January 9, 2017

Andy Slavitt
Acting Administrator
Centers for Medicare & Medicaid Services
ATTN: CMS-2404-NC
Department of Health and Human Services
P.O. Box 8013
Baltimore, MD 21244-8013

RE: Medicaid Program Request for Information: Federal Government Interventions to Ensure the Provision of Timely and Quality Home and Community Based Services (CMS-2404-NC)

Dear Acting Administrator Slavitt;

We write to you on behalf of the members of the Eldercare Workforce Alliance (EWA), a group of 31 national organizations – representing consumers, family caregivers, health care professionals, and direct care workers – joined together to address the immediate and future workforce crisis in caring for an aging America. We are writing to comment on the Request for Information on Federal Government Interventions to Ensure the Provision of Timely and Quality Home and Community Based Services (CMS-2404-NC). The Alliance appreciates CMS's commitment to the provision of high-quality home- and community-based services (HCBS) for our nation's older adults and we thank you for the opportunity to provide insights on this critical issue.

**Home- and Community-Based Services (HCBS) Workforce**

Older adults should be able to receive high-quality care to help them live independently in their homes and communities. To meet this goal, an interdisciplinary team is key to providing the necessary medical, behavioral, and social supports needed for older adults to live well. Unfortunately, as detailed in two recent National Academies of Science, Engineering, and Medicine (NASEM) reports, interdisciplinary health care teams with special training in geriatrics and gerontology will likely be in critically short supply to meet the burgeoning demand, unless we take sufficient steps to prepare for immediate and future workforce needs. The lack of standardized geriatric training requirements for both health care professionals and the direct care workforce results, in part, from a lack of recognition that older adults have distinct health care needs. EWA encourages CMS to focus on recruitment, training, retention, and compensation of all members of health care teams serving older adults in home- and community-based settings, as well as ways to evaluate and support participation in interdisciplinary teams.

Specifically, the U.S. is already dealing with an acute shortage of direct-care workers; a shortage that will only worsen over the next 20 years as millions of Americans will need long-term health care. Direct care workers who provide in-home care, specifically home care aides and personal care aides, are projected to be the two of the fastest-growing occupations in the nation within the next decade. To ensure that direct-care workers are able to provide the highest-quality care to all long-term care consumers, these positions...
should offer comprehensive training, certification, appropriate supervision, and career advancement opportunities; livable, family-sustaining wages; affordable health insurance and other benefits; as well as balanced workloads and full-time hours if desired. Any proposals focused on expanding access to high-quality care in the home should recognize these realities and include components directed at ensuring we have the workforce necessary to meet patient need.

Included with this letter is a EWA Issue Brief that outlines an advanced direct care worker position. This is a role envisioned to improve the quality and efficiency of care provided to older adults while strengthening career ladders for home care workers. The Alliance believes that with the appropriate training, supervision, and support, some home care workers can play an enhanced role, with more responsibility for improving safety and quality of care for older adults and their family caregivers. We recommend fostering an Advanced Direct Care Worker role that both improves the quality of person- and family-centered care and addresses current and future demand for a high-functioning eldercare workforce. Developing such a role and deploying workers in this capacity can lead to better health, better care, and potential cost-savings. More information can be found in the attached Issue Brief.

**Family and Unpaid Caregivers**

No discussion of the HCBS workforce would be complete without an acknowledgement of the role of family and other unpaid caregivers. According to a recent NASEM report, *Families Caring for an Aging America*, nearly 18 million Americans provide unpaid care to an older adult. Due to smaller family sizes, the divorce rate, and geographic relocation – the next generation of older adults may be less able to rely on their families for caregiving. Providing support and training opportunities to family caregivers is essential, especially during a time when nationally:

- More than three-quarters of caregivers feel they need more help or information related to caregiving.
- Nearly one in five family caregivers who assisted with medication management and one in three who assisted with changing dressings or bandages received no instruction or training in performing these tasks.
- 46 percent of family caregivers performed medical/nursing tasks for care recipients with multiple chronic physical and cognitive conditions.

Family caregivers need more recognition, training, and support in order to provide high-quality care to their loved ones and maintain their own health and well-being. At the same time, the health workforce needs better training to identify, assess, and engage caregivers to improve the quality of care delivered. Only one in three family caregivers indicated that a health professional asked what support they need to care for their loved one.

**Data Collection and Quality Measurement**

The Alliance strongly believes that data collection is an important part of measuring and otherwise assessing the workforce’s ability to care for older adults. To that end, we offer the following recommendations regarding HCBS quality measurement:

- Include measures that reveal whether care is person- and family-centered, as well as coordinated
- Include quality metrics for practitioners and providers that promote quality care and recognize the complexity of caring for older adults with multiple chronic conditions, including those who have cognitive impairment, and support the need to work collaboratively with family caregivers

The Eldercare Workforce Alliance is a project of The Tides Center.

*The positions of the Eldercare Workforce Alliance reflect a consensus of 75 percent or more of its members, and do not necessarily represent the position of individual Alliance member organizations.*
• Track and assess the geriatrics, gerontological, and eldercare training and education of the workforce
• Track and assess recruitment and retention practices and workforce data

The National Quality Forum released a report in 2016 on *Quality in Home and Community-Based Services to Support Community Living: Addressing Gaps in Performance Measurement* that provides more insights on data collection and quality measurement.

On behalf of the members of the Eldercare Workforce Alliance, we thank you for this opportunity to submit comments on the Request for Information on Federal Government Interventions to Ensure the Provision of Timely and Quality Home and Community Based Services (CMS-2404-NC) and for your commitment to improving the lives of older Americans.

Sincerely,

Nancy Lundebjerg, MPA
EW Co-Convener

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ADVANCED DIRECT CARE WORKER:
A Role to Improve Quality and Efficiency of Care for Older Adults
and Strengthen Career Ladders for Home Care Workers

CONCEPT
In its historic 2008 report, *Retooling for an Aging America: Building the Health Care Workforce*, the Institute of Medicine (IOM) recommended changes both to how care is delivered and the preparation of the healthcare workforce to provide that care. Specifically, it urged expansion of team-based approaches to health care delivery, with care provided by a better-prepared healthcare workforce, all working to the top of their skill sets. In line with the IOM recommendations, the Eldercare Workforce Alliance (EWA), with input from its member organizations, has identified gaps in care and inefficient uses of the current workforce. In this brief, EWA proposes one solution for improving care for older adults.

The Alliance believes that with the appropriate training, supervision, and support, some home care workers can play an enhanced role, with more responsibility for improving safety and quality of care for older adults and their family caregivers. We recommend fostering an Advanced Direct Care Worker (DCW) role that both improves the quality of person- and family-centered care and addresses current and future demand for a high-functioning eldercare workforce. Developing such a role and deploying workers in this capacity can lead to better health, better care, and potential cost-savings.

DISCUSSION
Our focus in this discussion is on advanced roles for direct care workers within the home care setting, although we recognize there may be opportunities for advanced roles within other settings. And, while our focus here is on direct care workers, we believe that all members of the care team should be supported to work to the top level of their skill set. Finally, while our proposal is for a subset of home care workers to receive additional training to perform advanced functions, we believe that all direct care workers should be well-trained and supported in their role and we echo the IOM’s call for strengthening training standards and improvements in training programs for the workforce as a whole.

In the interest of a clear, targeted dialogue and because of the anticipated surge in demand for home care, our discussions focused on the potential for an Advanced Direct Care Worker role in the home-care setting, with the understanding that this is a developing concept and no one model will meet the varied needs of every consumer. Further, implementation of advanced roles for direct care workers will likely occur at the state, local and provider level. Federal demonstration projects may be an effective means of testing the concept. EWA’s goal is to outline a concept, which represents a consensus by varied members of the health care team and can be drawn upon by those developing advanced direct care worker roles to achieve the highest-possible quality of care and support for older adults and their family caregivers.
NEED
Every 8 seconds, a person turns 65 in our country; that’s more than 10,000 people a day. Within twenty years, 1 in 5 Americans will be over 65 and by 2050 an unprecedented number - 19 million - will be over 85 years old.² Trends suggest these individuals will want to age in place. Most of these individuals will have one or more chronic conditions – potentially increasing hospitalization rates - that requires skilled care. Currently, direct care workers provide an estimated 75 percent of the paid hands-on care. However, if no action is taken to stabilize the eldercare workforce, vacancies and will only become more acute in the future as the need for services and supports increases.

One solution is to allow all health care providers to provide services to the full extent of their current knowledge, training, experience, and skills where evidence indicates services can be provided safely and effectively. The proposed Advanced Direct Care Worker role calls for expanding roles for home care workers commensurate with their demonstrated competency to take on additional responsibilities. Indicators of competency could include the amount of time on the job, successful completion of certain classes, level of education achieved, evaluations from individuals and families served, and evaluations by agency supervisors.

Wages would be commensurate to the Advanced Direct Care Worker’s training and experience and higher than those of current direct care workers, creating an incentive to remain in this field. By creating a meaningful career ladder for home care workers who wish to advance within their field, we will be better able to attract and retain a quality workforce, potentially keeping experienced workers in the field. This can help to create a home care workforce able to provide supports and services that improve quality and continuity of care for the consumer while reducing burdens on family caregivers.

METHODS & BACKGROUND
Between November 2010 and June 2013, the Eldercare Workforce Alliance convened a series of roundtable discussions to explore the perspectives of various members of the interdisciplinary care team with regard to advanced roles for direct care workers. With support and input from member organizations, EWA conducted in-person roundtable discussions with representatives from the direct care, nursing, social work, and physician workforces. Through an online survey, family caregivers identified areas of needed support, which helped to identify potential Advanced Direct Care Worker roles. A summary of the findings specific to these roundtable discussions and survey can be found in the addendum (Appendix B).

In the interest of a clear, targeted dialogue and because of the anticipated surge in demand for home care, our discussions focused on the potential for an Advanced Direct Care Worker role in the home-care setting, with the understanding that this is a developing concept and no one model will meet the varied needs of every consumer. Further, implementation of advanced roles for direct care workers will likely occur at the state, local and provider level. EWA’s goal is to outline a concept, which represents a consensus among varied members of the health care team, that can be drawn upon by those developing advanced direct care worker roles to achieve the highest-possible quality of care and support for older adults and their family caregivers.

Finally, the development of advanced roles for some direct care workers does not negate the essential role of traditional home health aides, home care workers, and personal care attendants, and of the invaluable supports they provide. Nor does it negate the ongoing need for nurses and social workers and the important roles that they play in home care service delivery and care coordination. The Advanced Direct Care Worker concept is intended for the segment of direct care workers who have the experience, knowledge, and training, demonstrated competency, aptitude, and desire to take on more advanced roles. For a growing number of older adults who wish to age in home- and community- based settings, advanced care will be needed and can benefit their quality of life.
FINDINGS

Points of consensus stemming from the roundtable discussions and survey input are as follows:

Need for Improved Respect, Engagement and Training for All Direct Care Workers: All direct care workers should be recognized as integral members of the care team with valuable and unique information to contribute. Workforce development strategies that ensure all direct care workers receive high-quality, comprehensive training, supervision, and support will enhance direct care workers’ effectiveness within the interdisciplinary team and will maximize the biopsychosocial well-being of older adults and family caregivers. Direct care workers play an important role in interdisciplinary team work, contributing first-hand information and hands-on experience.

Training: One key to successful implementation of advanced roles for direct care workers is support from the interdisciplinary care team and demonstrated competency to meet the responsibilities of an advanced role. For Advanced Direct Care Workers working with older adults, training specific to geriatric syndromes and unique needs and symptoms of older adults is necessary for this role to effectively improve outcomes. Additionally, training for the advanced direct care worker in effectively communicating with the interdisciplinary care team, the consumer and family members - as well as for the team members in communicating with the advanced direct care worker - is essential.

Due to the evolving development of this concept, EWA does not currently recommend a specific number of training hours to be required for an Advanced Direct Care Worker role. Rather, we emphasize more generally that an expanded role should be commensurate with demonstrated competency to take on additional responsibilities. This will be essential for realizing the full potential of advanced roles for direct care workers. Training should exceed levels required for current direct care workers and address cultural diversity, person-centered care, advanced illness and palliative care, communication, disease education and interventions, and competency in skills needed for the role. It may be advisable to require demonstrated competency for Advanced Direct Care and to require continuing education for certification renewal.

Support and Supervision: Ongoing support and appropriate levels of supervision (and/or oversight) for advanced direct care workers is important in achieving the desired health and quality outcomes, strengthening the workforce, and reducing liability. Oversight should be provided by the most appropriate person or interdisciplinary care team member, with consideration given to program purpose, design, and when applicable, level of consumer direction. In many cases this could be a registered nurse or social worker. Current efforts, such as nurse delegation models could mean an expanded supervisory role for registered nurses.

Observe, Record, Report: An Advanced Direct Care Worker can fill crucial gaps in care. Because of their regular in-person interaction with consumers, often over an extended period of time, all home care workers are in a unique position to identify shifts in consumers’ health. With additional training in particular illnesses and conditions, and with the consent of the consumer, an Advanced Direct Care Worker can observe, record, and report changes in consumer status or function to the appropriate team member. Early detection of these changes can be key to discovering or treating geriatric syndromes, chronic disease, cognitive changes, and complications. Recognizing changes in mobility, appetite, fluid intake, weight, skin color or condition, activity, mood, energy, and communication, and then reporting the information to the other team members can better meet the medical and social needs of the consumer. Such detection and communication could also help to prevent avoidable hospitalizations, readmissions, or institutionalization. Advanced roles, combined with technology and tele-health services, could be especially beneficial to consumers living in rural areas.
**Assist with Tasks:** Increasingly, family caregivers and some home care workers are being asked to perform medical and nursing tasks, often with minimal or no training. An Advanced Direct Care Worker could be provided additional training in order to safely assist with more advanced tasks and provide individualized, hands-on support and guidance to family caregivers. Subject to state scope of practice laws and contingent upon appropriate training and demonstrated competency, tasks performed by an Advanced Direct Care Worker could include: inserting, removing, and maintaining catheters; overseeing nebulizer treatments; administering enemas and suppositories; assisting with minor cuts, abrasions, and wound care; taking readings and measurements, such as those from a pulse oximeter; monitoring insulin levels, including performing finger sticks; and supporting pain management. Tasks and procedures should be supervised by a registered nurse or other member of the interdisciplinary care team. With training, supervision, and demonstrated competency, Advanced Direct Care Workers could perform many of the tasks currently performed by family members or consumers.

While restrictions differ from state to state, an Advanced Direct Care Worker could help support medication adherence by helping to monitor and/or administer medications, potentially including injectable, topical, oral, and suppositories. Appropriate training could include the recognition of side effects, knowledge of negative drug interactions, and the reporting of individuals’ and families’ medication-related concerns.

Generally speaking, many states will permit family members to be trained to perform health maintenance tasks, but will not allow paid direct care workers to be taught to perform them. Thus, family caregivers may have to rush home from work at lunchtime to administer medication or a tube feeding that direct care workers are prohibited from administering. Hiring a nurse to perform these routine procedures, typically performed several times a day, is not feasible nor efficient. Therefore, allowing nurses to train and delegate these tasks to advanced direct care workers could ease the burden on family caregivers.

**Provide Health Information & Resources:** Communication among interdisciplinary team members, including health care professionals, consumers, and their family caregivers, is vital to quality care. An Advanced Direct Care Worker could enhance channels of communication by serving as a link for consumers and family members to the other team members and by helping individuals and family members to navigate the health care system, when it is their wish and with their consent. With support from other members of the care team, an Advanced Direct Care Worker could educate consumers and their family caregivers on particular health conditions, share information on community resources and supportive services, navigate health coverage and schedule appointments, and when desired, advocate for the consumer and provide emotional support.

Additionally, the Advanced Direct Care Worker could serve as a significant resource by helping to provide continuity through care transitions across settings. By communicating with the interdisciplinary team and identifying and reporting status changes, the Advanced Direct Care Worker can help prevent avoidable hospitalizations or miscommunication. To address privacy concerns, it should be clear to the consumer what information would be shared with other members of the care team, and occur only with their consent.

Promoting healthy practices, through nutrition and dietary planning, physical activity, oral health and hygiene, vaccination, and disease and health self-management, can also be valuable roles for the Advanced Direct Care Worker to play. Additionally, assisting individuals with doing exercises, such as range of motion activities prescribed by a physical or occupational therapist or physician, could improve health outcomes and quality of life. Such health promotion and behavioral management can be especially beneficial for: management of diabetes, heart disease, and mental health conditions; prevention of pneumonia, flu, and falls; and maintenance of general mobility and socialization.
**Condition-Specific Roles:** While any direct care worker should be trained to recognize and report signs of mental health issues, advanced illness and palliative care needs, and early signs of dementia, an Advanced Direct Care Worker with specific skills could significantly improve quality for individuals with these specific needs. For example, an Advanced Direct Care Worker specializing in advanced illness and palliative care can support the individual’s advance directives, support a pain management plan, and support individuals and their families. The same is true for Alzheimer’s and dementia care, for which an Advanced Direct Care Worker could learn to recognize and defuse behavioral symptoms of distress, reduce triggers for agitation or confusion, stimulate the individual through non-medical engagement, and support families. While maintaining a whole-person approach, an Advanced Direct Care Worker with condition-specific training could provide critical guidance and expertise within the care team, enhancing the quality of care provided.

**CONCLUSION**

At this point, demonstration projects should be created to test the viability and functionality of Advanced Direct Care Worker roles. Quality care for older adults, now and in the future, depends upon the quality of the workforce providing that care, as well as other factors. In order to achieve our goals of better care and lower cost, it is essential to raise the skill level, especially with respect to geriatrics and gerontology, of all healthcare providers. The future cost and quality of healthcare will be determined in part by whether we have a well-trained, coordinated workforce. An Advanced Direct Care Worker has the potential to help meet the needs of our burgeoning older adult population by providing person- and family-centered care effectively and efficiently.

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1. Older adults, within this paper, are also referred to as “consumers” as well as “person” within the phrase “person-and family-centered care.”
Appendix A*

Identifying Gaps in Care

Meeting the care needs of an individual with a chronic condition demands cooperation between all members of the interdisciplinary care team. Older adults with conditions such as dementia, diabetes, and hypertension may be able to enjoy better health, greater autonomy and remain in their homes longer if current gaps in care were filled. Training some current direct care workers to assist consumers and their family caregivers with these best practices could ensure that all members of the care team work at the top of their skill set to provide the highest possible quality care.

Examples of Gaps in Chronic Care

The management of a chronic disease or multiple chronic conditions depends heavily on the routine administration of basic procedures and constant monitoring to ensure adherence to set protocols. Diabetes, for example, is a chronic disease most commonly diagnosed in individuals over the age of 65. This population requires considerably more oversight in healthcare, due to the effects of advanced age and compounding co-morbidities. Therefore, many people with diabetes are incapable of adequately caring for their condition, which requires daily (or more frequent) blood sugar tests, diet adjustments, and medication management.

Much diabetes care occurs in the home. However, some individuals struggle with adherence to a care plan, particularly if they are overwhelmed by a complicated medication schedule, or struggle with blood sugar testing. Daily self-monitoring of blood glucose (SMBG) is reported by only 39% of individuals who use insulin, and only 5% of individuals who are being treated with oral medications. Failure to regularly monitor blood sugar or take medication as directed often contributes to a complication called diabetic ketoacidosis (DKA) that results from a shortage of insulin. More than 110,000 annual emergency department admissions are attributed to DKA.

Similarly, hypertension is a condition that demands vigilant monitoring and consistent adherence to a care plan. Complications from hypertension are the leading reason for physician office visits in the US. Older adults with hypertension are the most likely to experience uncontrolled blood pressure than any other group; the largest relative risk and attributable risk of uncontrolled hypertension were associated with individuals age 65 and older. However, high rates of uncontrolled blood pressure are continually seen in people who have health insurance, but may lack the ability to monitor their blood pressure regularly.

Dementia is a condition that affects an individual’s ability to care for themselves and maintain their safety. Much of the care that those living with dementia require is non-medical in nature, since these individuals often struggle with activities of daily living, personal safety, and medication management. Individuals with dementia suffer from memory loss and confusion, which may lead them to express their needs through behaviors since they may not be able to tell you what is wrong. For instance, a person living with dementia and in pain might lash out since s/he cannot tell you what is wrong. In a recent study of two managed care plans, full compliance with recommended care processes for dementia was achieved only 35% of the time. More critically, poor adherence to recommended care processes is associated with higher rates of elder abuse, depression, and inappropriate use of psychoactive medication for those living with dementia.
Special thanks to Stephanie Parver for her work on Appendix A.
Appendix B
SUMMARY OF ADVANCED DIRECT CARE WORKER ROUNDTABLES

DIRECT CARE WORKERS
- The majority of participants are asked to perform tasks beyond their job description and the care plan, although they generally lack specific authorization and formal training to do so.
- Many participants assume the role of advocate for consumers who don’t have family members available to offer information and emotional support.
- The majority indicated an interest in advanced training in order to take on additional tasks. Priority training areas are: medication knowledge and management; health information and chronic disease, particularly specific illnesses, such as Alzheimer’s or diabetes; mental health; and use of technology to improve consumer care, including care from a distance.
- All agree on the importance of direct care workers being involved in the care team decision-making processes; but some feel ignored or discounted by other team members and want improved communication within the care team.
- Overall, the participants indicate support for an advanced care role. But any expansion of their responsibilities will require financial remuneration, additional training and respectful support from consumers, families and provider agencies.

NURSES
- Roundtable participants agreed that direct care workers play an important role in providing care and that some home health aides have the potential for playing a more advanced role in care coordination models.
- With formal training, support and supervision, some home health workers could perform a number of more advanced tasks which would enhance the quality of care received by individuals, including: health information and advocacy; observing, recording, and reporting; and assisting with clinical tasks.
- Overall, the participants indicated support for an advanced role for some home health workers with supervision. But any expansion of their responsibilities will require additional training, support and supervision from other providers, financial support and infrastructure changes, as well as person-centered models.
- The group stressed the importance of ensuring that the advanced direct care worker role is examined from both the individual and family perspective and a quality and safety perspective.

SOCIAL WORKERS
- Roundtable participants agreed that an advanced direct care worker could improve care either in a specialist role or a generalist role.
- With formal training and support, some home health workers could perform a number of more advanced tasks which would enhance the quality of care received by individuals, including: dementia care, culturally competent care, advanced illness and palliative care, health promotion, and other supports.
- Participants noted that the wage and benefit issues related to the direct care workforce field were social justice issues.
- They noted that challenges exist related to direct care worker participation within the team, financial constraints, and already heavy workloads.

PHYSICIANS
- Roundtable participants agreed that an advanced direct care worker could improve quality of care, serving as a potentially promising asset to the interdisciplinary team.
- With formal training and support, some home health workers could perform a number of more advanced tasks which would enhance the quality of care received by individuals, including: care plan implementation; observing, recording, and reporting status changes; management of behavioral health issues; and performance of certain clinical care tasks such as pulse oximeter readings, monitoring of insulin, and medication administration.
- The group discussed direct care workers performing tasks that are being performed by family caregivers now.
- Participants noted that system fragmentation might pose a challenge to incorporating the direct care worker or Advanced Direct Care Worker within the team.
- They noted that challenges exist related to training costs, although effective curricula are being created; liability; and scope of practice.
FAMILY CAREGIVERS

- Through an online survey, family caregivers identified the need for additional support.
- The respondents supported the proposed tasks collected through the round table discussions.
- Many family caregivers felt an Advanced Direct Care Worker could help them by identifying community resources, assisting with prescribed exercise adherence, promote health activities and nutrition, and provide specialized care for people living with dementia.