Frequently Asked Questions About Proxy Caregiving

General questions

1. What is a "proxy caregiver"?

A. A "proxy caregiver" is an unlicensed person who has been determined qualified to have the necessary knowledge and skills acquired through training by a licensed healthcare professional to perform documented health maintenance activities, including specialized procedures, for an individual with a disability who has delegated to the designated proxy caregiver the performance of such health maintenance activities through execution of a written informed consent by the individual with a disability or a person legally authorized to act on behalf of such individual with a disability.

2. What are "health maintenance activities"?

A. "Health maintenance activities" are those limited activities that, but for a disability, a person could reasonably be expected to do for himself or herself. Such activities are typically taught by a registered professional nurse, but may be taught by an attending physician, advanced practice registered nurse, physician assistant, or directly to a patient and are part of ongoing care. Health maintenance activities are those activities that do not include complex care such as administration of intravenous medications, central line maintenance, and complex wound care; do not require complex observations or critical decisions; can be safely performed and have reasonably precise, unchanging directions; and have outcomes or results that are reasonably predictable.

3. Is proxy caregiving mandatory?

A: It depends. No licensed facility/provider is required to use proxy caregivers. However, if a licensed facility/provider is using paid unlicensed staff to perform "health maintenance activities" such as assistance with medications for a person with a disability, who but for the disability would be performing the function, then it needs to use proxy caregivers.

4. Can family members provide health maintenance activities without the training and without being designated as a proxy caregiver?

A: Yes, family members can perform "health maintenance activities" without training and without being designated as a proxy caregiver PROVIDED, the family member is not getting compensated by the individual with the disability or others to perform the health maintenance activities.

5. Can a sitter provide health maintenance activities instead of a proxy caregiver?

A: If the "sitter" is getting compensated and is doing tasks that qualify as health maintenance activities (those activities that meet the broad definition of tasks encompassing the practice of nursing, such as administering medications), then the sitter is not just sitting and is either practicing nursing without a license or needs to qualify as a designated proxy caregiver and meet the proxy caregiver law requirements.

6. What do you do when a person does not have a "legally authorized representative"?

A: This term is defined in the rules and includes a person who is authorized under O.C.G.A. §31-9-2 to consent to medical treatment on behalf of the disabled individual where there has been a medical determination made that the individual with a disability lacks decision-making capacity regarding medical treatment or the ability to communicate such decisions by any means. The list of persons who are authorized to consent under O.C.G.A. §31-2-9 include in the following priority:

a. Advance directive
b. Married person for spouse
c. Parent for minor child
d. Person standing in loco parentis, guardian for ward
e. Female in relation to pregnancy/birth
f. Adult child for parent
g. Parent for adult child
h. Adult for sibling
i. Grandparent for grandchild
j. Adult grandchild for grandparent
k. Adult niece, nephew, aunt, uncle (1st degree)
l. Adult friend
m. Temporary consent-guarding

7. Define "legal" representative.

A.: Someone who is "allowed" under the law to speak on behalf of someone else. See answer to Q 6. above and definition in Rules for Proxy Caregivers, Rule 111-8-100-.03(i).

8. What are our options when our medical doctors are threatening to stop seeing our individuals due to increase regulations beyond their standards?

A: Work with doctors to explain law and draft plans of care that minimize need for multiple revisions. Law requires performance of "health maintenance activities" pursuant to "written orders" of an attending physician, an advanced practice registered nurse or physician assistant working under protocol or job description respectively. When rules were being developed, informal group advised that individuals have written plans of care completed by physicians now. Modifications

were made to written plan of care form to incorporate legal requirements for use of proxy caregivers.

9. If the physician refuses to write an order for proxy caregiving how should this be addressed?

A. See answer to 8.

10. Can staff from an agency be identified by the agency to be proxy caregivers?

A: It depends on whether the individual with the disability or the person legally authorized to consent executes an informed consent and designates the staff (by name) to provide health maintenance activities. The licensed agency can identify potential proxy caregivers, but the caregivers must be specifically designated by the individual with the disability.

Training and Supervision

11. Who determines that the health maintenance activity is within the licensed healthcare professional scope of practice?

A: The licensed agency would be held accountable for complying with the Rules for Proxy Caregivers. Ideally, it would have policies and procedures in place to ensure that the licensed healthcare professional is acting within scope.

12. Who educates the licensed healthcare professional?

A: A licensed facility/provider would be responsible for ensuring that its employees operate within the confines of the law and rules applicable to the licensed facility/provider.

13. Is ongoing supervision and training required for proxy caregivers? If yes, how often?

A: Yes. The law and rules requires the written plan of care to specify the frequency of training and evaluation requirements for the proxy caregiver, including additional training when changes in the written plan of care necessitate added duties for which the proxy caregiver has not previously been trained. Where the licensed facility/provider provides the proxy caregiver, the licensed program must complete an initial and annual skills competency checklist which reflects a testing of the knowledge and observation of the skills associated with the health maintenance activities. See Rule 111-8-100-.04(3) and (4). Also, where the proxy caregiver is an employee of the licensed facility/provider, the employee supervision requirements may also be applicable.

14. Who is responsible to hire and train the licensed healthcare professional to train the proxy caregivers?

A: Where a licensed facility/provider hires the licensed healthcare professional to train the proxy caregivers, it would be responsible for training functions performed by the licensed healthcare professional.

15. What is the implementation time for proxy caregiving?

A: The Rules for Proxy Caregivers, Chapter 111-8-100, took effect August 7, 2011. These rules apply to facilities and providers licensed by HFRD where proxy caregivers are permitted to function. We expect licensed facilities to comply with regulations. If they are unable to comply with a particular provision of the rules, then they need to request a waiver using the application form made available on our website.

Testing (TOFHLA)

16. Who should receive the Test of Functional Health Literacy Assessment Tool (TOFHLA)?

A: All proxy caregivers providing medication assistance who are employed by licensed facilities/ provders must be administered the TOFHLA and have scored a 75 on the exam. See rule 111-8-100-.05(6). Additionally, if the proxy caregiver employed by the licensed facility/provider to do other health maintenance activities does not have a high school diploma or GED, the licensed facility or provider is required pursuant to rule 111-8-100-05(1)(d) to administer TOFHLA as an assessment tool for training purposes.

17. Who administers, scores and verifies that the proxy caregiver has passed the TOFHLA test?

A: The licensed facility/provider that employs the proxy caregiver is held accountable for maintaining documentation reflecting that training requirements have been met. The rules do not specify who has to administer the TOFHLA. The rules do specify that the skills competency checklist must be completed by a licensed healthcare professional.

Medication Administration

18. Will individuals receiving self administration of medications be required to have proxy caregiver? Will this be referenced in HFR guidelines?

A: If the individual requires assistance with self-administration, meaning that but for the disability, the individual would be making decisions about and handling self--administration, then it seems that “assistance” falls within the definition of a health-

maintenance activity. The law allows/requires these tasks to be performed by proxy caregivers if the caregiver is not a family member and is working for pay. Guidelines for the rules will reiterate this.

19. Will hand over hand be more closely scrutinized in PCH?

A: Yes.

20. Where does supervision of self-administered medications fall under proxy caregiver rules?

A: See definition of health maintenance activity in law and rules.

21. Does proxy caregiving apply to all residential medication administration supervision of self-administration of medications?

A: It would depend on the individual's capacity and the location of the care.

22. Who can self-administer, most if not all of our folks cannot, then who decides and based on what parameter?

A: The licensed facility/provider that delivers "health maintenance activities" to persons with disabilities is responsible for complying with the law re: proxy caregiving and the Rules for Proxy Caregivers, Chapter 111-8-100. When HFRD inspects the licensed entity, we will hold it accountable for complying with the law and rules. There are very simple Self-Administration Assessment tools that can be used to decide whether someone is capable of self-administration. Here are some indicia of capacity to self-administer.

- I can recognize my medications by color, size, shape and/or by reading the label. I know enough not to take my medications if they look different.
- I can tell you generally what my medicine is for.
- I know and recognize how much medicine I am to take, e.g. ½ pill, 1 tbs.
- I will recognize and know who to tell if I don't feel good (nausea, pain, dizziness) since it may be a side effect.
- I know whom to tell when I only have 3-4 days of meds left so that I don't run out.
- I know whom to call if my medicine is wrong and will tell him/her right away.
- I take my meds at the right time every day using the clock or daily routine.
- I can get meds to and from storage, out of the container and to my mouth without spills.

23. Is medication administration treated like any other health maintenance activity?

A: Yes and no. Medication administration is a health maintenance activity, but it is a specialized health maintenance activity that requires more specific training under the proxy caregiver rules to ensure that this particular health maintenance activity is performed safely. The rules also require the licensed provider to make sure that the proxy caregiver passes the Test of Functional Health Literacy for Adults (TOFHLA) and has the skills necessary to administer the medications. The proxy caregiver needs to be able to read and follow directions associated with the medications for which they will be providing assistance. Licensed healthcare professionals are expected to use their judgment in determining which medications can be safely administered by proxy caregivers who have been properly trained, etc.

24. Will personal care homes be cited for violations of the current personal care home rules if unlicensed staff, who are not trained and designated as proxy caregivers are administering medications?

A: Yes. A personal care home cannot ignore the proxy caregiver law if the home serves residents who are not capable of self-administration of medications with assistance or supervision. While a personal care home may provide assistance with or supervision of self-administration of medications under its current license, the personal care home may not allow unlicensed staff who are not designated proxy caregivers to administer medications. A personal care home that serves residents who require administration of medications must have trained designated proxy caregivers authorized by the residents or their representatives to provide medications to the residents. Where the resident is not capable of exercising any judgment about whether the unlicensed caregiver if offering the right medication at the right time, then the staff are really administering the medications, not just assisting the residents with self-administration.

Plan of Care

25. Can the plan of care list more than one proxy caregiver?

A: Yes.

26. Is a plan of care required for each medicine to include but not limited to insulin, etc.?

A: The plan of care should list all the medicines that the individual is taking or is likely to take, e.g. over-the-counter antacid when the individual complains of heart-burn, x mgs. Ibuprofen when person complains of headache.

27. Will the individual have multiple plans of care if they have more than one PCP?

A: It is possible.

28. Is a licensed provider required by the rules to document the implementation of the written plan of care by designated proxy caregivers?

A: No specific documentation is required for implementation; however, the licensed provider must be able to prove that they are implementing the written plan of care. A licensed provider may want to require its proxy caregiver to document the performance of health maintenance activities on a daily basis, etc. so that the licensed provider can produce some written evidence that it implemented the plan of care as written in the event that the resident's condition worsens, etc. When HFRD staff perform inspections, they may look at staffing schedules to see that there is always a proxy caregiver designated by the resident to provide the health maintenance activity listed on the written plan of care. A licensed provider could be cited for violating the implementation of the written plan of care, if it used to staff who had not been designated as proxy caregivers for that particular resident.

Informed Consent

29. Can any competent adult not adjudicated give consent for Health Maintenance Activities?

A: It depends on the decision- making capacity of the individual to make informed medical decisions. HB 1040 gives the individual with the disability or a person legally authorized to act on the individual's behalf the right to execute a written informed consent and delegate authority for performing health maintenance activities to an unlicensed proxy caregiver. The execution of a consent cannot be "informed" if the individual lacks decision-making capacity regarding the medical treatment or the ability to communicate the decision by any means.

30. How is the ability to give informed consent for approval of a proxy caregiver being determined? Will it be legally established or obtained through a professional assessment? If refused what are the next steps? Will there be protocols?

A: Each licensed facility/provider must determine whether the individual has the capacity to give informed consent. It could be established through a legal proceeding, e.g. appointment of a guardian of the person or through a professional assessment of the individual's ability to make informed decisions about healthcare. If the individual, or someone who has the ability to make medical decisions on their behalf refuses consent, then health maintenance activities may not be provided by the licensed facility/provider. Rule 111-8-100-.04(4) requires the licensed facility/provider to develop written policies and procedures which do not conflict with the requirements of the law and rules and which address scope of activities, notification procedures and safety and security precautions, etc.

31. If the individual signs with an "X" will this suffice for the informed consent?

A: It depends. The real question is not whether the individual can write his or her name but whether the individual has the capacity to make informed medical decisions, such as, I am willing to get my "health maintenance activities" performed by an unlicensed caregiver whom I name, etc.

32. Please explain item #4 on the Informed Consent form which says: "I am consenting to my medical information being shared with my proxy caregivers to be trained to provide care to me". Does this cover person authorized to act? Is there a separate legal document that is required?

A: There is no additional legal document that is required by the rules for proxy caregivers, other than this consent form, **if** this form and the written plan of care are properly completed. However, other legal documents might be available that define the relationship between the disabled individual and the person signing the informed consent that might impact who would be authorized to sign this informed consent. For instance, if the individual has a legal guardian, then the legal guardian would be expected to sign the consent. Paragraph 4 is intended to authorize the healthcare professionals who will be interacting with the proxy caregivers who will be caring for the individual to share needed medical information with the caregivers.

33. Please explain item #5 on the Informed Consent which states: "the attending physician, an advance practice registered nurse or a physician's assistant whose orders or written plan of care allow health maintenance activities to be performed for me is not responsible for my proxy caregivers' negligent performance of those activities unless the proxy caregivers are employed by the physician, advance practice registered nurse or physician's assistant to perform the health maintenance activities for me"?

A: This statement is intended to make it clear to the person with disabilities that the doctor, etc. who signs the plan of care authorizing the performance of health maintenance activities by designated proxy caregivers is not generally responsible for how the proxy caregiver performs those activities. However, if the doctor, etc. who signed the plan of care actually employs the proxy caregiver to deliver health maintenance activities; then the doctor would be responsible for his employee's actions in some situations.

34. Is payment a factor? For example, if there is no charge, can any individual perform a health maintenance activity?

A: Yes, payment is a factor. Payment is a form of compensation. If the individual who is providing the care is truly doing it as a volunteer, for no compensation, then it would not be considered nursing within the meaning of the Nurse Practice Act and not trigger the need for the exception in the law created for unlicensed proxy caregivers performing health maintenance activities. HOWEVER, if an aide is getting compensated to help the person with a disability and as part of that "help" performs tasks that meet the definition of "health maintenance activities" then, that

aide is a proxy caregiver since they are doing the tasks for compensation. (Remember that the definition of nursing in O.C.G.A. §43-26-3(8) says, doing certain things, such as administering medications, "for compensation".)

35. Security and safety - why not simply require a criminal record check of those proxy caregivers who are not employees of the licensed provider?

A: Georgia law does not require proxy caregivers to have criminal records checks. (Proxy caregivers who work as employees in personal care homes are required to have criminal records checks.) However, individual employers may certainly require potential proxy caregivers to have a criminal background check done as a condition of employment. An individual can request a criminal background check from the FBI by submitting the request with fingerprint cards and a certified check or money order payment of $18. http://www.fbi.gov/about-us/cjis/background-checks

36. If an unlicensed proxy caregiver can perform health maintenance activities, can an LPN (or RN) perform health maintenance activities?

A: The exception to the definition of nursing contained in the law for the performance of health maintenance activities by proxy caregivers does not apply to licensed nurses. Proxy caregivers are defined in the law as "unlicensed" persons. Nurses are licensed and must exercise their nursing judgment in the provision of care to the individuals they serve.

37. Can the RN owner be the proxy caregiver trainer and develop the written plan of care for the resident/client being served by the licensed provider?

A: Yes, if the resident or the resident's authorized representative has executed an informed consent and designated by name the licensed provider's staff as proxy caregivers.

38. Can the facility staff/owner/administrator sign the Informed Consent? or designate him/herself as a PC?

A: Yes, such actions could be permissible <u>but only</u> if the staff/owner/administrator is the legally authorized representative of the individual with the disability.

39. Explain waiver/variance by DCH.

A: DCH has the ability to waive a regulation upon application by a licensed facility/provider who meets the criteria set forth in the statute, O.C.G.A. §31-2-7. DCH has no ability to waive what is contained in the law. So if a licensed facility/provider claims that it cannot comply with all aspects of a particular rule, then it can apply for a waiver of that specific portion of the rule, specifying why compliance would pose a hardship and explaining what alternative standards it would use to meet the underlying intent of the rule.