Assessing Capacity to Execute a Health Care Proxy: A Rationale and Protocol

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This article discusses the concept of capacity, various relevant mandates, and a rationale for the assessment of capacity to execute a health care proxy. Some specific New York State regulations, pertaining to the execution of a health care proxy by persons who have intellectual disabilities, are presented and contrasted with regulations in some other jurisdictions. A standard that psychologists and physicians may use in assessing the capacity of a person with cognitive impairments to execute a health care proxy is reviewed. Additionally a protocol for assessing capacity to execute a simple health care proxy is in the appendix.

Keywords: capacity, consent, developmental disability, health care proxy, intellectual disability, mental retardation, psychiatric

American law presumes that a person has the prerequisite capacity to perform a legal act (e.g., consent to medical treatment, sign a lease, get married) upon reaching the age of majority.⁵,⁶,⁹ Despite this presumption, persons whose decision-making ability may be considered questionable include those with a mental disability, minors, and those who have cognitive impairments.¹,¹⁷ Cognitive impairments can include intellectual disabilities and other developmental disabilities, dementia, and traumatic brain injury.

Growth trends in the elderly population suggest that capacity assessments are likely to become increasingly important. Ceas and Fisher⁶ predicted that there would be more people over the age of 65 than under the age of fifteen by the year 2030. According to the United States Census Bureau,³⁵ the number of people in the United States aged 65 and older increased by 12% between 1990 and 2000. The risk of developing dementia increases with age.⁶ Additionally, there is a higher incidence of mental health concerns as well as medical illness among older adults.³⁶ The complex issue related to assessment of capacity for persons who are elderly to give informed consent will probably receive increased attention.²⁹

Decision-making ability, or capacity, is a dynamic rather than static quality. A person’s decision-making ability can vary over time. Some examples follow. An individual with severe symptoms of mental illness may lack capacity until the symptoms of mental illness go into remission as a result of treatment with antipsychotic medication. Decision-making ability is task-specific. A person whose mental status has declined (e.g., due to dementia) may have lost decision-making ability that was once present.

Also, capacity is specific to the decision at issue and is not global.⁴,¹³ For example, an individual with intellectual disabilities may be capable of giving informed consent for a simple medical procedure (e.g., taking sleep medication for insomnia); but the risks and benefits of a complex medical procedure (e.g., organ transplant surgery) may be beyond that individual’s understanding. An individual with intellectual disabilities may be found capable of giving informed consent for a specific activity or procedure, yet lack capacity to give consent for a different activity or procedure.

Capacity is a cognitive ability which involves an individual’s rationality, knowledge, and voluntariness. A person with impaired cognitive ability may be capable of making certain decisions if needed supports are present. The needed supports may include patient, slow, and repeated communication with familiar and trusted people (e.g., family, staff) in ways that enhance the person’s understanding of the potential risks and benefits of the decision at hand, as well as understanding of an alternative. Without those kinds of supports the person may not be capable of making certain decisions. Capacity refers to a person’s ability to make a specific decision at a specific time, and under specific conditions.⁴

Usefulness of Capacity Assessment

The growing body of literature concerning ability to give informed consent for various procedures still has not resulted in a widely accepted capacity standard.⁵,⁶,²⁹ It is clear from legal and ethical codes that professionals are to
respect the basic rights of people by not taking the position that a disability automatically renders them unable to make their own decisions. In particular, professionals should avoid deciding that an individual lacks the ability to make health-care decisions simply because he/she has a mental disability.

It is important to discriminate those who can make decisions which must be accepted by others from those who lack capacity, and for whom someone else will function as a surrogate decision-maker. The principle of patient autonomy stems from the belief that every capable adult has the right to accept or refuse medical treatment. Capacity assessments help to ensure that capable persons are allowed to decide on their own treatment, and that incapable persons are protected from unwise decisions beyond their ability.

Depending upon their capacity, persons with cognitive impairments may or may not provide informed consent. An individual who has a legal guardian can have capacity to give informed consent for specific procedures. For example, an individual who has a plenary legal guardian was found capable of giving informed consent for surgical insertion of an abdominal feeding tube. If the guardian wanted the procedure to be done but the individual refused, neither would automatically prevail over the other’s desire. The conflict may need to be resolved via a judicial proceeding. If the guardian was unreasonably disregarding the individual’s decision-making capacity, a legal advocate for the individual could seek to have the guardianship overturned. In New York State a guardian is to make medical decisions in accordance with the ward’s wishes. In the case of a person for whom a guardian has previously been appointed, there must be a determination as to whether the individual is incompetent to make the decision at hand.

Persons with cognitive impairments have the same constitutional rights as those without such disabilities. Witness the American Association on Intellectual and Developmental Disabilities’ advocacy against unnecessary guardianships. Also, the New York State Legislature has clearly indicated that decision-making authority by the guardian of a person with intellectual disabilities should not infringe on the person’s right to make decisions where he or she is capable.

How Capacity is Determined

The two usual methods for determining capacity are a professional’s clinical assessment (psychiatrists, psychologists, and physicians are generally recognized) or a legal decision by a judge based on evidence and expert opinion. The clinical assessment method is quicker, cheaper, and more easily accessed. Unfortunately, some health care professionals, despite having the requisite experience and credentials, have often behaved in devaluing ways toward people with certain disabilities. Those who have behaved so unprofessionally should not be used to assess the capacity of people with disabilities.

There is not always a choice about which method for determining capacity will be used. Judicial determinations, rather than clinical assessments, must be used in some circumstances. The New York State Court of Appeals in Rivers v. Katz stated that the determination of capacity is a “uniquely judicial function.” If a psychiatric hospital wants to prevail over an involuntarily confined patient’s objection to psychotropic medications, there must be a judicial determination that the patient lacks capacity followed by a best interests determination.

The United States Supreme Court decided in Cruzan v. Missouri Department of Health that a state could require clear and convincing evidence of a person’s wishes to be shown in order to allow close family members to make decisions for the person with incapacity. Since 1990 every state has enacted legislation that allows their citizens to use a health care proxy. In any jurisdiction a person who has the requisite capacity should be allowed to execute a health care proxy or give an advance directive. New York State is more restrictive than most other states regarding advanced directives for a health care proxy concerning nourishment and hydration. In the majority of states health care proxy agents have much latitude. In some states an appointed guardian, who is unfamiliar with the individual, has greater latitude in health care decision-making than a health care proxy agent in New York State.

The Health Care Proxy

A health care proxy is a written record in which an individual (a principal) authorizes
Another person (an agent) to make health care decisions on his or her behalf when he or she is not capable of making such decisions. To validly execute a health care proxy, the principal must have reached the age of majority (i.e., 18 years of age in New York State) or be married or a parent. The principal may revoke or change the health care proxy at any time. People with intellectual disabilities, like other citizens, should have the option to change their mind regarding their end-of-life wishes.18

A legally valid form for a simple health care proxy may vary between jurisdictions. A valid form for New York State is accessible at the New York State Department of Health website.25 A simple health care proxy form is equivalent to the health care proxy form on the New York State Department of Health website without references to advanced directives.

In New York State a simple health care proxy does not cover end-of-life decisions or advanced directives. Examples of issues which end-of-life decisions and advanced directives pertain to include: nourishment and water provided by a feeding tube, cardio-pulmonary resuscitation, pain medication, blood transfusions, chemotherapy, artificial respiration and withdrawal of life support measures.26 In addition to an assessment of capacity to execute a simple health care proxy, an individual may receive an additional assessment regarding decision-making ability to give advanced directives. An advanced directive capacity assessment focuses on the risks, benefits, and alternatives for the specific advanced directive being considered. If an individual has been assessed and found capable of giving specific advanced directives, the agent’s authority would be limited by those advanced directives. Such a capable principal may have his or her wishes regarding specific health care decisions written into the health care proxy. There is a less challenging capacity standard for executing a simple health care proxy than there is for giving an advanced directive.

Risks and Benefits

Physicians are required to do what an incapacitated principal has requested through a health care proxy. In the absence of a health care proxy, or guardian, there may be postponements in securing health care treatments. Although informed consent is unnecessary for emergency treatment, there are health care conditions where postponement in treatment would be harmful (e.g., aggressive disease, extreme respiratory difficulties). The health care proxy can allow expeditious access to health care treatment. There is no requirement for review of proposed health care treatment by an outside source (e.g., the judiciary) when there is a health care proxy.

In New York State a guardian authorizes proposed health care treatment for an individual with intellectual disabilities who has no health care proxy. The guardian may make health care decisions for the individual without seeking approval from an outside source (e.g., the court, an agency whose mission is to protect the rights of persons with intellectual disabilities). Mental Hygiene Legal Services, a New York State agency staffed mainly with attorneys, is charged with protecting the rights of individuals with intellectual disabilities or other developmental disabilities or mental illness. Mental Hygiene Legal Services may object to a guardian’s end-of-life decisions on behalf of an individual. The vignette in the next paragraph illustrates this point.

Ms. A, a 50-year-old female, was on a ventilator in the intensive care unit of a hospital in New York State. She had Down syndrome and advanced dementia. Her physical status was very deteriorated, and she seemed near death. She lacked capacity to give or refuse consent for life-sustaining medical procedures. Unfortunately, she did not have a health care proxy. Her mother stated that, several years earlier, Ms. A indicated that she would not want to receive artificial respiration in a situation like her current one. In the past Ms. A may have had the capacity to execute a health care proxy and to give some advanced directives. The medical director of the Center for Disability Services, Ms. A’s residential provider agency, as well as a physician on staff at the hospital, agreed that her quality of life was very poor and was not likely to improve. New York State law does not allow a hospital to remove the ventilator in a case like this as it is considered likely to result in the patient’s death. If Ms. A had a health care proxy, and had given an advanced directive that she did not want artificial respiration, then the ventilator would not have been used. While Ms. A clung to life in the intensive care unit, the local Surrogate’s Court judge used an accelerated proceeding to issue a decree of guardianship, which named Ms. A’s sister as her guardian. The sister, thus empowered with authority as a guardian, then instructed the hospital to remove the ventilator.
from Ms. A. Mental Hygiene Legal Services objected because the removal was considered likely to result in Ms. A’s death. Consequently, implementation of the ventilator removal order was delayed until after the legal issues were resolved. Eventually the ventilator was removed. If no guardian had been appointed, the hospital may have been legally required to continue the use of a ventilator for an indeterminate time period. Surprisingly and happily, Ms. A recovered.19

If an agent was a beneficiary of the principal’s estate, the agent might be tempted to make unethical health care decisions which could hasten the principal’s death. Some elderly parents do not want their adult child with a disability to outlive them because they believe that others will not provide the proper care. An elderly parent, with guardianship authority, may tire of the burden of caring for an adult child with a disability; and that elderly parent may decide not to allow life-sustaining medical interventions.

Creating the Health Care Proxy

The principal, as well as two adult witnesses, must sign and date the health care proxy. In New York State neither witness may be the agent. The creation of a health care proxy requires a personal act by the principal. No surrogate, such as a guardian, may execute a health care proxy on behalf of the principal.

In the case of an individual with intellectual disabilities, who receives residential services from an agency that operates under the auspices of the New York State Office of Mental Retardation and Developmental Disabilities, there are special regulations that apply. At least one of the witnesses may not be an employee, officer, or board member of the agency that provides residential services to the principal. Also, at least one witness must be a New York State licensed physician or licensed psychologist who satisfies one of the following conditions: a) is employed by a New York State Developmental Disabilities Service Office; or has worked at least two years in a certified facility that provides services to individuals with intellectual or developmental disabilities; or b) has specialized training and two years experience serving persons with intellectual disabilities or developmental disabilities; or c) has at least three years experience serving persons with intellectual or other developmental disabilities.24,28

The health care proxy continues in effect until the principal revokes it. If an individual with intellectual disabilities wants to revoke a prior health care proxy, the previous assessment of capacity should be reviewed. A re-assessment may be needed if the individual’s mental status had deteriorated, e.g., due to agitation or a medical condition.14,16

It is important that planning for end-of-life care begin well before a person becomes terminally ill.18 In New York State special regulations apply to persons with intellectual disabilities who receive residential services from an agency certified by the New York State Office of Mental Retardation and Developmental Disabilities. Individuals with intellectual disabilities, who are candidates for residential services, may benefit from receiving an evaluation of capacity to execute a health care proxy. Each individual with intellectual disabilities who is found capable, should be encouraged to execute a health care proxy. A parent, guardian, or another actively involved family member would be an appropriate agent. If there is no willing relative or trusted friend who could be chosen as an agent, then an advocate could attempt to establish a trusting relationship between the principal and a potential agent (e.g., a family member of a housemate of the principal).

An individual with intellectual disabilities might select a person with cognitive impairments (e.g., a peer in a residential facility) as a potential agent. Unless the potential agent has capacity to give informed consent for complex medical procedures, then choice of that person would not be valid. In such a case the individual may benefit from supportive guidance from staff in order to make a valid selection.

When an attending physician determines that an individual lacks capacity to make health care decisions, the agent’s authority begins. The determination must be in writing, and must specify the cause, nature, extent, and likely duration of the individual’s incapacity. If the cause is an intellectual disability or developmental disability, a licensed physician or licensed psychologist who has had specialized training or experience identified earlier must be involved in the process of determining the incapacity.26 A tool, or standard, that physicians and psychologists can use in determining whether a person lacks capacity to make a health care decision is presented in Lyden and Peters.20
A Standard for Assessing Capacity

Appropriate assessment adaptations should be made in light of an individual’s disabilities. For example, persons with traumatic brain injury should be presented with recognition rather than recall memory task. Other disabilities for which adaptations may be needed include: intellectual disability, impaired speech, sensory or motor deficiencies. It may be useful for the assessment to be a collaborative effort between the primary clinical assessor and others (e.g., a caretaker) who are proficient in communicating with the individual. A caretaker may be more expert than the primary clinical assessor in communicating with the individual in understandable ways.

The law has recognized three elements to constitute legally sufficient capacity—an individual’s degree of rationality about the proposed action, his or her knowledge concerning the proposed procedure, and whether the person’s decision is voluntary.

Since the capacity assessment is cognitive, it should be based on a person’s optimal current cognitive functioning. The circumstances of the assessment should be geared to maximize cooperative and alert responding while minimizing undue anxiety and distraction.

Rationality

Rationality is the ability to weigh the pros and cons, to critically evaluate, and to make a knowledgeable decision. In assessing rationality several factors should be examined. Any diagnosed neurological, psychiatric, or medical conditions that may impair the individual’s judgment, perception, or thinking should be considered (e.g., dementia, schizophrenia, medication side effects, traumatic brain injury, drug intoxication).

An individual’s rationality could be temporarily impaired. Mental health problems might be implicated in some cases. In such circumstances the capacity assessment should be postponed until the impairment has remitted. Some examples follow:

1. If delusional statements interfere with a person’s responses to assessment items, the assessment could be re-presented at a later time when the person is able to respond in a more clear thinking manner.

2. A person may repeatedly ask irrelevant or disruptive questions (e.g., “Can I leave now?”).

“When will we be finished?” suggesting that there are distracting preoccupations that are interfering with focused attention to the items being presented. In a case like this, it may be wise to reschedule the assessment so as to arrange circumstances that might optimize the person’s responsiveness.

The individual’s level of intellectual functioning is very relevant. When the IQ is above 79 (i.e., intelligence that is low average or higher), and there are no physical or mental health impairments that might compromise mental status, the individual probably has capacity. However, if there are indications of a potential mental status impairment, then a mini-mental status exam, including orientation and memory items should be administered. If significant mental status impairments are found, there should be an assessment of knowledge and voluntariness.

If an individual’s IQ is below 40 (i.e., intelligence that is at or below the level of severe intellectual disability) that person probably lacks capacity. However, if an individual with an IQ below 40 has sufficient communication skills to allow a mini-mental status exam, and the results show that there is adequate orientation and memory, then the assessment of knowledge and voluntariness should also be done. All persons with intellectual disability should be afforded an opportunity to make decisions about their lives.

An individual whose IQ is between 39 and 80 should receive a thorough capacity assessment, including a mini-mental status exam and an evaluation of the individual’s relevant knowledge and voluntariness.

Knowledge

The three knowledge criteria the principal must satisfy are:

1. The individual must show understanding that another person (i.e., the agent) is being given authority to make health care decisions on his or her behalf, if he or she is or becomes incapable of making such decisions for himself or herself;

2. The choice of agent must not be arbitrary and must make sense (e.g., a trusted relative, a familiar person who has the capacity to make health care decisions); and
3. The individual has to demonstrate understanding that he or she has the right to revoke or change the health care proxy.\textsuperscript{24}

In order to consider circumstances in which one would be, or may become, incapable of making certain health care decisions for one's self, abstract thinking ability is required. Also, some individuals may try to avoid talking about it (e.g., "I won't be sick."). "I'm not going to the hospital."). "My mother won't die.") because it is stressful to consider such circumstances. If this occurs, then education and training that includes graduated exposure to the key concepts may be useful prior to the next attempt at assessing capacity.

Voluntariness

Unwillingness, inability, or ambivalence with regard to expressing a choice would compromise voluntariness.\textsuperscript{23} Also the presence of duress, coercion, or undue influence in this matter could render a person incapable of executing a health care proxy.

In assessing voluntariness it can be helpful to obtain information from files or records of recent years compiled by providers of residential and day program services. Direct discussions with the individual, as well as conversations with staff who currently provide services to him or her, are valuable sources of information. It is important to find out if any person of influence (e.g., a relative, a service provider, a physician) has unduly influenced him or her toward a particular course of action. There must be an evaluation of the person's ability to make a free choice, even if it flies in the face of what was urged by a person of influence.

Any impairments to an individual's voluntariness should be carefully examined with a view toward resolving them and promoting the individual's self-determination and independence.

Final Determination

Impairments in rationality, knowledge, or voluntariness may result in a determination of incapacity. Although some deficits (e.g., advanced dementia) may not be easily corrected, others may be subject to remediation. Paranoia or delusions may impair rationality until antipsychotic medication improves the individual's mental status. If there are shortfalls in knowledge, appropriate education may enable the individual to learn what is necessary to be deemed capable. When voluntariness has been compromised by an authority figure, it may be possible to decrease or limit the undue influence sufficiently to elevate the person's decision making from the level of incapacity to the level of capacity.

The following vignette illustrates a situation in which problems with knowledge and voluntariness compromised the validity of a health care proxy.

Ms. B was a 22-year-old female with mild intellectual disabilities who received residential services through the Center for Disability Services in the Albany area of New York State. Her father, with whom she had a good relationship, lived over 150 miles away. He arrived at her residence in the company of an attorney, who Ms. B was unfamiliar with. The father hurriedly pressured Ms. B to sign a health care proxy document, even to the extent of using hand-over-hand physical guidance for the signing, despite the fact that she was crying and showing confusion. That health care proxy document was invalid on more than one count. It was not clear that Ms. B understood what she was doing—there was no evidence that her knowledge was sufficient; and there was undue influence, which cast doubt on the voluntariness of her act.\textsuperscript{19}

Discussion

There has been a paucity of clinical standards for determining capacity. A standard for evaluating capacity to execute a health care proxy is in the appendix. The use of a clinical standard for assessing capacity helps afford respect for individual dignity and autonomy in compliance with legal regulations as well as “Principle E: Respect for People's Rights and Dignity” of the American Psychological Association's code of ethics and rules of professional conduct.\textsuperscript{1} The Center on Human Policy at Syracuse University has proposed "A Statement of Common Principles on Life-Sustaining Care and Treatment of People with Disabilities."\textsuperscript{7} The principles affirm the fundamental human, civil, and constitutional rights of all people, including the rights of persons with disabilities to life-sustaining treatment and to self-determination. This statement can be accessed at the following internet address: http://thecph.syr.edu/endorse/. Over 30 disability advocacy and rights organizations have formally endorsed it.

The protocol in the appendix lays out a useful process. It is like a road map through a legal and clinical landscape. Some standard assessment procedures and a clinical interview constitute core elements of the protocol.
The Mini-Mental Status Exam, which is included in the assessment of rationality, is a simple and widely used screening device. It has not been validated on persons with intellectual disabilities. The use of a mini-mental status exam is a well accepted practice in evaluating an individual’s rationality. The assessment process suggested in this article is closer to the infant stage than to the fully mature stage of development. Future research could focus on issues such as: elucidation of the process of assessing the capacity of a person with intellectual disabilities, validation of the mini-mental status exam with people who have intellectual disabilities, and validation of other parts of the capacity assessment.

There are many individuals with cognitive impairments who have capacity to execute a health care proxy, but who lack decision-making capability regarding proposed complex medical treatments. Ethical and moral codes dictate that reasonable efforts should be made to include individuals in decisions affecting their lives in order to avoid possible victimization.

Prejudice against people with severe intellectual disabilities is common in society. Biased attitudes even exist in some health care providers. The decisions of health care professionals and surrogates may sometimes fail to adequately take into account the thoughts, feelings, and wishes of persons with severe intellectual disabilities. This unfortunate situation underscores the importance of carefully done capacity evaluations.

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References


27. New York State Surrogate's Court Procedure Act, Article 17-A.


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APPENDIX
A PROTOCOL FOR ASSESSING CAPACITY TO EXECUTE A HEALTH CARE PROXY

Individual’s Name: __________________________  Residence: __________________________

Date: __________________________  Date of Birth: __________________________

Team Members Assessing Capacity: __________________________

Directions: Instructions to guide staff in speaking to the individual are underlined.

RATIONALITY: Ability to critically evaluate

1. Indicate diagnosed neurological, psychiatric, or medical conditions that may impair the individual’s judgment, perception, or thinking (e.g., dementia, schizophrenia, medication side effects, traumatic brain injury, drug intoxication).

2. Individual’s level of intelligence (if reported IQ seems valid, circle the relevant item; otherwise arrange for re-evaluation of IQ):

   - Average or higher [IQ >89]—if items 1, 3, 4, & 5 reveal no significant mental status difficulties, skip to #12.
   - Low average [80<IQ<90]—if items 1, 3, 4, & 5 reveal no significant mental status difficulties, skip to #12.
   - Borderline [69<IQ<80]—if circled, complete all items.
   - Mild intellectual disabilities [54<IQ<70]—if circled, complete all items.
   - Moderate intellectual disabilities [39<IQ<55]—if circled, complete all items.
   - Severe intellectual disabilities [24<IQ<40]—if circled, individual lacks capacity. Skip to #12.
   - Profound intellectual disabilities [IQ<25]—if circled, individual lacks capacity. Skip to #12.

3. Provide information about the individual’s highest communication skills from a standardized adaptive behavior scale such as the Scales of Independent Behavior-Revised, the Adaptive Behavior Assessment System, or the Vineland Adaptive Behavior Scale. Include language related age-equivalent score(s) and list a few of the highest-level specific skills (e.g., Asks simple questions such as “What’s that?”: Says last name when asked). Also indicate any specific language disorder (e.g., aphasia) the individual has, or any specialized communication procedure or apparatus used by the individual.

4. Orientation questions to be presented to the individual.

   Ask these questions, write the responses, and indicate if correct or not:

   **Person-related Questions and Responses**
   - What is your name? __________________________  Correct? yes no
   - What is the name of a staff person at your residence? __________________________  Correct? yes no
   - What is the name of a staff person at your job? __________________________  Correct? yes no

   **Place-related Questions and Responses**
   - Are you at home now? __________________________  Correct? yes no
   - Are you at work now? __________________________  Correct? yes no
   - Do you live in (correct town or city) or (incorrect town or city)? __________________________  Correct? yes no
   - Do you work in (incorrect town or city) or (correct town or city)? __________________________  Correct? yes no

   **Time-related Questions and Responses**
   - Is it day or night now? __________________________  Correct? yes no
   - Is it (correct season) or (opposite season) now? __________________________  Correct? yes no
   - Is it (incorrect weather, e.g., rainy) or (correct weather) outside now? __________________________  Correct? yes no
   - Are you (correct age) or (incorrect age, a decade off)? __________________________  Correct? yes no
### APPENDIX
#### A Protocol for Assessing Capacity to Execute a Health Care Proxy (cont.)

5. Immediate recall items to be presented to the individual.

(For individuals with traumatic brain injury use recognition rather than recall memory tasks. For an individual who uses a communication device select words on the device. Selected words should have concrete referents.)

Present these items slowly, write the responses, and indicate if correct or not:  
\[ \text{Correct?} \]

(a) “I am going to say some words. When I finish I will let you know. Then you are to repeat them. Now, repeat these words: floor, sun, hat.”  
\[ \text{__________} \]  
\[ \text{yes} \]  
\[ \text{no} \]

If individual was successful, go to item (b) after about five minutes; otherwise re-present item (a) one last time. Response to 2nd presentation  
\[ \text{__________} \]  
\[ \text{yes} \]  
\[ \text{no} \]

If individual was unsuccessful for 2nd time, do not present item (b). But, if individual was successful on 2nd attempt, do present item (b).

(b) “About five minutes ago I said some words and asked you to repeat them. What were those words?”  
\[ \text{__________} \]  
\[ \text{yes} \]  
\[ \text{no} \]

**KNOWLEDGE:** The individual must demonstrate understanding that:

(a) appointing a health care proxy (HCP) authorizes another person to make health care (HC) decisions for him/her if he/she becomes unable to do so;

(b) his/her choice of a HCP must make sense (e.g., a trusted relative, a familiar person who has the capacity to make health care decisions) and not be arbitrary; and

(c) he/she has the right to revoke or change the HCP.

6. Evidence of individual’s understanding of a HCP.

As needed, staff should use alternate words and individualized ways of conveying the information below to the individual. Staff should refer to and, when appropriate, provide the individual with a copy of the NYS DOH HCP FAQ document as well as the HCP form. Samples of simplified alternate wording are in *italics* in parentheses.

(a) If you become unable, even temporarily, to make HC decisions, someone else must decide for you. HC providers often look to family members for guidance. Family members may express what they think your wishes are related to a particular treatment. However, in NYS, only a HCP you appoint has the legal authority to make HC decisions if you are unable to decide for yourself. Appointing a HCP lets you control your HC treatment by: 1) allowing your HCP to make HC decisions on your behalf as you would want; 2) choosing one person to make HC decisions because you think that person would make the best decisions; and 3) choosing one person to avoid conflict or confusion among family members and/or significant others. You may also appoint an alternate HCP to take over if your first choice cannot make decisions for you. (*Alternative wording:* “If you go to the hospital and are not able to speak for yourself, you will want someone to speak for you to tell the doctors what you want.”)

(b) Your HCP may not work for our agency. The person you choose should be a capable person who you know and trust. (*Alternative wording:* “If you go to the hospital and are not able to speak for yourself, who do want to speak for you?”)
APPENDIX
A PROTOCOL FOR ASSESSING CAPACITY TO EXECUTE A HEALTH CARE PROXY (cont.)

KNOWLEDGE (cont.)

(c) It is easy to cancel your HCP, to change the person you have chosen as your health care agent, or to change any instructions or limitations you have included on the HCP form. Simply tell staff that you want a new HCP form filled out. In addition, you may indicate that your HCP expires on a specified date or if certain events occur. Otherwise, the HCP will be valid indefinitely. (Alternative wording: “Anytime you want, you can pick a new person to speak for you to the doctors.”)

After giving the explanation above, and addressing any relevant questions or concerns expressed by the individual, staff should ask the individual to explain what a HCP is, who they will choose as their HCP, and why they will choose that person. The individual’s response should be written below.

Circle “yes” or “no” to indicate if the individual showed understanding that:

<table>
<thead>
<tr>
<th>Determination</th>
<th>(a) appointing a health care proxy (HCP) authorizes another person to make health care (HC) decisions for him/her if he/she becomes unable to do so: yes  no</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(b) his/her choice of a HCP must make sense (for example, a trusted relative, a familiar person who has the capacity to make health care decisions) and not be arbitrary; and yes  no</td>
</tr>
<tr>
<td></td>
<td>(c) he/she has the right to revoke or change the HCP. yes  no</td>
</tr>
</tbody>
</table>

VOLUNTARINESS: Absence of coercion, duress, or undue influence.

Items 7 through 9 may not require direct discussion with the individual.

7. With respect to the HCP, is there evidence of coercion or undue influence by another (e.g., a parent, a physician, an authority figure)? yes  no

8. Does the individual have a history of acquiescence or of saying what others want to hear despite subsequently showing a different preference? yes  no

9. Ask whether the individual accepts or refuses the proposed procedure. Neither acceptance nor refusal compromises voluntariness. Is the individual unable, unwilling, or too ambivalent to express a choice in the matter at hand? yes  no

10. Ask these questions of the individual and write the responses:

   “Has anyone spoken to you about the HCP?” yes  no (circle one)

   If “yes,” ask “Who?”

   “What did he/she say?”

   “How do you feel about what he/she said?”

   “Would it be hard for you to go against what he/she said?” yes  no (circle one)

RESULTS OF CAPACITY EVALUATION

11. Domain specific assessments by the team:

<table>
<thead>
<tr>
<th>Domain</th>
<th>Relevant Items</th>
<th>Level of Capacity (circle choice)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rationality</td>
<td>1, 2, 3, 4, 5</td>
<td>insufficient  sufficient</td>
</tr>
<tr>
<td>Knowledge</td>
<td>6</td>
<td>insufficient  sufficient</td>
</tr>
<tr>
<td>Voluntariness</td>
<td>7, 8, 9, 10</td>
<td>insufficient  sufficient</td>
</tr>
</tbody>
</table>

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### RESULTS OF CAPACITY EVALUATION (cont.)

12. Team’s determination of individual’s capacity to execute a HCP:
   - Clearly capable
   - Clearly incapable
   - Uncertain—if circled, licensed psychologist must evaluate individual personally

Concerns ____________________________________________________________________________

13. Final determination by licensed psychologist:
   At this time the individual ______ (write “is” or “is not”) capable of executing a HCP. If
   the individual is determined to be incapable at this time, but in the future the conditions that
   resulted in the current incapacity get compensated for, there should be a repeat capacity
   evaluation.

Signature: ______________________________________________________________________________
Date: ____________________________________________________________________________________

Printed name, degree: _____________________________________________________________________