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December 21, 2015

Acting Administrator Andy Slavitt
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-3317-P
P.O. Box 8016
Baltimore, MD 21244-8016

Re: Medicare and Medicaid Programs; Revisions to Requirements for Discharge Planning for Hospitals, Critical Access Hospitals, and Home Health Agencies; CMS-3317-P

Dear Acting Administrator Slavitt:

AARP appreciates the opportunity to comment on this proposed rule that would revise discharge planning requirements that hospitals, including long-term care hospitals (LTCHs) and inpatient rehabilitation facilities (IRFs), critical access hospitals (CAHs), and home health agencies (HHAs) must meet in order to participate in the Medicare and Medicaid programs. AARP has previously commented on proposed rules that addressed discharge planning requirements for home health agencies and long-term care facilities (skilled nursing facilities [SNFs] and nursing facilities).

Overall, AARP believes the proposed rule – with suggested enhancements -- should significantly improve discharge planning and care transitions for millions of Americans and their family caregivers. Our comments note important provisions currently in the rule and suggest areas for improvement. Importantly, the proposed rule covers discharge planning for multiple types of providers and covers a broad scope of individuals for whom a discharge plan would now be required. We also urge CMS to avoid using the term “patient” to the extent possible in the final rule. We suggest using terms such as “individual”, “person”, “affected person”, or similar terms that are more person-centered than “patient”.

Effective discharge planning can help improve outcomes for the individual receiving services and provide smoother transitions to home or other settings upon discharge. The planning is important for the quality of care and quality of life of the individual and

Real Possibilities

helps to reduce and prevent unnecessary hospital admissions and readmissions, emergency room visits, and other institutional care. Effective discharge planning also saves taxpayer dollars and reduces unnecessary out-of-pocket costs for individuals.

Very often, smooth care transitions and successful discharge planning depends on the active involvement of family caregivers (defined broadly) who voluntarily provide support and assistance to their loved ones before, during, and after discharge. Thus, family caregivers also provide continuity of care across settings. We are defining family caregivers broadly as any relative, partner, friend, or neighbor who has a significant relationship with, and who provides a broad range of assistance for, a person with a chronic, disabling, or serious health condition. Family caregivers are the backbone of services and supports in this country, helping to make it possible for older adults and people with disabilities to live independently in their homes and communities. They help with activities such as eating, bathing, dressing, transportation and managing finances; perform medical/nursing tasks such as wound care and managing multiple, complex medications; arrange and coordinate care among multiple providers and settings; and pay for services to help their loved ones, such as home modifications, transportation, or a home care aide.

About 40 million family caregivers provide unpaid care valued at $470 billion annually to their adult loved ones. Their contributions are significant and essential. Equally important is the need to support family caregivers to sustain them in their caregiving role and ensure their own health and well-being. That is why AARP has made supporting family caregivers and helping people live independently an enterprise priority.

Proposed Discharge Planning Regulation and the Caregiver Advise, Record, Enable (CARE) Act

As part of our attention to family caregiving, AARP has focused in particular on the supports that family caregivers need as their loved ones go into the hospital and as they transition home. When someone is discharged from the hospital, it is most often their family members and friends who are on the front lines, helping to carry out discharge instructions and provide the after-care necessary to keep their loved ones healthy and safe at home. Their help is crucial to preventing hospital readmissions and keeping their loved ones out of costly nursing homes.

The assistance provided by family caregivers can also be complicated and demanding. In a national survey conducted by the AARP Public Policy Institute and the United Hospital Fund, almost half (46 percent) of family caregivers reported performing medical and nursing tasks for care recipients with multiple chronic physical and cognitive conditions.[1] These tasks include managing multiple medications, providing wound care, preparing food for special diets, using monitors, and operating specialized medical

[1] S. Reinhard., C. Levine, & S. Samis, *Home Alone: Family Caregivers Providing Complex Chronic Care* 1 (AARP PPI and United Hospital Fund, 2012), *available at* http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf.

equipment. These tasks were in addition to the assistance they were already providing with bathing, dressing, eating, and other household tasks. Most caregivers said that they received little or no training to perform these medical and nursing tasks.

To help address this significant need, AARP developed the Caregiver Advise, Record, Enable (CARE) Act, which has been enacted in 18 states and Puerto Rico since 2014. Although each version enacted in states has slight variations, the CARE Act requires hospitals to: give individuals the opportunity to designate a family caregiver and have that caregiver's name and information recorded in the individual's medical record; inform the designated caregiver when the person is to be discharged to another facility or back home; and consult with the family caregiver on the person's discharge plan and give the caregiver an opportunity to receive a demonstration of and ask questions about the after-care tasks the family caregiver will be expected to perform at home. AARP state offices worked in collaboration with many state hospital associations on this effort and we hope to continue our push for the CARE Act across the country.

AARP is pleased that the proposed rules recognize the crucial role that family caregivers play in the transition from hospital to home and adds specificity to the ways caregivers can be involved in the hospital discharge process. Based on our learnings from advocating for the CARE Act, there are a few key provisions in the proposed rules, however, that we believe can be clarified and improved to ensure that individuals and family caregivers get the support they need:

1. **Definition of Caregiver** - The proposed rules use a number of terms and phrases, including "caregiver", "caregiver/support person(s)", and "family and/or caregiver" -- none of which are defined. We recommend that the proposed rules clearly define the term "caregiver" broadly to encompass the many types of relationships between individuals and caregivers. For example, the CARE Act defines "caregiver" as "any individual duly designated as a caregiver by a patient …who provides after-care assistance to a patient" and specifies that this may include "a relative, partner, friend, or neighbor who has a significant relationship with the patient." The proposed rules should be clear that family caregivers do not need to have a familial or legal relationship with the individual to be involved in the discharge process if the individual requests their involvement.

2. **Patient Designation of Caregiver** – Importantly, under the proposed rules, a hospital must consider "caregiver/support person…availability and…capability" as part of the identification of discharge needs (§482.43(c)(5)) and "[t]he patient and caregiver/support person(s) must be involved in the development of the discharge plan, and informed of the final plan to prepare them for post-hospital care" (§482.43(c)(6)) – but there is no explicit requirement that hospitals give individuals an opportunity to designate a caregiver. All individuals should be given this opportunity to make sure that their caregivers can be involved in the discharge process and can benefit from the other hospital requirements in the proposed rules.

We recommend that the proposed rules require hospitals to ask each individual for whom a discharge plan is required under the proposed rules if he or she would like to designate a caregiver who will be involved in the individual's post-discharge care and then record that caregiver's name and information in both the individual's electronic and paper medical records. As written, the proposed rules do not require the caregiver's information to be recorded in the person's medical record, except that the caregiver's contact information needs to be sent along with the person when being transferred to another health care facility (§482.43(e)(2)(ii)) and should be sent to practitioners responsible for follow-up care, if they have been identified (§482.43(d)(3)(iii)). Once a family caregiver has been identified, this information should be collected and recorded in both electronic and paper medical records for all individuals for whom a discharge plan is required under the proposed rules. Recording the caregiver's name and information in the individual's electronic and paper medical records is also consistent with proposed §482.43(c)(9) that "[a]ll relevant patient information must be incorporated into the discharge plan" which "must be included in the patient's medical record." The caregiver's name and information is certainly relevant "patient information." See also our later comments regarding the caregiver's information.

3. **Caregiver Notification** - While the proposed rules call on the hospital to ensure that "appropriate arrangements for post-hospital care are made before discharge" (§482.43(c)(9)) and that the caregiver "must be involved in the development of the discharge plan, and informed of the final plan" (§482.43(c)(6)), they do not specifically require the hospital to notify the caregiver if the individual is to be discharged home or transferred to another facility. This might be relevant, for example, when an individual is transferred to another facility and there is no discharge planning process -- the caregiver should still be notified of this transfer. We recommend that the proposed rules require hospitals to notify an individual's caregiver as soon as possible prior to the individual's discharge or transfer to another facility. Notifying caregivers as soon as possible is also important so that they have adequate time to plan or make appropriate arrangements for post-discharge care.

4. **Caregiver Instruction** - Under the proposed rules, discharge instructions must be given at the time of discharge to the "patient and/or the patient's caregiver/support person(s)" (§482.43(d)(1)(i)) and must include "[i]nstruction on post-hospital care to be used by the patient or the caregiver/support person(s)" (§482.43(d)(2)(i)). While the preamble goes into much greater detail on the form that these instructions might take – including teach-backs, electronic formats, and an opportunity for questions -- there is nothing in the text of the proposed rule itself that specifies anything more than written instruction. Given the complexity of many post-hospital care tasks, written instructions alone are often insufficient. As modeled in the CARE Act, both

individuals and caregivers would benefit tremendously from the opportunity to receive more enhanced instruction on post-hospital care *tasks* (in addition to post-hospital care generally) and this should be clearly set forth in the rules. We recommend that the proposed rules require hospitals to offer individuals and caregivers a demonstration of post-hospital care tasks and an opportunity for the individuals and caregivers to ask questions and receive answers on post-hospital care.

AARP urges CMS to apply the above set of recommendations to hospitals, critical access hospitals, and home health agencies.

Caregiver Availability and Capability

AARP appreciates the clear intent of these regulations to involve caregivers in discharge planning and help provide the information and tools they need for such involvement. In particular, the proposed regulations specify that hospitals, home health agencies, and critical access hospitals must "consider caregiver/support person…availability and…capability to perform required care" (§482.43(c)(5), §484.58(a)(3), and §485.642(c)(5)). While AARP believes the intent of these proposed regulations is to allow providers to conduct realistic assessments of a caregiver's availability and capacity to provide care to help identify discharge needs, it is also important to help ensure that discharge does not just mean handing everything over to a family caregiver who is overwhelmed and/or unable to provide care.

Given the need to determine the care and support needs of the individual post-discharge and assuming a caregiver is involved in discharge planning and post-discharge care, it would be best for the provider – including hospitals, home health agencies, and critical access hospitals -- and caregiver designated by the individual to have a conversation where the provider asks the caregiver questions to help both parties think through post-discharge needs and care. The provider should ask the caregiver questions directly that consider caregiver availability and capability without regard to age, such as questions about their willingness and ability to provide care; whether or not they work outside the home; and how comfortable they feel in carrying out medical/nursing tasks or assisting with activities of daily living. This conversation between the provider and designated caregiver can provide helpful insights to both parties, including insights related to the demonstration of post-discharge care tasks and questions the family caregiver might have or information she or he may need. It would also help the provider better understand a particular caregiver's situation and the post-discharge care environment in order to best provide discharge instructions. We recommend that the final rule require documentation of this conversation and information in the individual's medical record. It is also important to note that individuals must not be penalized if they do not have a caregiver or if the caregiver is unable or unwilling to perform all necessary post-discharge tasks. The provider must explore the availability and accessibility of other non-health care resources, social services, and community-based services and organizations that may be necessary for the individual and possibly the caregiver post-discharge and help facilitate access to those supports as needed for safe discharge of the individual. These community resources can help

provide essential support post-discharge. As CMS notes, technology, such as telehealth, may also support an individual's health and the caregiver post-discharge.

Making Contact with Caregivers in Order to Include them in the Discharge Planning Process

AARP appreciates the clear intent of the proposed regulation to involve willing caregivers in the discharge planning process, in recognition of the fact that these caregivers are "active partners in post-discharge care" (§482.43 and §484.58). If the person designates a caregiver, it is not specified how the provider (hospitals, home health agencies, or critical access hospitals) may contact the caregiver. This omission presents a problem when, for example, the provider claims that they cannot contact the designated caregiver, which may impede the discharge process. The solution to this problem requires a careful balance between two competing concerns expressed in the proposed regulations: (1) full involvement of caregivers and other support persons in the discharge process; and (2) facilitating the prompt and safe discharge of the individual to a less-restrictive environment.

AARP recommends that the proposed regulations at §482.43(c), §484.58(a), and §485.642(c) clarify that the provider must make reasonable attempts to reach identified caregivers. If the provider is unable to reach the identified caregiver after reasonable attempts, it may continue the discharge planning process under the assumption that the identified caregiver is unavailable. If, however, the caregiver contacts the provider after the discharge planning process has begun, that individual must be involved in the discharge planning process in accordance with §482.43(c)(6), §484.58(a)(4), and §485.642(c)(6). To support this requirement, the final rule should include a requirement that all providers collect caregiver telephone contact and e-mail address information when the provider offers the individual an opportunity to designate a caregiver. We encourage providers to ask about the caregiver's preferred mode of contact. Providers must be required to document all attempts to reach caregivers in the individual's medical record. Discharge planning should not be delayed because providers are not able to reach caregivers after making good faith (and documented) attempts.

Discharge Planning Provisions Relevant to Multiple Provider Types

Comments in this section generally apply across hospitals, home health agencies, and critical access hospitals, unless otherwise noted.

<u>§482.43(a)(1) and §485.642(a)(1) *Standard: Design.*</u> This requirement provides that discharge planning process policies and procedures must be developed with input from the hospital's medical staff or CAH's professional healthcare staff, nursing leadership and other relevant departments. However, there is no mention of an opportunity for individuals or caregivers to provide input on these policies and procedures that affect them. We urge CMS to add a requirement that the hospital or CAH must develop these policies and procedures also with input from individuals and caregivers. They are

greatly affected by these policies and procedures and could provide helpful insights and perspectives to hospitals and CAHs.

§482.43(b) and §485.642(b) *Standard: Applicability.* AARP is pleased with the types of individuals to whom the discharge planning process would apply, including all inpatients and outpatients receiving observation services. Individuals receiving observation services may be receiving care indistinguishable to them from inpatient care.

§482.43(c) *Standard: Discharge planning process.* We support CMS' clear clarification that certain individuals must have a discharge plan (see also the applicability standard). We provide additional comments regarding this standard in other sections of our letter. This standard also applies to CAHs.

§482.43(e) *Standard: Transfer of patients to another health care facility.* This standard requires the hospital to send necessary medical information to the receiving facility at the time of the transfer. AARP is particularly pleased that "necessary medical information" includes "[c]ontact information for…the patients' caregiver(s)/support person(s), if applicable", an advance directive, if applicable, social supports, and the individual's goals and treatment preferences. This standard also applies to CAHs. We urge CMS to also require home health agencies in §484.58(b) to provide contact information for the individual's caregiver(s)/support person(s) to the receiving facility or health care practitioner. While electronic health records and health information technology can be valuable in transmitting information from one provider to another, interoperability is vital for this to work and providers should have back-up plans to transmit information if they are not able to do so electronically. While hospitals are required to provide this necessary information at the time of the individual's discharge and transfer to the receiving facility, it would also be helpful if the providers communicate pre- and post-discharge to help ensure a smooth transition.

§484.58 *Condition of participation: Discharge Planning.* Unless specified elsewhere, CMS should ensure that in the final discharge planning rule home health agencies are explicitly required to provide a copy of the discharge plan to the individual and the caregiver at the time of discharge and that home health agencies are required more clearly to involve the individual and caregiver in the discharge planning process.

Olmstead and Discharges to Home and Community-Based Settings

§482.43(c) *Standard: Discharge planning process.* The preamble of the proposed rule explains under this section, the following:

> [E]ffective discharge planning will assist hospitals in complying with the U.S. Supreme Court's holding in *Olmstead v. L.C.* (527 U.S. 581 (1999)), which found that the unjustified segregation of people with disabilities is a form of unlawful discrimination under the ADA. We note that effective discharge planning may assist hospitals in ensuring

> that individuals being discharged who would otherwise be entitled to institutional services, have access to community based services when: (a) Such placement is appropriate; (b) the affected person does not oppose such treatment; and (c) the placement can be reasonably accommodated. *Federal Register*, Vol. 80, No. 212 at 68130-31.

While the proposed regulation requires the hospital discharge planning process include consideration of the availability of a caregiver/support person and community-based care (§ 482.43(c)(5)), it should specifically incorporate the obligation to provide care in the most integrated setting appropriate to the individual's need under the Supreme Court's *Olmstead* decision. This can be accomplished by including in the discharge planning process a requirement that hospitals inform the individual and his or her caregiver that s/he has the right to receive post-acute care in their home or a community setting if the placement is appropriate for her/his treatment needs, s/he does not oppose treatment in a home or other community setting, and the placement can be reasonably accommodated. Other requirements of the discharge planning process that help facilitate discharge to home and other community settings — such as consideration of access to non-health care services and community based providers (§482.43(c)(5)(vii)), assistance in selecting post-acute care providers (§483(c)(8)), and consideration of the individual's goals and treatment preferences (§482.43(c)(5)(viii)) — are meaningful only if the person is aware of his/her rights and of the discharger's obligation to consider the *Olmstead* factors. Additionally, §482.43(c)(9)'s requirement that: "The evaluation of the patient's discharge needs and the resulting discharge plan must be documented and completed on a timely basis, based on the patient's goals, preferences, strengths, and needs..." must include documentation that home and community based-care options were presented, discussed, and, if applicable, include the reasons why such placement was not selected. AARP suggests that these changes should also be made to the discharge planning process for critical access hospitals (§485.642(c)).

We also want to reinforce the importance of providers taking necessary steps to give individuals with limited English proficiency and physical, mental or cognitive and intellectual disabilities meaningful access to the discharge planning process. Providing language assistance or other aids and services are vital to ensure that all individuals and caregivers are able to be active partners in discharge planning, and that they have the information they need and understand what they need to do post-discharge to ensure appropriate follow-up care. If these individuals do not receive discharge planning that meets their needs, they may have poor outcomes and/or be unnecessarily readmitted to the hospital.

<u>§482.43(d) *Standard: Discharge to home*.</u> AARP supports the requirements to reconcile "all discharge medications with the patient's pre-hospital admission/registration medications (both prescribed and over-the-counter)" (§482.43(d)(2)(iv)). This is important across provider types and important for individuals and caregivers after discharge. We agree with CMS that "patients or caregivers (or both) should be informed, in advance of the hospital discharge, of the anticipated need for filling outpatient (discharge) prescriptions…[w]hen necessary, assistance should be offered to

the patient with identifying a pharmacy to fill the prescriptions post-discharge in a timely manner." AARP also appreciates the specific requirement that the discharge instructions must be provided at the time of discharge to the "patient and/or the patient's caregiver/support person(s)."

CMS proposes to require at §482.43(d)(4) that for individuals discharged to home, the hospital must establish a post-discharge follow-up process. CMS does not propose specific mechanisms or their timing, deferring to the hospital to determine how to best meet the needs of its individuals. However, CMS cites research showing several "components of transitional care that were significantly associated with reduced short-term readmission rates", including a home visit within three days, care coordination by a nurse, and communication between the hospital and primary care provider. CMS should consider whether to require these or other evidence-based components to be part of a hospital's post-discharge follow-up process.

§482.43(f) *Standard: Requirements for post-acute care services*. AARP commends the proposed regulation's requirements that hospitals provide individuals a list of post-acute care providers if such care is deemed appropriate post-discharge (§482.43(f)(1)), that the hospital document that it provided such a list to individuals or their representatives (§482.43(f)(1)(iii)), that the hospital inform the individual of their freedom to choose among participating Medicare providers and must, when possible, respect the individual's goals of care and treatment preferences (§482.43(f)(2)), and that the discharge plan identify any HHA or SNF to which the individual was referred in which the hospital has a disclosable financial interest (§482.43(f)(3)). All of these requirements help to ensure that the discharge plan is person-centered and gives due weight to the individual's choice of treatment setting. We also agree with CMS that hospitals should help individuals as they choose a quality post-acute care provider, but hospitals should "not make decisions on PAC services on behalf of patients and their families and caregivers and instead focus on person-centered care…the patient as the locus of control, supported in making their own choices and having control over their daily lives."

In order to better protect individuals from any institutional undue influence in the selection of the post-acute care provider, AARP suggests that the regulations encourage -- to the extent possible -- that the list provided to individuals contain all available post-acute care providers. This would help eliminate potential bias in favor of SNFs who may, for example, have sales representatives at the hospital or frequently meet with hospital staff to promote their services. This is also consistent with the proposed requirement at §482.43(f)(2) that "The hospital must not specify or otherwise limit the qualified providers or suppliers that are available to the patient." Similarly, AARP is concerned that the requirement that "HHAs must request to be listed by the hospital as available" may unduly limit the listed HHA options presented to the individual. AARP notes that SNFs, IRFs, and LTCHs are not similarly required to request to be listed by the hospital.

Related to the selection of a post-acute care provider, there are proposed requirements for all providers to assist "patients, their families or the patient's representative in selecting a post-acute care provider by using and sharing data that includes but is not limited to HHA, SNF, IRF, or LTCH data on quality measures and data on resource use measures…relevant and applicable to the patient's goals of care and treatment preferences" (§482.43(c)(8)). AARP strongly supports providers sharing information on quality measures, such as from the various Medicare provider Compare tools, and resource use measures with individuals and caregivers. It is important for individuals and their caregivers to have access to useful and easy-to-understand quality information to help them compare providers. CMS should ensure that in the final discharge planning rule and any future rulemaking to implement Improving Medicare Post-Acute Care Transformation (IMPACT) Act provisions, it is clear that providers can and should provide quality or other information to individuals and caregivers beyond that specifically required under the IMPACT Act, if it is relevant to the person's goals of care and treatment or other preferences. Providers should not be limited to providing just the required information to consumers when additional information would be helpful and relevant to them in selecting a post-acute care provider. It would also be helpful if individuals and caregivers could find out how much various post-acute care options might cost out-of-pocket. Finally, the requirements of this section should apply to critical access hospitals.

Enforcement

A provider's willingness to engage in careful and prompt discharge planning has a direct impact on individuals' health, safety, and well-being, as poor discharge planning is linked to higher rates of adverse events in post-acute care settings and hospital readmission. AARP believes that strong overall enforcement of the federal Conditions of Participation, including these proposed new discharge planning requirements, is essential to consumer protection and quality of life because tangible penalties give providers a clear incentive to comply.

AARP notes that while existing regulations require hospitals to "establish a process for prompt resolution of patient grievances" that "include[s] a mechanism for timely referral of patient concerns," there exists no corresponding language under the home health services regulations at §484.10. Home health agencies must also be expected to promptly resolve all grievances, including those arising under the proposed regulations.

Finally, regarding discharge for cause from home health agencies, there needs to be a process for the individual (or their caregiver or representative) to follow if they disagree with the agency's decision to discharge the individual. There should be due process for the individual when the individual disagrees with the agency's decision. We urge CMS to build due process protections for the individual into these discharge planning standards.

Enforcement of the proposed regulations depends on the completeness of medical records available to surveyors. AARP commends CMS for including requirements to

document discharge planning in individuals' medical records, as this will enable surveyors to assess a provider's degree of compliance with the regulations. AARP suggests the following enhancements to the documentation requirements:

Section 482—Conditions of Participation for Hospitals. For individuals returning home from a hospital setting, proposed §482.43(d)(1) requires the hospital to provide discharge instructions at the time of discharge. To allow surveyors to assess the adequacy of these instructions, AARP recommends inclusion of the actual instructions provided to the individual in the individual's medical record and documentation that the person and caregiver were offered a demonstration of post-discharge care tasks and an opportunity to ask questions and receive answers on post-discharge care. For persons transitioning to post-acute care services outside the hospital setting, proposed §482.43(f)(1)(iii) requires the hospital to "document in the patient's medical record" that a list of providers was presented to the individual or the individual's representative. To allow surveyors to determine the adequacy of the post-discharge options presented to the individual, AARP recommends that the individual's medical record include the actual list of referrals "presented to the individual."

Section 484—Home Health Services. Proposed §484.58(a)(7) requires HHAs to include the individual's discharge plan in the "clinical record." Unless the term "clinical record" is broader than the term "medical record" and would include everything that would also be part of the "medical record," AARP recommends that the final regulation substitute the term "individual's *medical* record" in place of "clinical record" for consistency.

Section 485—Conditions of Participation Specialized Providers. Consistent with AARP's comments on Section 482 above, AARP recommends that the proposed regulations at §485.642(d) also require that specialized providers (critical access hospitals) include in the medical record the actual discharge instructions "presented" to the individual and documentation that the individual and caregiver were offered a demonstration of post-discharge care tasks and an opportunity to ask questions and receive answers on post-discharge care.

AARP appreciates the opportunity to provide comments and suggested improvements on this very important proposed rule to help ensure smooth care transitions for individuals and their family caregivers. If you have questions, please contact me or Rhonda Richards (rrichards@aarp.org) on our Government Affairs staff at 202-434-3770.

Sincerely,

David Certner
Legislative Council & Legislative Policy Director
Government Affairs