically trained administrator can administer the scale. The DAFS has been used for staging functional impairment in dementia, from one to three, in a group of 205 individuals with probable Alzheimer's disease.

9. Financial Capacity Instrument (FCI)

Primary Reference: Daniel C. Marson et al., Assessment of Financial Capacity in Patients with Alzheimer's Disease: A Prototype Instrument, 57 Arch. Neurol. 877–884 (2000).

Area Assessed: Financial

Description: The Financial Capacity Instrument (FCI) was designed to assess everyday financial activities and abilities. The instrument assesses six domains of financial activity: basic monetary skills, financial conceptual knowledge, cash transactions, checkbook management, bank statement management, and financial judgment. The FCI is reported to require between 30–50 minutes to administer, depending on the cognitive level of the examinee. The FCI uses an explicit protocol for administration and scoring.

10. Hopemont Capacity Assessment Interview (HCAI)

Primary Reference: Barry Edelstein et al., *Assessment of Capacity to Make Financial and Medical Decisions* (1993) (paper presented at Toronto meeting of the American Psychological Association, August 1993).

Area Assessed: Financial, Medical Decision-Making

Description: The Hopemont Capacity Assessment Interview (HCAI) is a semi-structured interview in two sections. The first section is for assessing capacity to make medical decisions. The second section is for assessing capacity to make financial decisions and will be discussed here. In the interview the examinee is first presented with concepts of choice, cost, and benefits and these concepts are reviewed with the examinee through questions and answers. The examinee is then presented medical or financial scenarios. For each scenario the individual is asked basic questions about what he or she has heard, and then asked to explain costs and benefits, to make a choice, and to explain the reasoning behind that choice. The HCAI uses a semi-structured format. General instructions are provided. Specific standardized introductions, scenarios, and follow-up questions are on the rating form.

11. Independent Living Scales (ILS)

Primary Reference: Patricia A. Loeb, Independent Living Scales (1996).

Areas Assessed: Care of Home, Health Care, Financial (Guardianship)

Description: The Independent Living Scales (ILS) is an individually administered instrument developed to assess abilities of the elderly associated with caring for oneself and/ or for one's property. The early version of the ILS was called the Community Competence Scale (CCS). The CCS was constructed specifically to be consistent with legal definitions, objectives, and uses, in order to enhance its value for expert testimony about capacities of the elderly in legal guardianship cases. The ILS consists of 70 items in five subscales: Memory/ Orientation, Managing Money, Managing Home and Transportation, Health and Safety, and Social Adjustment. The five subscales may be summed to obtain an overall score, which is meant to reflect the individual's capacity to function independently overall. Two factors may be derived from items across the five subscales: Problem Solving and Performance/ Information. The ILS has extensive information on norms, reliability, and validity.

12. MacArthur Competence Assessment Tool - Treatment (MACCAT-T)

Primary Reference: Thomas Grisso & Paul S. Applebaum, Assessing Competence to Consent to Treatment (1998).

Area Assessed: Medical Decision-Making

Description: The MacCAT-T utilizes a semi-structured interview to guide the clinician through an assessment of the capacity to make an actual treatment decision. It does not use a standardized vignette. Patients receive information about their condition, including the name of the disorder, its features and course, then are asked to "Please describe to me your understanding of what I just said." Incorrect or omitted information is cued with a prompt (e.g., "What is the condition called?"), and if still incorrect or omitted, presented again. A similar disclosure occurs for the treatments, including the risks and benefits of each treatment alternative. Next, patients are asked if they have any reason to doubt the information and to describe that. They are then asked to express a choice and to answer several questions that explicate their reasoning process, including comparative and consequential reasoning and logical consistency.

13. Multidimensional Functional Assessment Questionnaire (MFAQ)

Primary Reference: Center for the Study of Aging and Human Development, Multidimensional Functional Assessment: The OARS Methodology (1978).

Area Assessed: Functional Abilities for Independent Living

Description: The Multidimensional Functional Assessment Questionnaire (MFAQ) was developed to provide a reliable and valid method for characterizing elderly individuals and for describing elderly populations. The MFAQ supersedes the nearly identical Community Survey Questionnaire (CSQ, a predecessor which also was developed by the Duke Center). Both instruments frequently have been called the "OARS," in reference to the program that developed the instrument throughout the 1970s. The MFAQ or the CSQ was already

in use by well over 50 service centers, researchers, or practitioners nationally when the MFAQ was published (1978). Part A provides information in five areas of functioning, including activities of daily living. The Activities of Daily Living (ADL) dimension assesses 14 functions including both instrumental and physical ADLs. *Instrumental ADLs are*: use telephone, use transportation, shopping, prepare meals, do housework, take medicine, handle money. *Physical ADLs are*: eat, dress oneself, care for own appearance, walk, get in/out of bed, bath, getting to bathroom, continence. Part B of the MFAQ assesses the individual's utilization of services, that is, whether and to what extent the examinee has received assistance from various community programs, agencies, relatives, or friends, especially within the latest six months. Questioning also includes the examinee's perceived need for the various services.

14. Philadelphia Geriatric Center Multilevel Assessment Inventory (MAI)

Primary Reference: M. Powell Lawton & Miriam Moss, Philadelphia Geriatric Center Multilevel Assessment.

Instrument: Manual for Full-length MAI (undated).

Area Assessed: Functional Abilities for Independent Living

Description: The Philadelphia Geriatric Center Multilevel Assessment Inventory (MAI) was designed to assess characteristics of the elderly relevant for determining their needs for services and placement in residential settings. The MAI is a structured interview procedure that obtains descriptive information about an elderly respondent related to seven domains. Each of the domains (except one) is sampled by interview questions in two or more subclasses, which the authors call sub-indexes. The full-length MAI consists of 165 items; the middle length MAI has 38 items, and the short-form has 24 items. The domains assessed are physical health, cognitive, activities of daily living, time use, personal adjustment, social interaction, and perceived environment. The MAI manual provides considerable structure for the process of the interview, sequence and content of questions, and scoring. It describes criteria for 1 to 5 rating of each of the domains, but these criteria are not tied specifically to item scores. The manual discusses general considerations for interviewing elderly individuals and dealing with special problems of test administration with this population (e.g., dealing with limited hearing or vision).

E. Cognitive Screening Tests

Cognitive screening tests are useful for giving a general level of overall cognitive impairment, but they are notoriously insensitive to deficits in single domains. They may be used as an overall screening to determine whether additional testing is needed. They may also be used for individuals with more severe levels of impairment who cannot complete other tests.

1. Blessed Information-Memory-Concentration Test (BIMC): The BIMC is a 33-point scale with subtests of orientation, personal information, current events, recall, and concentration. There is a short version with six items. It has adequate test-retest reliability and correlation with other measures of cognitive impairment.

2. Mental Status Questionnaire (MSQ): The MSQ is a 10-item, 10-point scale assessing orientation to place, time, person, and current events. It has low to modest sensitivity for detecting neurological illness.

3. Mini Mental State Examination (MMSE): The MMSE is a 30-point screening instrument that assesses orientation, immediate registration of three words, attention and calculation, short-term recall of three words, language, and visual construction. The MMSE is widely used and has adequate reliability and validity. Positive findings require more in-depth evaluation. Limitations of the MMSE, discussed in Chapter IV, include the potential for false positives or false negatives, and the association of MMSE scores with age, education, and ethnicity. Longer versions and telephone versions of the MMSE are available.

4. The Seven Minute Screen (7MS): This screening instrument consists of four subtests: recall, verbal fluency, orientation, and clock drawing. It has adequate test-retest reliability and inter-rater reliability.

5. Short Portable Mental Status Questionnaire (SPMSQ): The SPMSQ is scored as a sum of errors on subtests of orientation, location, personal information, current events, and counting backwards. Race and age corrections to scores are available.

F. Key Test Reference Books

Thomas Grisso et al., Evaluating Competencies: Forensic Assessments and Instruments (2d ed. 2002).

Asenath LaRue, Aging and Neuropsychological Assessment (1992).

Muriel D. Lezak, Neuropsychological Assessment (3d ed. 1995).

Peter A. Lichetenberg ed., Handbook of Assessment in Clinical Gerontology (1999).

Otfried Spreen & Esther Strauss, A Compendium of Neuropsychological Tests: Administration, Norms, and Commentary (2d ed. 1998).

Appendix 6-10 Everyday Functioning and Functional Assessment

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What Is "Function?" How do Judges and Clinicians Think Differently?

A comprehensive assessment of capacity should include a "functional assessment." When the law refers to "function" it often means someone's thinking and decision-making, as well as everyday behavior where the person lives. When clinicians refer to "function" they usually mean only the everyday behavior, whereas thinking and decision making is assessed separately as "cognition."

How Do Clinicians Divide Everyday Functioning? What Are ADLs and IADLs?

Clinicians often divide everyday function into the "Activities of Daily Living" (ADL) and the "Instrumental Activities of Daily Living" (IADL). There is fairly good agreement on the ADLs as comprising dressing, eating, toileting, transferring or moving from one sitting position to another, walking or mobility, and bathing. There is less agreement on what are the main categories of IADLs and how to divide them.

How Is Functioning Assessed by Clinicians? Informal and Formal Assessments of Capacity

Functioning can be assessed through informal means, such as observing the individual, and asking the individual, family, and staff questions, or through formal testing, such as that performed by an occupational therapist. Nurses, social workers, and psychologists are often prepared to assess everyday functioning.

What Tests Are Used to Assess Everyday Functioning? ADL Rating Scales and Capacity Tools

There are two main ways that functioning is formally assessed. One way is through ADL and IADL rating scales. These are often used by nurses and social workers and are usually brief check lists for categorizing everyday functioning. Similar and more sophisticated tools are used by occupational therapists who tend to directly assess and observe ADL/IADL performance in their evaluations. ADL and IADL rating scales have been available for more than 30 years.

ADL/IADL Rating Scales include:

- Adult Functional Adaptive Behavior Scale (AFABS)
- Barthel Index
- Direct Assessment of Functional Status (DAFS)
- Functional Independence Measure (FIM)
- Index of ADL ("Katz")
- Kenny Self Care Evaluation
- Multidimensional Functional Assessment Questionnaire (MFAQ)
- Philadelphia Geriatric Center Multilevel Assessment Inventory (MAI)
- Physical Self-Maintenance Scale

Another approach to functional assessment is instruments designed specifically to assess legal capacities. These are formal testing instruments designed specifically to assess capacity in terms of legal definitions. Such tools have only recently been developed, since the 1990s, and are summarized in the following table. They are called "tools" because it is not possible to have an exact "test" of capacity. Capacity is a professional, clinical, and, ultimately, legal judgment. Since some of these tests are newly developed, not all meet the "Daubert standard" of scientific admissibility.

Acronym	Capacity Tool Name	Description
ACE	Aid to Capacity Evaluation	Semi-structured interview for capacity to consent to treatment; Developed in Canada.
CAT	Capacity Assessment Tool	Structured interview to assess capacity to choose between two treatment options.
ССТІ	Capacity to Consent to Treatment Interview	Two clinical vignettes are used to assess capacity to consent to medical treatment in terms of legal standards of understanding, appreciation, reasoning, and expression of choice.
CIS	Competency Interview Schedule	A 15-item interview for capacity to consent to electro- convulsive-therapy (ECT).
DAM	Decision Assessment Measure	Assesses capacity to consent to medical treatment through a vignette regarding blood draw. Developed in England.
DIG	Decision-Making Instrument for Guardianship	Eight vignettes evaluate capacity to make decisions about hygiene, nutrition, health care, residence, property acquisition, routine money management in property acquisition, major expenses in property acquisition, and property disposition.
FCI	Financial Capacity Instrument	Structured instrument assesses six domains of financial activity: basic monetary skills, financial conceptual knowledge, cash transactions, checkbook management, bank statement management, and financial judgment.
HCAI	Hopemont Capacity Assessment Interview	Semi structured interview for medical and financial decisions. Uses two vignettes for each.
ILS	Independent Living Scales	Structured instrument with 70 items in five subscales: memory/orientation, managing money, managing home and transportation, health and safety, and social adjustment. Can be summed to reflect the capacity to function independently.
MacCAT-T	MacArthur Competence Assessment Tool - Treatment	Semi-structured interview to assess medical decision making in terms of four legal standards.

Appendix 6-11 Means to Enhance Capacity

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Cause of Confusion	Possible Intervention
Alcohol or other substances intoxification	Detoxification; supplement diet or other intake needs
Altered blood pressure	Treat underlying cause of blood pressure anomaly with medication or other treatment
Altered low blood sugar	Management of blood sugar through diet or medication
Anxiety	Treatment with medications and/or psychotherapy; support groups
Bereavement; Recent death of a spouse or loved one	Support; counseling by therapist or clergy; support group; medications to assist in short term problems (e.g., sleep, depression)
Bipolar disorder	Treatment with medications and/or psychotherapy; support groups
Brain tumor	Surgery and medication
Delirium	Obtain standard labs; obtain brain scan if indicated; assess vitals; treat underlying cause; monitor and reassess over time
Dementia	Treatment with medications for dementia; simplify environment; provide multiple clues within environment; use step-by-step communication
Depression	Treatment with medications and/or psychotherapy; add pleasurable activities to day; ECT if indicated; support groups
Developmental disability	Education and training
Difficulty hearing	Use hearing amplifiers; have hearing evaluated; provide hearing aids; write information down; repeat information; slow down speech; speak clearly and distinctly
Difficulty seeing	Use magnifying glass; have sight evaluated; provide glasses; provide spoken information; repeat information; ensure sufficient lighting; use large print; have access to Braille materials
Difficulty understanding English	Use translator

Cause of Confusion	Possible Intervention
Head injury	Treatments for acute effects (e.g., bleed, pressure, swelling) as necessary; monitoring over time; rehabilitative speech, physical, occupational therapies
Infection (e.g., urinary, influenza, pneumonia, meningitis)	Treat underlying infection with antibiotic or other treatment
Insomnia	Sleep hygiene practices (e.g., limit caffeine, light exercise, limit naps); medications
Liver or kidney disease	Treatment of underlying illness with medication, dialysis, surgery
Loneliness	Social and recreational activities; support groups
Low educational or reading level; illiterate	Provide information in simple language without "talking down"; provide information in multiple formats
Malnutrition or dehydration	IV fluids; fluid/food by mouth; food supplements; food by feeding tube
Mania	Treatment with medications and/or psychotherapy; support groups
Medications and sudden medication withdrawal	Review of medications by clinical pharmacist or specialist; slow one-by-one tapers or changes of medications
Poor heart or lung function (e.g., hypoxia)	Treatment of underlying condition with medication, surgery, supplemental oxygen
Post surgical confusion (usually related to anesthesia or pain medicines)	Monitoring and reassessment over time; try alternative medications and treatments for pain management
Recent stressful event; depression and anxiety	Support, counseling by therapist or clergy; support group; medications to treat symptoms
Religious, cultural, or ethnic background	Sensitivity to religious, cultural, and ethnic traditions; inquire about views and needs; involve professional from similar background
Schizophrenia; hallucinations or delusions	Treatment with medications for schizophrenia; simplify environment; provide support
Transfer trauma (a recent move that has the individual disoriented)	Monitoring over time; re-orientation to environment
Transient ischemic attacks (TIA)	Treatment of risk factors to prevent future recurrence
Urinary or fecal retention	Treat underlying cause of retention through medication or surgery
Vitamin deficiency; imbalances in electrolytes and blood levels	Vitamin or electrolyte supplement; balanced diet; diet supplements

Appendix 6-12 Additional Resources

Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers (Washington, DC: American Bar Association, 2005).

Judicial Determination of Capacity of Older Adults in Guardianship Proceedings (Washington, DC: American Bar Association, 2006).

Stephen J. Anderer, *Determining Competency in Guardianship Proceedings* (Washington, DC: American Bar Association, 1990).

Charles P. Sabatino and Suzanna L. Basinger, *Competency: Reforming Our Legal Fictions*, 6 J. MENTAL HEALTH & AGING 119 (2000).

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Michael Smyer, et. al. (eds.), Older Adults' Decision-Making and the Law (New York: Springer Publishing Co., 1996).

Jennifer Moye, *Evaluating the Capacity of Older Adults: Psychological Models and Tools*, NAELA QUARTERLY (Summer 2004).

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Marshall B. Kapp and D. Mossman, *Measuring Decisional Capacity: Cautions on the Construction of a Capacimeter*, 2:1 PSYCH., PUB. POL. & LAW 73 (1996).

Lawrence A. Frolik, *Promoting Judicial Acceptance and Use of Limited Guardianship*, 31 STETSON L. Rev. 735 (2001).