



May 1, 2023

Dr. Lee A. Fleisher
Chief Medical Officer and Director
Center for Clinical Standards & Quality
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Dear Dr. Fleisher:

Thank you to you and your colleagues for meeting with AARP recently to discuss ways Medicare can better support family caregivers. AARP appreciates the Center for Clinical Standards & Quality's (CCSQ) attention to the need and opportunity to support family caregivers in Medicare, which benefits both Medicare beneficiaries and their family caregivers.

One area we discussed was Hospital at Home (HaH) programs under the Acute Hospital Care at Home (AHCaH) waiver and the work underway at CMS to study and report on the initiative. We strongly support the President's recent Executive Order on Care that specifically includes that the Secretary of Health and Human Services shall consider how better to evaluate and clearly set expectations for family caregivers in the Acute Hospital Care at Home Program. Following up on our recent conversation, we write to share feedback in greater detail on items and questions discussed related to the study and report. But there is a general lack of data about family caregivers and HaH programs. We continue to believe it's critically important to better understand the role of the family caregiver and have previously shared this AARP Public Policy Institute paper, [Family Caregiver Considerations for the Future of Hospital at Home Programs](#). As this paper notes, the "...AHCaH waiver neither requires caregiver inclusion nor specifies what caregiver involvement in the care episode should or should not be."

The study that the agency will be conducting provides an important opportunity to shine a light on family caregivers, HaH programs, and the often-invisible role of family caregivers in this model. Including these issues in the study would benefit Medicare beneficiaries, family caregivers, CMS, HaH programs, researchers, and advocates. Broadly speaking, the questions and items we identified fall into three categories:

- capturing the team who is in the home and providing services, including help with activities of daily living (ADLs such as bathing, eating, dressing, help getting out of bed safely, and toileting), instrumental daily activities (such as cooking, cleaning, changing the sheets, and laundry), and technical tasks (such as administering medications, all day and night, incontinence care, and managing pain) and what leads to the outcomes;

- capturing and understanding what happens when there is no family caregiver; and
- how to collect the data.

We elaborate on each of these categories below.

Care Team Members, Responsibilities, and What Leads to Outcomes

Given that this care is provided in a home setting instead of an inpatient hospital setting, the care is not as visible, thus a descriptive study is important. The law extending the AHCAH waiver notes that hospitals must meet all patient safety standards determined appropriate by the Secretary of Health and Human Services, in addition to those that otherwise apply to the hospital with some exceptions. Are family caregivers being relied on to meet patient safety standards? It is important to look at the impact on beneficiaries, family caregivers, quality, cost, and the standards noted.

The law also notes in the waiver criteria that the standard of care to treat an individual at home is the same standard of care to treat such individual as a hospital inpatient. Inpatient hospital care is provided 24 hours a day, seven days a week and often hospitalized individuals are unable to care for themselves.

- Who is providing 24/7 care in HaH under the waiver, including when no nurse or nursing personnel are physically present and providing care?
 - Who are the team members in the home and who provides what care?
 - For how many hours?
 - At home, who is turning the individual in bed, making sure they are fed, can get to the bathroom safely without falling, ensuring they have water and are drinking it, are walking if they are able, etc.?
 - Who is assisting with ADLs such as eating, bathing, dressing, help getting out of bed safely, and toileting?
 - Who is managing instrumental activities of daily living such as bringing in and preparing food, keeping the care area clean, changing the sheets, and other hands-on supportive care?
 - Who is helping to administer medications throughout the day and night, manage pain, provide incontinence care and other technical tasks? This contrasts with who provides the medical care, such as checking vitals, physiological function, and more, which should also be noted.
- What does the hospital and health team do versus the family caregiver?
- Is there any agreement sought from the family caregiver, so that their participation is voluntary, even if it is a conversation prior to transitioning the patient to HaH vs. an inpatient admission where the caregiver is provided information about expectations and can ask questions?
- If the family caregiver is engaged, what do they do and for how many hours?

- Is there consideration given for the family caregiver, their availability and desire to be involved in the care provided? For example, is there consideration that a patient with a working caregiver may require additional support services when setting up the care plan?
- In planning for discharge from HaH, how is the family caregiver involved in developing the plan of care?
- What are the factors and the processes that led to the outcomes for the beneficiary?
- How many, and how often, are people depended on beyond a doctor and nurse?
- What are the range of needed services to achieve outcomes?

We note it is important to ensure the equitable availability of HaH and that technical or perceived fitness of home requirements are not used to mask inequitable access. In considering the various questions about care team members, responsibilities, and outcomes, it is then also important to examine whether there are differences among beneficiaries and family caregivers of different racial and ethnic groups and other demographic characteristics to help address health equity.

When There is No Family Caregiver

Not all individuals have family caregivers (broadly defined), and it is important to understand what that does and does not mean for such individuals in HaH. What happens to individuals who do not have access to family caregivers? It is important to describe the process, including for tasks that a family caregiver might assist with if they were present.

- Are there differences in beneficiary outcomes with and without a family caregiver? Do people on their own do just as well?
- What individuals have access to what services, including outside traditional care teams? What does it take to meet their needs?
- Did Meals on Wheels or a home care aide come in to assist individuals without family caregivers?
- Does the availability of support services, like a home care aide, keep the patient from being eligible for HaH? Were those same services available to individuals with a family caregiver?
- What is the full picture of care and outcomes for individuals without family caregivers?
- If an individual has no family caregiver, is there a subset of diagnoses that are not eligible for treatment under HaH programs? Is there cherry picking or full coverage of Diagnosis-Related Groups (DRGs) that are otherwise eligible for treatment?

- Regardless of a family caregiver's presence, under what conditions is it optimal to support acute care at home? What services are needed and must be available 24/7?
- Are supports and services offered equally to patients with and without a family caregiver if there is ongoing need for those supports post-discharge?

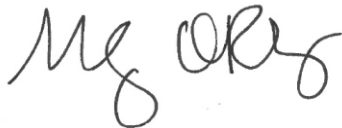
Data Collection

The best source of data about family caregivers with loved ones in HaH programs would be family caregivers themselves. They will know what they do and do not do to support their loved one. They could fill out a survey or questionnaire, be interviewed by someone who is independent of the HaH program or participate in focus groups or listening sessions. While providers may be able to document what family caregivers do, it will likely not be as accurate and comprehensive. Some providers acknowledge family caregivers more than others. Providers could collect information, such as whether a person has a family caregiver and who the caregiver is, which can also assist with outreach to them.

We hope this feedback is helpful as you undertake the current study and report and any other research, study, or evaluation CMS considers on HaH programs, as well as in implementing the Executive Order. AARP also notes that the results of this study and report could be very useful and informative beyond HaH programs, given efforts to move more types of care into the home, where individuals want to be. Beyond the study and report, AARP also urges CMS to incorporate the family caregiver considerations we referenced previously into HaH programs to benefit beneficiaries and their family caregivers.

We appreciate your consideration of AARP's comments and look forward to continued work with CCSQ and CMS more broadly to improve recognition of and support for family caregivers. If you have any questions, please do not hesitate to contact me, or have your staff contact Rhonda Richards on our Government Affairs staff at rrichards@aarp.org.

Sincerely,



Megan O'Reilly
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