Assessment of Capacity of Older Adults: A Growing Challenge for Physicians A Proposal to the Retirement Research Foundation By Rush University Medical Center, American Bar Association Commission on Law and Aging

Application Organization's name, address, and phone number

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Project title

Assessment of Capacity of Older Adults: A Growing Challenge for Physicians

Project purpose

To create an on-line curriculum for training physicians to understand clinical and legal concepts of capacity and to inform the national health care community that capacity training exists and is easily accessible. The curriculum will help physicians, other health care professionals, and administrators (who set institutional policy and practice) to address current barriers to treatment for vulnerable, frequently chronically ill, patients.

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Cost requested of RRF \$302,240

TABLE OF CONTENTS

1.	Cover Page
2.	Summary4
3.	Project Significance
4.	Statement of Objectives14
5.	Description of Methodology16
6.	Dissemination
7.	Budget and Timetable23
8.	Plans for Continued Support
9.	Personnel
10.	Applicant Organization

Appendices

- A. References
- B. Biosketches for Key Personnel
- C. Logic Model
- D. Letter of Commitment from ABA
- E. ABA Budget
- F. Letters of Commitment from Consultants
 - a. Jennifer Moye content consultant
 - b. Daniel Marson content consultant
 - $c. \ \ \, Jim \ \, Vanden \ \, Bosch-video \ \, consultant$
 - d. Karin Kuby web developer
- G. Letters of Support from Pilot Sites
 - a. Saint Louis University
 - b. University of Maryland/Johns Hopkins University
- H. Letters of Support from National Organizations
 - a. The American Geriatrics Society

- b. American Medical Directors Association
- c. The Gerontological Society of America
- I. Tax Exempt Status
 - a. Certification of Tax Exempt Status
 - b. Rush University Medical Center and Subsidiaries: Consolidated Financial Statements (original only)
 - c. Rush University Medical Center Annual Report (original only)

2. Summary

Background:

The 21st century is bringing about vast changes in the demographics of the United States. Notably, the population is aging at a rapid rate, incidence of chronic illness and dementia is increasing, the disability population is aging, the nature of medical choices is changing due to evolving medical technology, and healthcare delivery systems are becoming increasingly complex. These trends bring healthcare clinicians up starkly against a growing challenge: the rising tide of patients with diminished decisional capacity.

Every day, physicians without specialized training in capacity assessment are required to make decisions about the ability of patients to provide informed consent for medical treatment, or to weigh in on other decisions such as driving, evaluation for independent living, research consent, and sexual consent. Determinations may be particularly difficult if the patient is elderly and if his or her capacity is fluctuating. Moreover, there is no clearly defined line of capacity and no definitive test to determine a patient's decision-making ability. Clinician assessment of capacity does not occur in a vacuum, there are many factors that may affect a patient's decision making ability such as diet, disorientation, depression or drugs. Additionally, there are a variety of system factors that may affect the patient's orientation. Capacity determination may be especially problematic for low-income, socially isolated patients for whom little is known of their background or health preferences. Those who are marginal to society, without advocates, and with multiple chronic conditions, are at the greatest risk of poor assessment.

This issue becomes more apparent when clinicians are requested to make statements on patient capacity in judicial guardianship proceedings. Often, health care professionals are called upon to provide evidence to the court on the individual's condition, functional abilities, and cognitive impairment. The health care professional's statement is typically the key element in the judge's determination, and is instrumental in how the guardianship order is fashioned. Most clinicians have little training in capacity assessment. Many are unfamiliar with the elements of a capacity determination, and may fail to provide the specific functional evidence required for a well-grounded judicial determination in guardianship, or may neglect to make necessary referrals.

Misguided assessments of capacity can cause a patient to be subject to over-treatment, undertreatment, treatment not in accord with his or her values – or inappropriate loss of rights through guardianship proceedings. Ill-informed practices and lack of knowledge about capacity may prevent the kinds of medical and ethical scrutiny needed in care, especially for frail, vulnerable individuals unable to speak for themselves. Concise and effective clinician education on capacity assessment could create striking and immediate changes in practice, integrating new techniques into care; and could bring about needed reforms in institutional protocols across the country.

Project Goals:

- 1. Develop training for physicians on the clinical and legal aspects of capacity to improve their ability to assess patient capacity.
- Inform the national health care community that capacity training exists and is easily accessible. Encourage physicians to access curriculum.

Proposed Methods:

Rush University Medical Center and the American Bar Association (ABA) Commission on Law and Aging propose to combine their cross-disciplinary expertise to develop and test a training curriculum for clinicians on capacity assessment of older adults. In a brief survey of 45 clinicians at Rush, the majority said they would be more likely to complete a web-based training accessible through the internet than an in-person training. The curriculum will be created in an electronic web-based format and disseminated through the internet. The project will benefit from consultation with nationally recognized psychologists experienced in capacity issues, as well as an advisory group of experts from multiple disciplines and organizations. The steps we will take to complete this project are as follows:

- Step 1: Complete an <u>Environmental Scan</u> to identify any existing resources on capacity assessment for the intended clinical audiences.
- Step 2: Design a draft <u>curriculum unit with downloadable handbook for physicians on capacity assessment, along with a laminated pocket guide for fingertip reference.</u> The draft will build on the ABA Commission's experience working with the American Psychological Association in designing materials on capacity assessment for lawyers and for judges, as well as the Medical Center's knowledge, strategic placement, and leadership in the medical community. Rush's strong history in interdisciplinary care with strengths in psychiatry, forensic psychiatry and geriatrics, along with its culturally diverse patient population make Rush an ideal institution to participate in and provide leadership for this project. <u>Video clips will be incorporated into the draft curriculum providing brief case presentations. Preand post tests</u> will be developed for each module within the curriculum.
- Step 3: <u>Send content and video clips to web developer</u> to create electronic curriculum application.
- Step 4: Send draft on-line curriculum to an <u>expert review panel</u> including experts in capacity assessment, ethics, and gerontology. Curriculum will be reviewed and discussed via conference call and then revised accordingly.
- Step 5: <u>Pilot</u> the draft curriculum, including pre- and post-tests, final evaluation, downloadable handbook, and reference card, with physicians at three academic and community medical groups across the country.

- **Step 6:** <u>Conduct telephone-focus groups</u> with a random selection of pilot participants from all three sites immediately following completion of training and again, six months later.
- Step 7: <u>Revise the curriculum</u> and materials based on pilot data including analysis of preand post-tests, and focus group feedback.
- Step 8: Post the final curriculum with CME credits on-line.
- **Step 9:** <u>Disseminate</u> information about the curriculum broadly throughout the medical community via collaborating organizations, links on these organizations' websites, and at national conferences.

Estimated Cost: Total cost: \$382,149 Amount requested from RRF: \$302,240

- 6 -

3. Project Significance

Increasingly physicians and other health care professionals face a grave challenge for which their previous education and training has not prepared them: the growing number of patients with diminished capacity for decision-making. Converging twenty-first century trends – including the graying of the population, the increase in chronic illnesses and dementia, the aging of the disabled population, the changing nature of medical choices due to evolving medical technology, and increasingly complex health care delivery systems – bring physicians up starkly against a rising tide of patients who might be unable to make informed decisions about their own health care. Physicians also are called upon with increasing frequency to prepare statements about a patient's capacity in a court guardianship proceeding, as well as to make assessments in specific contexts such as driving, sexual consent, research consent, and capacity for independent living.

Misguided assessments of capacity by health care professionals can cause a patient to be subject to over-treatment, under-treatment, or treatment/referrals not in accord with his or her values – or inappropriate loss of rights in a guardianship proceeding. Ill-informed practices and lack of knowledge about capacity may prevent the kinds of medical and ethical scrutiny needed in good care – especially for frail, vulnerable individuals unable to speak for themselves.

Clearly, physicians could benefit from training to help them understand the clinical and legal concepts of capacity and to improve patient capacity assessments. Currently, to our knowledge, no such training resources exist. The proposed project will develop and test a training curriculum for physicians (and medical students) on patient capacity assessment. The project will bring to bear extensive legal, medical, psychological and social work expertise, with a combined total of over 130 years of experience with care and issues affecting older persons and individuals with disabilities.

a. Capacity is a Complicated Phenomenon – Legal and Clinical Approaches. Webster's *Dictionary* defines capacity as the "power to grasp and analyze ideas and cope with problems." The concept of capacity – and lack thereof or "incapacity" – has a long history in both the legal and clinical arenas, based on underlying concepts that are remarkably similar.

(1) Legal Approach. Historically, the law's approach to incapacity reflects a longstanding paradox. On the one hand, our legal system has always recognized situation-specific standards of capacity, depending on the event or transaction at hand – such as capacity to make a will, marry, enter into a contract, vote, drive a car, stand trial in a criminal prosecution or take other particular actions (Parry, 1985). A finding of incapacity in any of these matters could nullify or prevent a given legal act, but not necessarily impede the person's right to make other decisions or handle other affairs.

On the other hand, until very recently, determinations of incapacity in the context of guardianship proceedings were routinely quite global, absolute determinations of one's ability to manage property and personal affairs; guardianship determinations were "all or nothing" assessments of an individual's ability. A finding of incapacity under guardianship law traditionally justified intrusive curtailments of personal autonomy and resulted in a virtually complete loss of civil rights (Frolik, 1981; Horstman, 1975). Within the last 15-20 years, the concept of incapacity in guardianship law has moved away from an "all or nothing" approach to a more finely tuned, functional assessment (Sabatino & Basinger, 2000). Recent usage favors the term "diminished capacity" because it avoids the all or nothing connotation of the term "incapacity" or "incompetency" (Wingspan, 2001).

Fundamental principles underlying the concept of legal capacity include the following:

<u>Presumption of capacity</u>. The law presumes that all adults are "competent" until proven otherwise (Furrow, 1995; Parry, 1985; Parry & Gilliam, 2002). Adults have the right – even when frail, vulnerable, or eccentric – to make their own decisions and govern their own affairs, even if their decisions are unwise.

<u>Capacity is task-specific, not global.</u> The definition of "incapacity" in everyday legal practice depends on the type of transaction or decision involved (Walsh, 1994). One may lack the capacity to handle one's financial affairs but still retain the capacity to make health care decisions or to vote.

<u>Capacity can fluctuate</u>. Capacities that were initially lost (e.g., as a result of a head injury, transient acute psychosis, severe depression that later remits) may be recovered over time. Dementias such as Alzheimer's disease typically result in fluctuating levels of capacity through the early and mid-stages. Also, cognitive deficiencies that suggest incapacity often are caused by treatable and reversible physical causes such as overmedication. Moreover, capacity can vary by time of day ("sundowning") or other factors, and has been said to be "like a lava lamp – you can't pin it down, it keeps changing."

<u>Capacity is situational and contextual.</u> Capacity is affected by the social and technological resources and supports available to a person. Capacity assessment may also consider how an individual interacts with others and with the environment. Issues of undue influence, exploitation or threat can directly affect functioning, as can the familiarity and comfort of a physical setting.

<u>What capacity is *not*</u>. Advanced age, eccentricity, refusal of care, disagreements in high risk situations, medical diagnosis alone – and even poverty – have all in some contexts been unjustifiably equated with incapacity.

(i) Decisional capacity in *health care* is rooted in the concept of *informed consent* (Meisel, 1995; Grisso & Appelbaum, 1998). The concept is based on the principle that a patient has the right to prevent unauthorized contact with his or her person, and a clinician has a duty to disclose relevant information so the patient can make an informed decision. A person must have capacity

to make a treatment decision, and the consent must be voluntary and informed. It is up to the clinician to evaluate the patient's capacity for medical treatment (ABA, APA 2005).

Capacity to make a health care decision is defined by statute in most states under their advance directive laws. The Uniform Health Care Decisions Act defines capacity as "an individual's ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health care decision." Similarly, a well-known set of biomedical principles lists as elements of capacity for informed consent that the patient: understands information on the nature of the treatment and consequences; is able to judge in light of his or her own values; intends the likely outcome; and is able freely to communicate a decision (Beauchamp & Childress, 1994).

(ii) Physicians increasingly encounter capacity issues in a host of *additional specific contexts* beyond health care consent. For instance, physicians may be required to report to the division of motor vehicles on a patient's capacity to drive (Rinkert & Naimark, 2005). If a patient is at risk of institutionalization, a physician may have a role in assessing an individual's ability to live independently in the community (Loeb, 1996). Other specific contexts in which capacity may be an issue include consent for participation in research, sexual consent – and more.

(iii) Definitions of incapacity in state *guardianship law* differ among the states and have evolved markedly over time. Originally the law required a finding that an alleged incapacitated person was an "idiot," "lunatic," or "person of unsound mind." Extensive reform of state guardianship law in the past 20 years has resulted in four basic elements that states mix and match in different ways: (1) a disabling condition; (2) a cognitive impairment affecting the ability to receive and evaluate information; (3) a functional impairment affecting the way an individual provides for essential needs such as medical care, nutrition and shelter, and performs everyday activities; and (4) a finding that such factors put an individual at risk or cause harm (Sabatino & Basinger, 2000; Wood, annual guardianship law updates). It is ultimately up to the judge to determine capacity in a guardianship case, but medical evaluation is key and frequently dispositive evidence.

(2) <u>Clinical Approach</u>. A widely recognized clinical model of capacity ("the Grisso model," Grisso, 2003; Grisso & Appelbaum, 1998) addresses four elements that are distinctly similar to the legal elements outlined above (ABA, APA 2005):

<u>Causal component.</u> What is the diagnosis that is causing the problem? A diagnosis almost always will be found in the *Diagnostic and Statistical Manual of Mental Disorders – IV* (*DSM-IV*), which lists and describes currently recognized psychiatric disorders. <u>Cognitive functioning</u>. An individual may have cognitive problems with attention, memory, understanding or expressing information, reasoning, organizing, planning, or other areas.

These problems could be caused by a cognitive disorder such as Alzheimer's disease or a psychiatric disorder such as schizophrenia.

<u>Functional behavior</u>. What is a person's ability to function in society? For example, can the person write a check, pay bills, make change, live independently, name a health care agent, get nutrition, maintain hygiene? Functional behavior is assessed through reports of others, direct observation, and performance-based testing.

<u>Interactive component.</u> Contextual factors such as an individual's history, values, risks at hand, and available resources and supports are also part of a clinical model of capacity assessment.

b. The Incidence of Diminished Capacity is Growing. Ongoing demographic trends will sharply boost the number of cases in which capacity is an issue in coming years. The older population (age 65+) numbered 35.9 million in 2003. As the baby boomers come of age, the older population will more than double, reaching 71.5 million by 2030. Within the older population, the number of "old old" (age 85+) is growing especially rapidly and is expected to increase from 4.7 million in 2003, to 9.6 million in 2030 (U.S. Administration on Aging 2004).

At the same time, Alzheimer's disease and related dementias are becoming more prevalent. Today, 4.5 million Americans have Alzheimer's disease. The number has more than doubled since 1980 and will continue to grow—reaching 11.3 to 16 million by 2050 unless a cure or preventive measures are discovered (Alzheimer's Association, Fact Sheet, <u>www.alz.org</u>). Moreover, capacity also involves a younger population of adults with mental retardation, developmental disabilities, and mental illness. Today "it is estimated that there are seven to eight million Americans of all ages who experience mental retardation or intellectual disabilities. Intellectual disabilities affect about one in ten families in the USA" (President's Committee, <u>www.acf.hhs.gov</u>). This number will rise with new forms of medical treatment, and an increasing number will outlive family caregivers.

c. Clinicians Face Increasing Challenges in Determining Capacity for Informed Consent for Treatment – and in Other Contexts. Physicians and other clinicians must make daily determinations about the ability of patients to provide informed consent for medical treatment. Moreover, informed consent has become increasingly more challenging to obtain as treatments become ever more sophisticated and technologically complex. Capacity issues persistently confound informed consent.

Advance directive laws in every state also place the determination of capacity to make health care decisions squarely in the hands of physicians. Yet, there is no "bright line" for determining such capacity and there is no ultimate and definitive test or "capacameter" (Kapp, 1996). Physicians are on the front line and often time is of the essence. Clinicians may be confused about the legal standards for and meaning of capacity. One study found that agreement among physicians on capacity determinations was "near chance" (Marson, et. al., 1997). A complex list of questions makes this tough task even more problematic:

- 10 -

Are there reversible causes of impairment such as the "five D's" – Diet, malnutrition, vitamin deficiency; Drugs, polypharmacy; Depression, grief; Dehydration; and Disorientation, transfer trauma?

Are other conditions masquerading as or affecting a judgment about lack of capacity – for instance undiagnosed hearing loss, vision loss, cultural or language differences?

Is the physician more likely to question a patient's capacity if the patient disagrees with the recommendation for medical treatment, and especially if the risk is high?

Do concerns about liability enter into the physician's calculus of the patient's ability to consent to treatment?

Does the capitated health care delivery system work to reduce the amount of time a physician spends interacting with patients and assessing their understanding? If the patient is unable to give informed consent, how does the physician interact with

surrogates?

Does the physician encounter socially isolated, low-income "unbefriended" individuals with diminished capacity and with multiple chronic conditions, about whom little is known and for whom there is no advocate?

In addition, the instances in which physicians are called upon to give statements or make assessments of other situation-specific capacities are growing. There are currently 23 million drivers over the age of 65 and this number is rapidly increasing. Physicians require guidance in screening for cognitive and physical driving-related deficits among suspected high-risk elderly drivers (Rinkert & Naimark, 2005). On another front, the landmark *Olmstead* decision by the Supreme Court in 1999 requires states to integrate individuals with disabilities into community settings if possible. This in turn requires an assessment of the capacity of such individuals to live in community-based settings, and to make a decision about their living arrangement. Physicians may provide evidence in such assessments. Finally, individuals with questionable capacity may be asked to – and may or may not benefit from – participation in medical research studies, and it is important for physicians to be able to make a determination about their ability to consent.

d. Clinicians Commonly Lack an Understanding of their Role in Guardianship

Capacity Determinations. Most state guardianship laws require a clinical statement or report as evidence of capacity in adult guardianship proceedings. Physicians often are called upon by the petitioner or the alleged incapacitated person, or ordered by the court, to examine the individual and submit a report or complete an assessment form. Research over many years has found these reports frequently inadequate, often conclusory and missing information that might be critical for judges in making a determination of capacity (Frolik, 1981; Peters, Schmidt & Miller, 1985; Quinn, 2005).

A recent study of adult guardianship files in three states found clinical evaluations uneven at best and frequently unreliable and lacking in specific information useful for the court. The mean average number of words of the assessment in one state was 83. While many reports had

- 11 -

conclusory comments such as the individual "is unable to make decisions" or "is unable to manage his affairs," few had specific information about cognitive or functional abilities. Across the three states, description of cognitive strengths and weaknesses was missing in over 27% of the reports and description of functional strengths and weaknesses was missing in close to 73% of reports (Moye, et. al., 2006). This study, as well as a recent *Handbook for Judges on Judicial Determination of Capacity in Guardianship Proceedings*, recommended that clinical assessments include consideration of six key elements: (1) the patient's medical condition; (2) the cognitive impairment; (3) a functional evaluation of the individual's ability to care for self and property; (4) a consideration of the person's values; (5) a consideration of the risk involved; and (6) a statement on ways in which the person's capacity might be enhanced (ABA, APA, NCPJ 2006).

Clearly, the expertise of physicians is an important ingredient in guardianship decisions. Clinicians could best contribute if they understood the nature of the court determination, its effect on people's lives, and the kinds of information required for a thorough assessment by the court. Moreover, clinicians are increasingly called up to make determinations about capacity in a growing range of other contexts. They may be asked to provide an evaluation of an individual's ability to drive safely, to give sexual consent, to participate in medical research projects or to live independently. In addition, physicians may provide affidavits or be witnesses in will contests on testamentary capacity.

e. Clinicians Lack Training and Resources in Capacity Assessment. Despite the increasing prevalence of patients with questionable, fluctuating or diminished capacity, physicians, physicians in training and medical students are not trained in capacity assessment. While they may be quite familiar with the elements of informed consent (voluntary, informed, requisite capacity) in everyday practice, they lack a conceptual framework for evaluating the complexities of patient ability to consent. Moreover, they may be challenged in situations where they are expected to make evaluations in connection with other specific capacities such as driving, independent living and medical research. Finally, while physicians may provide statements for court guardianship proceedings, they may lack an understanding of the elements of capacity under state statute, and may fail to provide the specific functional evidence required for a well-grounded judicial determination.

Medical literature on patient capacity assessment by physicians is growing but still scant; and training resources are lacking. A 1996 article in *Neurology* described "cognitive predictors of capacity to consent in Alzheimer's disease" (Marson, 1996). In 1998, the American Medical Association launched a project to teach physicians the basics of caring for dying patients. The resulting EPEC (Education for Physicians on End-of-Life Care) curriculum covers fundamental skills in palliative care, ethical decision-making and more – but does not focus on patient capacity.

In 1998, Grisso and Appelbaum published Assessing Competence to Consent to Treatment: A Guide for Physicians and Other Health Professionals. This landmark volume for medical

practitioners introduces the concept of capacity (or "competence"), sets out the clinical model of capacity assessment, discusses consent for medical treatment, outlines use of one particular capacity assessment instrument, and discusses the process of reaching a capacity judgment. The Grisso & Appelbaum work is a critical resource, and provides a good basis for the proposed project, which would advance the field significantly by developing a practical curriculum tool. The Grisso & Appelbaum work focuses exclusively on informed consent for treatment, and does not include capacity assessment in the guardianship context, nor does it include a specific focus on issues of capacity of elders.

A 1999 article on "Competency and the Capacity to Make Treatment Decisions" was directed toward primary care physicians and offered a brief summary of standards upon which capacity assessments are made and practical suggestions for patient interviews conducted to assess capacity (Leo, 1999). In 2001, a notable volume (second edition) on *Informed Consent: Legal Theory and Clinical Practice* by Berg et al provided suggestions for incorporating informed consent into clinical practice.

A 2001 overview of "The Role of Bioethics in Medical Education" fails to mention the issue of capacity (McCrary, 2001). However, a slightly later 2001 article in *American Family Physician* focuses on "Can the Patient Decide? Evaluating Patient Capacity in Practice" (Tunzi, 2001). This article includes illustrative cases that underscore the pressing need for a practical curriculum for physicians and other medical professionals on patient capacity evaluation, demonstrating dramatically how good capacity assessment directly affects patients' lives:

"A 68-year-old woman with diabetes and schizophrenia has been hospitalized with unstable angina, bilateral heel ulcers, urinary retention caused by an acute urinary tract infection and anemia caused by a combination of gastritis and chronic renal failure. One year ago, she was hospitalized with diabetic ketoacidosis after reporting that "voices" told her to stop taking her insulin. Currently, she is improving but requires a urinary catheter and must keep her legs elevated at rest. She says she is now able to take care of herself and wants to return home. Does this patient have the capacity to make this decision?"

"A 78-year-old man has a recent diagnosis of metastatic cancer of unknown primary. He returned to the office today after having a computed tomography (CT) scan showing a pancreatic lesion that may be the primary cancer and is the only lesion accessible for biopsy. He requires large doses of narcotics for pain control and his level of consciousness fluctuates greatly. It is not clear if he understands his prognosis or that a tissue diagnosis will probably not affect treatment or outcome. When he is more lucid, he wants "the test"–a CT-guided pancreas biopsy. Does this patient have the capacity to consent to this procedure?"

In 2002 a literature review on the current state of research on decision making competence of impaired elderly persons pointed out the lack of a criterion standard for competence and concluded that the use of expert judgment-based methods could mitigate the problem (Kim,

2002). In 2003, Karlawish reviewed and discussed "Determination of Decision-Making Capacity" for physicians (Karlawish & Pearlman, 2003).

Finally, in 2003 Ganzini, et al., published the results of a compelling study showing that clinician misunderstandings and knowledge deficits about patient decision-making capacity are common (Ganzini, et al., 2003). A total of 395 psychiatrists, geriatricians and psychologists rated the frequency and importance to patient care of 23 potentially common and important pitfalls in capacity assessment. Of the 23 potential pitfalls, 22 were rated as common. The two pitfalls ranked by the largest proportion as most important to address concerned the decision-specific nature of capacity assessment - "Practitioner assumes that if the patient lacks capacity for one type of medical decision, the patient lacks capacity for all medical decision," cited by 36% of those surveyed, and "Practitioner does not understand that capacity (or incapacity) is not 'all or nothing' but specific to a decision," cited by 35%. Other common pitfalls included: believing that capacity is only relevant to decisions requiring informed consent; assuming that if a patient has a conservator (for decisions concerning property) he/she lacks capacity to make medical treatment choices; confusing a judicial determination of capacity in a guardianship proceeding with a clinical determination of capacity for informed consent to treatment; and assuming that a diagnosis of dementia is synonymous with lack of capacity to consent to treatment - and more. This landmark study squarely supports the critical need for the proposed project.

4. Statement of Objectives

Rush University Medical Center and the ABA Commission on Law and Aging, with assistance from nationally recognized psychologists with expertise in capacity issues, aim to advance the understanding and practices of physicians concerning patient capacity assessment. In this regard, the project team has identified the following project objectives and their anticipated outcomes.

Goal 1: Develop training for physicians on the clinical and legal aspects of capacity to improve their ability to assess patient capacity.

Objectives:

- Draft an on-line training curriculum on capacity assessment for expert review. Outcome: A pilot version of the on-line training curriculum will be in place by month 15 of the project.
- 2. Pilot on-line training curriculum with a total of 75 physicians at three sites across the country.

Outcome: Completion of training with 75 physicians including results of pre- and post-tests at pilot sites after 18 months of the project.

Outcome: Post-test responses will show at least 50 of the 75 participants found the training valuable and will impact how they practice.

- Conduct two telephone focus groups in month 16 of the project with a total of 25 randomly selected physicians who completed the pilot curriculum.
 Outcome: Completion of two telephone focus groups with a total of 25 physicians who completed the pilot phase of testing.
 Outcome: Identify participants' outstanding questions, what information the participants believe will be most useful to them in their practice, and what information the participants found less meaningful.
- 4. Two additional focus groups will be conducted with the same group of physicians six months following the first two focus groups.
 Outcome: Completion of two additional telephone focus groups with the same participants who were in the previous focus groups.
 Outcome: Identify how training impacted physicians' daily practice over a six month period of time.
 Outcome: Twenty of the 25 focus group participants will say that the training was beneficial to their daily practice.
- Finalize the curriculum based on focus groups and analysis of pre- and post- test responses by the end of the second year of the project.
 Outcome: Curriculum will be completed.

Goal 2: Inform the national health care community that capacity training exists and is easily accessible. Encourage physicians to access curriculum.

Objectives:

 Broadly disseminate the final curriculum and reference cards beginning in month 25 of the project.

Outcome: Three collaborative organizations will have link to the training on their website by the end of year two of the project.

Outcome: Reference cards will be distributed at three national conferences in the year following completion of the project.

Have physicians complete online capacity training beginning in month 25.
 Outcome: Fifty physicians will complete the full training course in the first year it is available.

Outcome: One hundred fifty physicians will complete one or more modules of the training in the first year it is available.

Outcome: The on-line curriculum will become a mandatory component of the curriculum for all medical students at Rush University Medical Center. **Outcome:** Continuing Medical Education (CME) credit will be offered for physicians who complete the entire training.

5. Description of Methodology/Education and Training

a. Target Group Description

The proposed training will primarily target physicians (and secondarily medical students) including clinicians in acute and long-term care settings, outpatient facilities and office settings; and will include a diversity of medical disciplines such as internal medicine, geriatrics, neurology and psychiatry. While the training will target physicians, other professionals such as nurses, social workers, occupational therapists, psychologists and gerontologists also will find the curriculum useful.

b. Educational Needs to be Met

The project will address a current deficiency in physicians' understanding of both the legal and clinical concepts of capacity; improve patient capacity assessments; and teach effective strategies to maximize patient capacity. A key advantage of this product is that it will be useful in both a continuing education setting as a pre-packaged CME curriculum and in the front-line clinical setting as an easily accessible reference tool.

The project will aid practicing clinicians and students to overcome current barriers to patientcentered treatment for vulnerable, frequently chronically ill patients. In addition, this resource will be helpful to medical personnel in developing institutional health care policies and practices in accord with the patient-centered and interactive approaches to capacity assessment at the heart of this curriculum. For example, developers of policies concerning the institutional review board, ethics committee, use of a patient representative, and others will benefit from the training.

c. Content, Methods, Sequence and Location of Educational Experience

The project will require the following sequence of steps:

- (1) The project team (Gorbien, Eisenstein, Wood, Sabatino, Golden and Dong) will complete an <u>environmental scan</u> currently underway to identify existing resources on capacity assessment for the intended clinical audiences. (A literature review focusing on the need for capacity assessment training was completed in preparation for this proposal. See "List of References" located in the Appendix.) The project team is in the process of identifying and reviewing existing on-line medical and related trainings to become more familiar with web-based design and existing tutorials. For example, the project team will continue their initial examination of the Department of Veterans Affairs' web-based training site, the Institute for Geriatric Social Workers' training site and others. Additionally, the project team will seek initial input from clinicians and collaborators at Rush and the ABA as well as consultants to the project.
- (2) Combining the results of the literature review, environmental scan, input from key physicians/collaborators, and the previous experience of the ABA Commission and the American Psychological Association (APA) in developing multi-disciplinary capacity

assessment guides, the collaborators will design a <u>draft curriculum unit for physicians on</u> <u>capacity assessment</u>, consisting of:

- a. A <u>capacity assessment on-line curriculum</u> that will serve as the core of the training. It will incorporate training strategies including case studies, videos, and pre- and post- tests.
- b. A <u>take-away electronic handbook</u> that clinicians can print out as a reference following successful completion of the course. (The handbook would be accessible for printing only after the course has been completed.)
- c. A <u>laminated pocket-sized reference card</u> highlighting key concepts in a readily usable and easily portable summary.

The draft curriculum will be structured as five, one-hour modules for on-line learning. Each one-hour module will include electronic linkages to more in-depth information and additional references; and will include multiple choice pre- and post- tests that will be taken on-line. The pre- and post- tests will assess knowledge gained by participants from the training, and will track changes in their perception of the number of cases they encounter on a daily basis that require knowledge of capacity assessment. If participants are completing the course for CME credit they will need to successfully complete the tests associated with a particular module to move on to the next module.

The project team anticipates the curriculum to include the following:

- I. Introduction
 - A. <u>Importance of Accurate Clinical Assessment of Patient Capacity</u> the role of physicians.
 - B. Clinical vs. Legal Models of Capacity

Key elements in general clinical model and specific domains Legal standards of diminished capacity – specific transactions and general guardianship standards Relationship of legal to clinical models

- II. Clinical Assessment Elements
 - A. Assessment of medical condition
 - B. Cognitive assessment
 - C. Psychiatric assessment
 - D. Polypharmacy assessment
 - E. Functional assessment
 - F. Interactive component, including patient values and risks
 - G. Assessing specific key domains of capacity

Capacity to make or consent to a health care decision Determination of capacity based on relative risks Capacity to live independently

- 17 -

Financial capacity Other specific capacity domains (such as driving, sexual consent)

- III. Techniques for Enhancing Patient Capacity
 - A. Engendering patient trust and confidence
 - B. Recognizing "ageism"
 - C. Understanding culture and religious values
 - D. Accommodating sensory changes
 - E. Accommodating cognitive impairments
 - F. Strengthening patient engagement in the decision-making process
 - G. Correcting the underlying confounding factors (dehydration, delirium, depression, polypharm, etc.)

IV. Working with the Legal, Judicial and Mental Health Systems

- A. Basic considerations in consultations and referrals
 - Making assessments "on your own" versus consulting with assessment professionals

Consent for assessments and referrals

- B. Understanding the elements of a capacity report
- C. Clinical capacity opinions versus legal capacity outcomes
 - Understanding the reversibility of capacity, (i.e., Temporary incapacity due to illness, meds, etc.)

Distinguish episodic poor judgment versus permanent incapacity

- Capacity level or requirement differs depending on the questions asked
- D. Documentation and use of the capacity assessment report
- E. What the court needs to know assessments for guardianship
- F. Undue influence relationship to diminished capacity

V. Myths and Pitfalls in Capacity Assessment - Case Examples

- A. The project will seek to incorporate the "pitfalls in capacity assessment" by physicians identified by Ganzini, and building parts of the curriculum around these common misunderstandings; for example, "ten myths about capacity assessment you should know."
- B. Electronic linkages will enable the reader to view the following key resources: State-specific legal provisions on capacity;

A clinical algorithm of capacity assessment;

- A brief guide to psychological and neuropsychological assessment instruments; and
- A listing and description of less restrictive alternatives to guardianship.

The draft curriculum will build on the ABA's and APA's experience in designing materials on capacity assessment for lawyers and for judges, as well as the Medical Center's strategic placement and leadership in the medical community.

- 18 -

- (3) The project team will <u>identify and review existing video clips</u> on capacity assessment such as those used by Moye and Marson in previous presentations on behalf of the ABA and APA. If existing clips do not capture the cases required for the curriculum, the project team is prepared to tape and produce additional clips, using production facilities and clinical resources at the Medical Center. The project team will incorporate these into the curriculum to bring to life key points about capacity assessment. Jim Vanden Bosch from Terra Nova Films will serve as a consultant and direct production for this aspect of the project.
- (4) The project team will use the draft curriculum as the basis for an expanded <u>electronic</u> <u>handbook</u> that users can print out upon course completion. The project also will condense the key elements and techniques of capacity assessment into a two-sided <u>pocket-sized</u> <u>laminated card</u> that physicians can carry or use for quick reference to recall the main concepts of the curriculum. The card will provide the website address for the on-line training and for updates by jurisdiction.
- (5) The draft curriculum with video clips and handbook will be put into an on-line format, <u>loaded onto the internet</u> and placed in a password-protected website while reviews and piloting take place.
- (6) The draft curriculum, electronic handbook, and laminated reference card will be <u>reviewed</u> by a 5-person advisory group including experts in capacity assessment (the American Geriatric Society has recommended Dr. Greg Sachs, Dr. Jason Karlawish, and Dr. David Casarat) and expert representatives from our two pilot sites: Dr. John Morley of Saint Louis University and a well-qualified collaborator either from the University of Maryland or Johns Hopkins University. This advisory group will convene through structured phone-based discussion and individual feedback.
- (7) The project team will <u>test and evaluate</u> the draft curriculum, handbook, and laminated reference card by arranging for test runs of the course by 75 physicians in three selected medical settings across the country. The three sites were chosen based on their availability of physicians and students in a broad range of disciplines who work with patients of various cultural backgrounds in order to assure validity and cultural applicability of the curriculum. Twenty-five clinicians including psychiatrists, neurologists, internists, geriatricians, and students from each site will complete the training along with pre- and post- tests. An evaluation form included in the final post-test will solicit the participants' input, evaluation and suggestions for changes and improvements.

The three states where the curriculum will be piloted include Illinois, Missouri and Maryland. Rush University Medical Center will be the pilot site in Illinois. Engaging

- 19 -

Rush as a pilot site for this project capitalizes on Chicago's demographic diversity and Rush's longstanding commitment to high quality geriatric health care. Chicago reflects the changing demographic profile of other large, urban U.S. cities with a significant growth in minority populations relative to non-Hispanic whites. Rush is located in the heart of a racially and ethnically diverse community, providing a unique opportunity to enhance physician understanding of the health care needs of a diverse patient population. In Missouri, we will engage Saint Louis University. Saint Louis University, a top ten ranked program, has a long and distinguished track record in the development and implementation of innovative geriatric educational programs. Their patient population reflects great diversity including indigent, inner-city seniors, and patients from rural backgrounds, as well as University faculty. They also work closely with Saint Louis University's very large and well regarded geriatric psychiatry program. Their clinical, research, community outreach, and educational programs are among the most robust in the country. Finally, with the help of Jack Schwartz, Assistant Attorney General and Director of Health Policy Development at Maryland Attorney General's office we will arrange for a test site in Baltimore with a well-qualified collaborator at the University of Maryland or Johns Hopkins University. The use of three pilot sites will help ensure the curriculums relevance across jurisdictions.

- (8) Two <u>telephone focus groups</u> of 11-13 people each (for a total of 25 participants) will be conducted with physicians who piloted the curriculum immediately following their training. The focus groups will be conducted with participants chosen at random from a list of participants from all three sites. The purpose of the focus groups will be to find out what questions participants still have, what aspect of the training they value the most, and what knowledge they will use the most in their daily practice. Conducting a phone focus group serves two purposes: 1) to evaluate usability in a variety of jurisdictions, and 2) to evaluate the cultural sensitivity and applicability of the program. Six months following the first round of focus groups, the project team will reconvene the groups for a <u>second discussion</u> to evaluate the training's "real life" applicability and impact on physicians' daily practice.
- (9) Following the test-runs and focus groups, investigators will <u>revise the curriculum</u>, <u>handbook</u>, and <u>laminated reference card</u> as needed.
- (10) Application for <u>CME credits</u> will be completed and submitted with the expectation that the course will be worth five hours of CME credits, the credits will be provided by the CME office at Rush University Medical Center. Credits will only be awarded after completion of all five modules along with pre- and post-tests for each module. It is expected that 50 physicians will complete the full training in the first year it is available, and 150 physicians will complete one or more training modules.

- (11) The training will be <u>implemented at Rush University Medical Center as a mandatory</u> <u>part of the curriculum</u> for all second year Medical Students. The online curriculum will be incorporated into an existing course.
- (12) The revised curriculum will be announced, and information will be <u>disseminated</u> <u>broadly</u> within the clinical community, especially through groups such as the American Geriatrics Society, the Gerontological Society of America, and the American Psychological Association. Links to the training website will be displayed on each of these organizations websites. Additionally, laminated reference cards will be distributed at each of their National Conferences that take place during the first year following completion of the training.

d. Evaluation Criteria and Methods

The PIs and project team will measure their progress against the goals, objectives and anticipated accomplishments outlined in the Statement of Objectives portion of the proposal. While some components of evaluating the proposed project are outcome oriented, the majority seem to be best evaluated using Process Evaluation. In that regard, the project team has developed a logic model that addresses many of the questions posed on the Retirement Research Foundation's Process Evaluation portion of its website. The logic model can be found in the Appendix.

Three phases of evaluation are included in this project. The first of the evaluation occurs in the pilot phase of the project and will test and evaluate the draft curriculum by presenting the draft curriculum in three structured training settings across the country. A total of 75 physicians including neurologists, psychologists, students, geriatricians, and internists will complete the five module training along with pre- and post- tests for each module, and a final evaluation form. Based on the pre- and post- tests we will evaluate the knowledge that participants gain from the training and a possible change in their perception of the number of elders with competency questions with whom they work. The final evaluation form will help us determine the effectiveness of the training, to find out what aspects of the curriculum the participants valued the most, and to learn how physicians foresee using the information they learned in their daily practice. Additionally, the evaluation form will question participants for their opinions on payment options for obtaining CME credit for the training.

The second phase of evaluation includes a series of focus groups that will be conducted with physicians and students who completed the pilot phase of the project. Two separate telephone focus groups of 11-13 people (for a total of 25 focus group participants) will be conducted immediately following their completion of the curriculum. Participants will be chosen at random from a list of names of all pilot participants from all three sites. Monetary incentive will be offered to focus group participants. From the focus groups we will further evaluate the benefit of the knowledge gained from the curriculum, the usefulness of the downloadable handbook and reference card, and what aspects of the curriculum were most valuable to participants. A second

round of focus groups will be conducted six months later with the same two groups of participants for further feedback and to evaluate whether completion of the curriculum changed the way they practice.

Finally, continued evaluation will occur after publication of the final curriculum. We will continue to receive data regarding the number of participants who complete the training and the primary disciplines in which they work. Additionally, the pre- and post- tests and the final evaluation form will be a permanent requirement in order for participants to receive CME credits.

6. Dissemination

Information about this critical new web-based resource on capacity assessment will be disseminated broadly within the clinical community, especially through groups such as the American College of Physicians, American Medical Association, the American Geriatrics Society, the American Society on Aging, the American Medical Directors Association; the American Psychological Association, the Gerontological Society of America, the American Association of Geriatric Psychiatry, and the Illinois Self-neglect Consortium. In addition to displaying the link to the training on organization websites, reference cards with the link will be distributed at three national conferences within the first year following the project. Conferences for dissemination include the Gerontological Society of America, the American Geriatric Society, and the American Psychological Association. Finally, the curriculum will be built into on-going trainings at Rush in the form of mandatory in-service trainings for residents, geriatric fellows, and social workers and will be incorporated into an existing course for all second year medical students.

Expense by Category	% Effort	RRF	In-kind	Total
Personnel				
Co-PI, Martin Gorbien	5%	XXXX		XXXX
Co-PI, Amy Eisenstein	50%	XXXX		XXXX
Co-I, Robyn Golden	5%		XXXXX	XXXX
Co-I, XinQi Dong	5%	XXXX		XXXX
Fringe Benefits (at 21%)			XXXX	XXXX
Subtotal – Personnel		\$44,879	\$14,816	\$59,695
Consulting Expenses				
Jennifer Moye - Content review		XXXX		XXXX
Dan Marson - Content review		XXXX		XXXX
Jim Vanden Bosch – Video component		XXXX		XXXX
Karin Kuby – Online application development		XXXX		XXXX
Subtotal – Consulting Expense		\$32,300		\$32,300
Other				
Incentives for expert review panel		\$8,000		\$8,000
Subtotal – Other		\$8,000		\$8,000
Total Direct Costs		\$85,179	\$14,816	\$99,995
Indirect Costs* (at 26%)		\$8,518	\$13,629	\$22,147
Sub-contract, ABA Year 1 (See Appendix for detailed		\$55,835	\$8,192	\$64,027
budget and justification.)				
TOTAL		\$149,532	\$36,637	\$186,169

7. Budget and Timetable

*Represents 10% and 16% respectively of the \$85,179 in direct project costs for year 1 requested from RRF.

Budget Justification - Year 1

Personnel

<u>Co-Principal Investigator, Martin Gorbien</u> – Responsible for overall supervision of the project; liaison to advisory group and organizations within the broad clinical community; will work on draft curriculum and facilitate group discussions with other investigators. Dr. Gorbien will contribute 5% of his total time to this project.

- 23 -

<u>Co-Principal Investigator, Amy Eisenstein</u> – Will manage the day-to-day project activities; facilitate meetings with project participants; work with other investigators in curriculum development, and oversee preparation of progress and financial reports. Ms. Eisenstein will contribute 50% of her total time to this project.

<u>Co-Investigator</u>, Robyn Golden – Work with project PIs as liaison to Retirement Research Foundation, expert review panel, and organizations within the broad clinical community; will cofacilitate meetings with project participants; will work with other investigators to create a draft curriculum and facilitate discussion groups. Ms. Golden will contribute 5% of her total time to this project on an in-kind basis.

<u>Co-Investigator, XinQi Dong</u> – Liaison to medical settings for testing the curriculum; will work with other investigators to create draft curriculum and facilitate discussion groups. Dr. Dong will contribute 5% of his total time to this project.

Consultants

Dr. Jennifer Moye and Dr. Daniel Marson – Drs. Moye and Marson will provide ongoing expertise to this project. Dr. Moye is the Director of the Geriatric Mental Health Clinic at VA Boston, an outpatient mental health clinic focusing on the needs of older veterans, and an associate professor of psychology in the department of psychiatry at Harvard Medical School. Dr. Moye is the primary editor of the ABA/APA *Handbook for Lawyers: Assessment of Older Adults with Diminished Capacity* and the ABA/APA/National College of Probate Judges *Handbook for Judges: Judicial Determination of capacity of Older Adults in Guardianship Proceedings.* Her published research has focused on clinical evaluations of medical consent capacity and clinical evaluations for guardianship. In addition to the Handbooks, she has written extensively on the assessment of capacity, and was involved in a national effort to write guidelines for psychologists for capacity evaluation. Dr. Daniel Marson is Professor of Neurology at the Department of Neurology, University of Alabama at Birmingham. He is both an attorney and a licensed clinical psychologist. He has conducted extensive research and has written about capacity issues since the early 1990s, including examination of financial capacity. Dr. Marson was co-author of both ABA/APA handbooks.

<u>Jim Vanden Bosch</u> – Mr. Vanden Bosch is the founder and director of Terra Nova Films, a nonprofit company dedicated to sharing the experience and contribution of older adults through film. The company has taken a leadership role in promoting the use of educational videos by human service professionals and educators in aging-related fields. Mr. Vanden Bosch will work with the project team in using video to illustrate key components of the capacity curriculum.

<u>Karin Kuby</u> – Ms. Kuby is the founder and director of Vanstin Advertising, a Chicago-based advertising and marketing firm with particular expertise in website design as related to medical education. Ms. Kuby will work with the project team to develop an online application for the capacity curriculum that will enable education, participation tracking and data collection.

Specifically, Ms. Kuby will enable the site to allow password-protected access to the test curriculum during the pilot phase, house the final functioning online curriculum in a format and with navigation that facilitates the learning process, enable online assessment of education, tracking of participation, and data collection, and facilitating ongoing maintenance of online content and data collection.

Other

<u>Incentives for expert review panel</u> -- A \$2,500 incentive will be given to the experts at the two sites that are piloting the online curriculum. This payment is compensation for both their role on the review panel and their role in coordinating a pilot site. One thousand dollars will be given to each of the three other expert review panel members for their participation in the review process.

Sub-Contract

Personnel from ABA will provide ongoing collaboration at each step of this project. A detailed budget and related justification can be found in the Appendix.

Expense by Category	% Effort	RRF	In-kind	Total
Personnel				
Co-PI, Martin Gorbien	5%	XXXX		XXXX
Co-PI, Amy Eisenstein	50%	XXXX		XXXX
Co-I, Robyn Golden	5%		XXXX	XXXX
Co-I, XinQi Dong	5%	XXXX		XXXX
Fringe Benefits @ 21%			XXXX	XXXX
Subtotal – Personnel		\$46,226	\$16,127	\$62,353
Consulting Expenses				
Jennifer Moye- content review		XXXX		XXXX
Dan Marson - content review		XXXX		XXXX
Jim Vanden Bosch – video component		XXXX		XXXX
Karin Kuby – Online application development		XXXX		XXXX
$Subtotal-Consulting\ Expense$		\$30,500		\$30,500
Other				
Incentives for focus group participants		\$2,500		\$2,500
Telephone focus groups		\$392		\$392
Laminated reference card		\$3,500		\$3,500

Year 2

Total (Year 1+Year 2)	\$302,240	\$79,910	\$382,149
TOTAL	\$152,708	\$43,273	\$195,980
Sub-contract, ABA Year 2 (See Appendix for detailed budget and justification.)	\$50,278	\$12,247	\$62,524
Indirect Costs* (at 26%)	\$9,312	\$14,899	\$24,211
Total Direct Costs	\$93,118	\$16,127	\$109,245
Subtotal – Other	\$16,392		\$16,392
CME credits	\$10,000		\$10,000

*Represents 10% and 16% respectively of the \$93,118 in direct project costs for year 2 requested from RRF.

Budget Justification - Year 2

As the use of funds remains fairly consistent over the course of the project, the narrative below simply highlights any changes from the previous year's budget.

Personnel

Salaries are shown to reflect a 3% cost of living increase.

Other

<u>Incentives for focus group participants</u> – The 25 focus group participants will receive \$100 for their participation in two sessions. Participants will receive \$25 after the first session and \$75 after the second session.

<u>Phone focus group</u>– Phone focus groups will be coordinated through Rush's Department of Telecommunications at a rate of .09 per minute per participant. Budget assumes two 75 minute phone calls with a total of 29 participants (11-13 participants and 2 facilitators on each call).

<u>Laminated reference card</u> – Key information will be captured on a pocket-size, accordion-fold laminated card for physician's easy reference. Five thousand quick cards will be printed at a cost of \$3,500. Quick cards will be distributed at three national conferences in the year following the project's completion.

<u>CME-related costs</u>- This line covers the management and application fee for five CME credit hours for the on-line training module through the Rush University Medical Center CME department.

Rush University Medical Center

Assessment of Capacity of Older Adults Rush University Medical Center January 2, 2007

PROJECT TIMETABLE

Assessment of Capacity in Older Adults: A Growing Challenge for Physicians

TASK Month→	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	22	23	24	25	26	27	28
1. Environmental Scan	x	X								1														
2. Design a draft curriculum including pre and post tests		X	X	Х	Х	X	Х	Х	Х															
3. Tape/edit/ produce video case presentations						Х	Х	X	Х															
 Design a draft reference card 								Х	X	Х														
 Transfer draft curriculum to on-line format 							Х	Х	X	Х	Х				1									
 Expert review & feedback of draft curriculum 												Х	Х											
7. Revise based on expert review													Х	Х										
 Pilot the draft curriculum in three settings across the country 															Х	Х	Х							
 Conduct first two telephone focus groups 																Х								
10. Conduct second two telephone focus groups																		Х						
 Revise the curriculum and materials and website based on focus groups and evaluations 																		Х	Х	Х				
12. Apply for CME credits																			Х	X				
13. Publish and disseminate					-																X	X	X	X

- 27 -

8. Plans for Continued Support

Upon completion of the curriculum and widespread dissemination, a small amount of continued support will be necessary. Rush will seek additional internal and foundation funds to help maintain the website and database on an on-going basis. Philanthropic funding will be sought for future research opportunities that will build on the evaluation component of this project to further understand, through randomized trials, what impact that training has on physicians' daily practice. Finally, depending upon physician responses regarding payment options for CME credit we will either be required to charge participants for CME credits or to obtain further funding in order to be able to offer the training to groups of clinicians free of charge.

9. Personnel

See Appendix.

10. Applicant Organization

Detail qualifications of applicant organization to implement project. Include a brief history, accomplishments, financial reports, and an annual report.

At <u>Rush University Medical Center</u>, physicians, nurses, social workers and other health professionals work together to meet the care needs of older adults. In addition to treating disease and working to prevent disability, health care professionals work closely with older adults and their families to help maintain health, independence and active lifestyles. The geriatrics team at Rush also includes researchers and educators dedicated to advancing the interdisciplinary practice of geriatrics, through the education of health care professionals to meet the care needs of older adults and through research seeking knowledge about common disorders and diseases that affect older adults.

Rush is identified as a leader in older adult services in the city of Chicago and has ongoing collaborations with the Area Agency on Aging as well as a variety of city and suburban entities. *U.S. News and World Report* regularly ranks Rush as an institution with demonstrated excellence in geriatric medicine. In the July 12, 2005* issue, Rush was ranked fourteenth in the nation in geriatrics. (*The publication did not provide rankings in geriatrics in 2006.)

Education and Training

Preparing current and future generations of students and professionals to meet the challenges and complexities of caring for the aged is one of the most important missions of any academic health care institution. Through its residency programs, interdisciplinary education and applied practice initiatives, and nursing and allied health degree programs, Rush is viewed as a leader in gerontological education.

Residency programs at Rush include specific training directed toward educating young physicians on the complexities and challenges of caring for the aged. The residencies in internal medicine and rehabilitation medicine at Rush both include comprehensive rotations in geriatric medicine. In addition, the longest standing fellowship in Geriatric Medicine in Illinois is located at Rush. The geriatric medicine fellowship serves as a destination for internists and family

practitioners seeking to dedicate time to learning to be expert in the care of older adults from Rush's faculty and staff. Rush also offers a Geriatric Nurse Practitioner training program that draws both from Rush's expertise in geriatrics and in nursing care. Rush's nursing programs have a long history of excellence and in addition have received Magnet recognition from the American Nursing Credentialing Center. Rush also co-sponsors The Illinois-Missouri Geriatric Education Center funded through the Health Resources and Services Administration. Rush has hosted the Illinois Geriatrics Society's activities for the past three years and has hosted the Society's annual meetings for the past five years.

Recognizing that the care of older adults is an interdisciplinary commitment, Rush has offered an interdisciplinary training program in geriatric education for the past ten years, making it one of the oldest and most successful programs of its kind in the United States. Established in 1996 through a grant from the John A. Hartford Foundation's geriatric interdisciplinary team training (GITT) initiative, the Rush GITT Program has provided training for over 1000 participants representing eleven different disciplines. These include medicine, nursing, social work, occupational, speech and physical therapy, audiology, clinical nutrition, pastoral care, ethics and pharmacy. Rush's achievements in interdisciplinary education and practice were recognized in an article on interdisciplinary education in <u>New Physician</u> magazine in 1999 and in a special report devoted to the topic featured on the web site of the Association of Academic Health Centers in 2003.

Treatment and Research

Investigators and program directors at Rush regularly strive to establish treatment plans that emphasize quality of life. An example of these efforts is a current project known as BRIGHTEN -- Bridging Resources of an Interdisciplinary Gero-mental Health Team via Electronic Networking. This project, which is supported by a three-year grant from the Retirement Research Foundation, applies new approaches to identify and treat depression in older adults by screening patients in four diverse medical practices. The project offers an assessment and treatment plan specific to each individual's needs through a coordinated, interdisciplinary treatment program, which includes specialties not routinely involved in depression-treatment programs. The team uses e-mail, fax and telephone conferencing to hold discussions about each patient with other clinicians, such as occupational therapists, physical therapists and dietitians. With this approach, physicians can pool their expertise even if they can't physically meet to discuss cases due to time or travel constraints. Project investigators believe that this will result in more comprehensive, cohesive care and better outcomes for people with depression.

Rush has the most comprehensive services in the region for diseases and afflictions associated with aging, such as Alzheimer's, Parkinson's, cancer, stroke, and osteoarthritis. The stroke program at Rush is one of the world's first to use magnetic fields to treat strokes less invasively. Physicians at Rush provide the most advanced approaches to treating osteoarthritis, including new drug therapies, groundbreaking methods for restoring damaged cartilage, the latest implant technology and innovative approaches to knee and hip replacements. Rush Physicians use minimally invasive technology such as fiber optics to clear clogged arteries near the heart instead of open-heart surgery. Rush also offers more targeted, gentler cancer treatments – some of which are available at few other hospitals. For example, Rush is the only hospital in Chicago that provides a noninvasive laser therapy to destroy lung cancer cells in the windpipe.

- 29 -

In terms of translational research, Rush investigators are responsible for breakthrough studies on the role of diet in enhancing learning and memory in older adults and advancing the field of caregiving with studies of the physical and emotional impacts of providing care for a relative. Rush scientists are taking the fight against osteoarthritis down to the cellular level, looking to uncover the very roots of the disease. Rush was originally awarded a National Institutes of Health (NIH) Specialized Center of Research in osteoarthritis grant in 1987. Since that time, Rush's five-year SCOR grant has been renewed four times due to Rush's excellence in osteoarthritis research. Rush is also home to the Rush Alzheimer's Disease Center, one of only 29 centers in the nation funded by the NIH. Currently, it is the only place in the country conducting research on a new gene-therapy agent that could prevent cell damage and possibly reverse the affects of Alzheimer's.

Services

Rush truly provides one-stop shopping for older adults, coordinating the many different services people need to lead healthier, more fulfilling lives as they age. Examples of these services include the following:

The Johnston R. Bowman Health Center has served older adults for over 25 years. The facility is located on the Rush campus and provides a range of services from inpatient programs that focus on geriatric medicine and restorative care to independent senior living apartments that are located within the building. The Bowman Center houses inpatient acute rehabilitation services as well as inpatient geriatric psychiatry services.

The Bowman Center also administers a health and aging program known as Rush Generations. This is an initiative designed to provide education and resources to older adults in order to maximize their health. Programs range from educational classes, SHIP Counseling (Senior Health Insurance Program – a collaboration with the state of Illinois), to health screening and includes the Anne Byron Waud Patient and Family Resource Center.

The Waud Center is a dedicated resource center with services made available at no charge to the general public. It contains resource materials such as books and videos available for review as well as an area to relax and study the materials. The Waud Center is staffed by two individuals who are available by direct interaction or via telephone or e-mail also at no charge. The Waud Center focuses its attention on older adults themselves and their caregivers (typically family members). Additional services include support groups as well as one on one education on computer literacy and internet usage.

<u>The American Bar Association Commission on Law and Aging</u> seeks to strengthen and secure the legal rights, autonomy, quality of life and quality of care of elders through research, policy development, technical assistance, advocacy, education and training--focusing particularly on elders who are most vulnerable because of economic status or societal isolation. Established by the ABA in 1978, the Commission is a 15-member multidisciplinary group and has a longstanding professional staff with an average experience of 23 years in law and aging.

The Commission has played a leadership role in health care decision-making and adult guardianship reform for 20 years. Commission staff have provided extensive technical assistance in guardianship and health care decision-making law, policy and practice to state lawmakers, attorneys, judges, the aging and disability networks and advocates. Each year the Commission develops and distributes state statutory legislative updates on advance directives, end of life statutory measures, and adult guardianship reform.

The Commission's 1994 video narrated by actress Helen Hayes, entitled *In Your Hands: The Tools for Preserving Personal Autonomy*, has been widely distributed and acclaimed. Over a million copies of the Commission's publication, *Health Care Powers of Attorney: An Introduction and Sample Form* have been distributed. The Commission's 2003 publication on *Health Care Decision-Making for the Unbefriended Elderly* paved the way in examining the current state of law and practice concerning medical treatment decisions on behalf of incapacitated individuals with no family or friends and no advance planning documents.

The Commission responded to inquiries from the press, from individuals, and from policy makers in the wake of the 2005 Terri Schiavo case, and on end-of-life and advance planning documents, in general. Staff actively speak and write on the issue, and most recently published a *Consumer's Tool Kit for Health Care Advance Planning* and a guide for health care proxies entitled *Making Medical Decisions for Someone Else: A Guide for Marylanders.*

The Commission is working with the National Hospice and Palliative Care Organization and others on a 50-state survey of legal and regulatory barriers to end-of-life decision-making medical orders called "Physician Orders for Life-Sustaining Treatments" or POLST.

The Commission has worked on adult guardianship reform since the mid-1980s. In 1986, the Commission joined with the National Judicial College to sponsor a National Conference of the Judiciary on Guardianship Proceedings for the Elderly. In 1988, the Commission worked with the ABA Commission on Mental and Physical Disability Law to convene the landmark "Wingspread" National Guardianship Symposium, a working session of interdisciplinary guardianship experts that resulted in a widely-used set of recommendations for guardianship reform. In 1991, the two ABA Commissions and the National Judicial College sponsored a national conference on court-related needs of the elderly and persons with disabilities. Also in 1991, the Commission, along with the disability law Commission and with support from the State Justice Institute, produced an extensive study with recommendations on guardianship monitoring. The same year, the Commission published comprehensive training materials on alternatives to guardianship.

The Commission has worked closely with the National College of Probate Judges on guardianship issues and has made presentations at its conferences and produced articles for its newsletter. Commission staff speak and write frequently on guardianship and surrogate decision-making issues and are active in the National Guardianship Association. The Commission is part of a new National Guardianship Network of organizations aiming to develop good guardianship laws and practices.

- 31 -

In 2001, the Commission joined with other national organizations seeking to strengthen the adult guardianship system in convening the Second National Guardianship Conference, known as "Wingspan," which produced recommendations for action and a set of extensive background papers in the *Stetson Law Review*. In 2004-2005, the Commission collaborated with the University of Kentucky, with support from The Retirement Research Foundation, on the first national study of public guardianship in 25 years; and currently is working on phase II of that project, which will result in extensive recommendations and identification of best practices.

The Commission and the <u>American Psychological Association</u> have collaborated in two handbooks on capacity assessment. A *Handbook for Lawyers on Assessment of Older Adults with Diminished Capacity* (see <u>http://abanet.org/aging</u>), published in 2005, has been widely distributed in the legal community, with much acclaim. A *Handbook for Judges: Judicial Determination of Capacity of Older Adults in Guardianship Proceedings*, published in 2006, was presented at the May 2006 meeting of the National College of Probate Judges, and is currently being distributed to a wide range of judicial organizations. The proposed project would be a natural progression of the Commission's work on capacity assessment. Dr. Jennifer Moye and Dr. Daniel Marson both worked on the earlier handbooks (with Dr. Moye as editor), and both would contribute immensely to the quality of the proposed project.

- 32 -