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June 6, 2011

The Honorable Don Berwick
Administrator
Centers for Medicare and Medicaid Services
U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, DC 20201

RE: File Code CMS–1345–P

Dear Administrator Berwick:

The Disability Rights Education and Defense Fund (DREDF) and Access Living, along with the undersigned organizations and individuals, appreciate the opportunity to comment on the proposed rule regarding Medicare Shared Savings Program: Accountable Care Organizations (ACOs). DREDF is a leading national law and policy center that advances the civil and human rights of people with disabilities through legal advocacy, training, education, and public policy and legislative development. Access Living, nationally recognized as a leading force in the disability advocacy community, is Chicago's consumer-led Center for Independent Living that champions social reform for people with disabilities through independent living services, advocacy and legal action.

The Medicare Shared Savings Program has the potential to have a significant, positive impact on health care available to individuals with disabilities by delivering coordinated and patient–centered care. We applaud the Department's focus on strengthening primary care and the emphasis on establishing core principles for patient centered care, which the Institute of Medicine (IOM) has identified as a primary aim for improving health care. However, while these elements represent important conceptual advances, they could be rendered ineffective without rigorous standards and quality controls. We are particularly concerned that ACOs could be structured and operate in a manner whereby they avoid enrolling patients whose care is perceived as costly, provide less care than the intended beneficiaries require, and in the final analysis, exacerbate known health disparities among people with disabilities whom the organizations are intended to serve.

Overarching Concerns

Our comments specifically focus on an overarching concern that stems from the fact that healthcare policymakers and health care delivery systems alike have historically failed to recognize and acknowledge health care disparities and barriers to care that people with disabilities experience. Despite a growing body of research that identifies these problems and barriers, the proposed rule fails to acknowledge their presence and impact on the health and length of life of people with disabilities and it is silent on specific steps that ACOs must take to identify and mitigate them. Moreover, while the proposed rule sets forth important principles and criteria defining patient–centeredness, essential elements required to ensure patient–centered care for people with disabilities are absent. We think that these omissions substantially undermine the potential of the ACO model. Thus we urge HHS-CMS to seriously consider our recommendations, which, if implemented will begin to address some of these historic problems.

We begin by providing an overview of health disparities and barriers to care experienced by people with functional and activity limitations and a description of such limitations among Medicare beneficiaries. Specific comments and recommendations are provided on patient-centeredness criteria and beneficiary involvement in governance set forth in the proposed rule.

Barriers to Health Care and Health Disparities—People with Functional and Activity Impairments

The Institute of Medicine (IOM), the Surgeon General of the United States, the National Council on Disability (NCD), and others recognize that people with disabilities experience health and health care disparities and barriers to care as compared with people who do not have disabilities.[1] Barriers to primary, specialty, diagnostic, and acute care that can affect people with disabilities disproportionally include limited medical facility accessibility and lack of accessible examination and diagnostic equipment; [2] lack of Sign Language interpreters; [3] lack of educational and health care instructional materials in formats that are accessible to people who are blind or have visual impairments; [4] and lack of individualized accommodations that are critical to ensure that people with intellectual, cognitive, emotional, speech and language impairments can communicate effectively with their health care providers. [5] Prevalent disability stereotypes and limited provider training and disability awareness further exacerbate the problem. [6]

People with certain types of functional impairments experience specific health disparities that are not necessarily related to their primary disability, but rather to the aforementioned fundamental structural and policy barriers in health care. For example, women with significant disabilities are likely to have fewer Pap tests and mammograms than women who do not have disabilities.[7] Women with disabilities are often examined inappropriately in their wheelchair, and those with breast cancer are diagnosed later and are more likely to die from the disease than women who do not have disabilities.[8] People with disabilities also experience poorer health outcomes. For example, low-income women with disabilities are nearly three times more likely to postpone needed medical care, resulting in substantially worse outcomes.[9] Adults who are deaf or who experience significant problems hearing are three times as likely to report fair or poor health compared with those who did not have hearing impairments.[10] Three out of five people with serious mental illness die 25 years earlier than other individuals, from preventable, co-occurring chronic diseases, such as asthma, diabetes, cancer, heart disease, and cardiopulmonary conditions.[11] People with significant vision loss are more likely to experience a greater prevalence of obesity, have hypertension and heart disease, and smoke more than the general public.[12]

Medicare beneficiaries, who will be affected directly by the structure and accountability of ACOs, experience significant functional and activity limitations and disabilities. According to the Kaiser Family Foundation, 29 percent of Medicare beneficiaries have difficulty managing basic activities of daily living such as bathing and eating. Thirty percent of all beneficiaries are limited in their ability to perform essential activities of daily living such as housework, preparing meals, and using the telephone. Such limitations affect 54 percent of nonelderly beneficiaries with disabilities and those ages 85 and older. Moreover, approximately 9,000,000 low-income seniors and people with disabilities are dually eligible for Medicare and Medicaid. These individuals are more likely than other Medicare beneficiaries to be frail, with multiple chronic conditions and functional and cognitive impairments.[13]

Providing effective and equitable healthcare for these individuals requires a comprehensive, integrated approach that recognizes the role, for example, of care coordination, rehabilitative services, specialty care, and availability of home and community-based long-term care. As a practical matter, barriers to care such as inaccessible medical facilities and diagnostic equipment, lack of accommodation such as Sign language interpreters and printed materials in accessible formats such as Braille or digital forms, and inflexible exam times must also be acknowledged and processes developed to reduce or remove them. We make the following recommendations related to patient–centered criteria and beneficiary involvement in governance in response to these concerns.

Evaluation by the Secretary of the Quality of Care Provided by an ACO

Section 1899 (b)(3)(B) of the ACA requires an ACO to submit data in a form and manner specified by the Secretary on measures the Secretary determines necessary for the ACO to report in order to evaluate the quality of care furnished by the ACO. In light of the known health disparities experienced by people with disabilities and the diverse barriers to care they encounter, we think that it is imperative for HHS-CMS to establish overarching criteria that will guide ACOs in the development of processes to identify and evaluate these barriers and implement methods to mitigate or remove them. Doing so will fulfill the Department's obligation to ensure compliance with Section 504 of the Rehabilitation Act of 1973 by health care entities that receive federal financial assistance as well as the nondiscrimination provisions of Section 1557 of the ACA, and it will also begin to address some of the intransigent barriers to care experienced by people with disabilities.

Specifically, the Secretary should require that ACOs acquire information on the extent to which their health care services partner organizations are physically accessible to individuals with functional and activity impairments. This information can be obtained by requiring partners to assess their own facilities, through contract with other organizations, or by other means. The ACO should be required to report survey findings to HHS-CMS along with other assessment data and also provide the information to Medicare beneficiaries via whatever means it uses to communicate with beneficiaries such as websites and provider-specific publications. Survey results should also be used to determine the capacity of participating care providers to meet the accessibility needs of beneficiaries with various activity and functional limitations and to recruit additional primary and specialty care, and diagnostic and treatment provider participants if needed to increase availability of providers whose facilities are accessible.[14] In addition, ACOs should assess the awareness of its healthcare provider partners concerning methods they use to accommodate the specific needs of people with disabilities (e.g., hire a Sign Language interpreter, provide print materials in accessible formats for people with visual impairments, adjust appointment times to ensure effective communication for people with speech, cognitive or mental health disabilities or who require assistance) and develop organization-wide processes for assisting participating healthcare providers to arrange for these accommodations.

Patient–Centeredness Criteria

We support the eight patient–centered criteria presented in the proposed rule and strongly urge HHS-CMS to include them in the final regulation. In addition, we also recommend that an additional criterion be added that recognizes that lack of facility and medical equipment accessibility, lack of certain critical accommodations such as Sign Language interpreters, print materials in alternative formats, provider modification of examination times, and poor provider disability awareness and literacy are threshold barriers to care for some people with disabilities. In the absence of accessible facilities and equipment or other needed accommodations, quality measures such as receiving an annual mammogram for women over a certain age or regular weight checks will be rendered meaningless because these tests and measurements simply will not be carried out for wheelchair users and others with ambulatory limitations. In light of the high percentage of Medicare beneficiaries who have functional and activity limitations, basic facility and equipment accessibility and accommodations are therefore a threshold measure of meaningful patient–centeredness. Thus we recommend that a criterion be added that requires a process for evaluating healthcare facility and medical equipment accessibility, and capacity of ACO participating health care providers and entities to provide needed accommodations for patients with disabilities. Such an assessment should lead to creation of an ACO-wide plan for mitigating or removing barriers, acquiring accessible equipment such as examination tables and weight scales, and creating and implementing policies, procedures and mechanisms for providing accommodations either by the ACO itself or by participating entities.

Evaluation of Population Health Needs and Consideration of Diversity Comments

We recognize that the Department has proposed a patient-centered criterion that ACOs have a process for evaluating the health needs of the population, including consideration of diversity among its patients, and a plan to address the needs of various populations. Theoretically, under this criterion the health needs of people with functional and activity limitations would be captured using existing evaluation tools that promote cultural sensitivity and address disparities through a variety of means including education. Unfortunately, most multicultural health care standards and guidelines do not recognize or address the specific, threshold barriers to care we have identified here. Unless HHS-CMS adopts the additional criterion previously described under “Patient-Centered Criteria,” ACO entities will likely not be aware of these long-standing and embedded structural problems and will not voluntarily establish and implement mechanisms for evaluating and mitigating them. Thus the cycle of exclusion from care, inequitable care, and resulting health disparities will continue unnoticed and unreported for many with disabilities.

We recognize that the requirements ACOs must meet in order to participate in the Medicare Shared Savings Program should not be overly burdensome or they will serve as a disincentive. We think that our recommendation does not create such a burden. In fact, it emanates from the experience of five Medicaid managed care health plans operating in California that have voluntarily conducted accessibility surveys with 2860 primary care physician facilities. At the same time, these plans also evaluated the availability of height adjustable examination tables and wheelchair accessible weight scales in those provider facilities. Moreover, this year the California Department of Health Care Services established a policy requiring Medicaid health plans operating in the state under a 1115 waiver applicable in 16 counties to conduct such surveys, not only because they are necessary to ensure access to care for Medicaid beneficiaries, but also because the experience of the five plans that voluntarily conducted such surveys revealed that it was feasible and not overly burdensome to do so.[15] While we recognize that ACOs differ from health plans and will be made up of primarily health care provider entities, the overarching ACO entity still will be expected to fulfill a variety of assessment, data collection, and administrative duties and will have explicit reporting obligations. Thus, the assessment we propose is congruent with these and other similar obligations.

Beneficiary Experience of Care Survey

We agree that it is important for ACOs to measure and report beneficiary experiences of care and that outcome metrics be used to determine whether ACOs are meeting fundamental patient–centeredness criteria. However, we have two concerns related to assessing the experience of beneficiaries with functional and activity limitations and disabilities. First, healthcare provider organizations do not currently have a method to identify people with disabilities according to their functional limitations—information that is essential in order to understand some of the basic healthcare experiences of this large and diverse group. We are pleased to see that the proposed rule mentions the intent to require adoption of an appropriate functional status survey module that may be incorporated into the CAHPS survey, but we think that step alone is inadequate. We set forth a two-step process below as an alternative. Second, most current survey tools in use do not include questions that relate to accessibility and accommodation problems typically experienced by beneficiaries with physical, communication, or cognitive impairments or about their interaction with health care professionals. Thus, these instruments will not capture many common beneficiary concerns that directly relate to their experience of care.

<u>A Two-Step Process</u>

Based on these limitations, we recommend that HHS-CMS require a two-step process that lays the foundation for understanding the functional limitations of the patient population and that also evaluates the experiences of care by beneficiaries with disabilities. First, we recommend that HHS-CMS require ACOs to identify beneficiaries with functional and activity limitations at the time of their transfer or enrollment by requesting that beneficiaries voluntarily complete a short, six–question survey based upon questions that ask about functional limitations that have been in use by the American Community Survey (ACS) since 2008 following cognitive testing and non-response assessment.[16] We recommend that these questions be used because population researchers are moving toward standardizing questions about functional limitations and these six questions are increasingly being used to identify the population of people with disabilities. Collecting data about functional limitations of Medicare beneficiaries in this manner will not only assist ACOs to move toward meaningful patient-centered care, it will also meet some of the new data collection requirements set forth in Section 4302 of the Affordable Care Act that call for collection of data on disability status for applicants, recipients, or participants by any federally conducted or supported healthcare program, activity or survey.[17] Moreover, as a practical matter, health care providers need this information in order to plan for and provide appropriate accommodations, coordinate care, and carry out other care functions for beneficiaries with various impairments. It is also important to recognize that identification of individuals with disabilities in health care settings is a dynamic process. People need to be able to identify multiple functional limitations for themselves, and there needs to be a means to update this information over time. With the establishment of electronic medical records, it will be feasible to incorporate the functional limitation questions into the record, completed by the patient (or proxy) as a part of the assessment information routinely collected when patients appear for care.

Second, we recommend that HHS-CMS consider adopting the “Assessment of Health Plans and Providers by People with Activity Limitations (AHPPPAL),” an enabled survey of primary care, which sets forth adjustments to the current Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey to measure and reflect the experiences of people with disabilities.[18] This new instrument has been cognitively and field tested, and provides for multiple administration modes. It also contains functional limitation questions that hew closely to the six ACS questions previously discussed, which allows answers to the survey to be linked to specific disabilities of respondents. These functional limitation questions should not be used as a stand-in for the ACS questions we recommend be asked of all new enrollees and of patients when they seek care, which serve a different and separate purpose. In light of the growing body of research identifying gaps in access to care and processes for people with disabilities, this enabled CAHPS Clinician and Group Survey provides an important, new tool for measuring beneficiary experiences.

Beneficiary Involvement in Governance

While we endorse extensive beneficiary involvement in governance, policymaking, program evaluation, and oversight generally, the voice of beneficiaries with disabilities specifically must be included in the operations of Medicare ACOs. Those beneficiaries, who have lived years with disabilities, are the experts when it comes to their needs. Based on their own experiences across the disability spectrum, they can provide unique insights into ways to make the ACO service delivery system fit their needs rather than shoehorn them into a predesigned and inflexible system designed for people who do not have disabilities. In addition, it is beneficiaries with disabilities who are more likely to notice and flag environmental, communication, and other access barriers and thus to trigger responses likely to increase Americans with Disabilities Act (ADA) compliance. In light of the upcoming new regulatory standards on accessible medical diagnostic equipment from the U.S. Access Board and possible expansion of those standards into Titles II and III of the ADA by the U.S. Department of Justice, a strong voice from the disability community on accessibility will be to the advantage of all Medicare ACOs and beneficiaries. In this context, it must also be emphasized that Medicare ACOs must be made mindful of the reasonable accommodation and modification needs of beneficiaries in their advisory and governance roles and must be prepared to assure that meetings are held in accessible facilities, that meeting materials are produced in alternative formats, that Sign Language interpreters are available for people who are deaf or hard of hearing, and that Internet communications and materials meet accepted accessibility standards and Section 508 of the Rehabilitation Act.

With the caveat that we are addressing in particular the role of beneficiaries with disabilities in Medicare ACO operations, we make the following observations about criterion (b) of patient-centeredness, the beneficiary role in governance. In its notice of proposed rulemaking, HHS-CMS notes that an advisory committee voice may be more effective than that of a single beneficiary representative on the ACO governing body. By the same token, a committee with purely advisory functions may provide an inadequate avenue for meaningful participation in governance. Because the two forms of partnership are qualitatively different, **we propose that both forms of beneficiary participation be required in Medicare ACOs**. In either context, we endorse the overarching recommendation of the National Council on Disability that:

> [c]onsumers representing a wide range of disability perspectives should be included in decision making at every step in the process that ultimately shapes programs: from development and implementation of a research agenda through policymaking to program design, oversight, and evaluation. Consumers provide a truly unique source of information about the human services and health care delivery system.[19]

Beneficiary Participation on the ACO Governing Body

A preeminent example of consumer governance in health care is the member-owned and member-run health care cooperative. Two examples are HealthPartners in Minnesota and Wisconsin and Group Health in Washington and Idaho.

HealthPartners serves over 1.3 million members. Its Board consists of thirteen directors elected by members and two directors who are physicians. The organization’s CEO serves as a nonvoting director. Andrea Walsh, Executive Vice President and Chief Marketing Officer, states that a member-governed organization provides the critically important benefit of “regular and reliable feedback and insight from the customers who use our system and are directly impacted by the decisions we make” and that it is consumer governance that assures that value to customers is measured on health outcomes rather than shareholder returns.[20]

Group Health evolved over sixty years from a single clinic to an organization that owns and operates thirty medical facilities, currently contracts with over 6,000 physicians and 44 hospitals, and serves 650,000 residents of the States of Washington and Idaho. Members elect a diverse Board of Trustees, whose expertise in various areas contributes to high quality and patient-centered results in the hiring and directing of executive leadership, setting of policy, and reviewing of financial plans. Diana Birkett Rakow, Public Policy Executive Director, credits Group Health’s successes in implementing innovative service delivery models at reduced costs to a consumer governance structure that is central to the organization’s identity and that assures systematic participation in business decisions.[21]

The success of the cooperative model of health care is a testament to the high value of consumer/beneficiary participation in decision-making. We recommend that this governance model be imported into the ACO context and that beneficiaries, particularly those from populations that experience health and health care disparities and including those with disabilities or their representatives from community-based consumer organizations, be substantially involved at the level of the ACO's governing body, comprising at least 50% of the members. The tokenism of placing a single beneficiary representative on the governing body may serve a symbolic purpose but it does not serve the interest of inclusiveness and meaningful participation in the organization's operations, nor does it serve the organization's interests in maximizing feedback from beneficiaries with diverse talents and fostering a sense of legitimacy in its policies.

Beneficiary Participation on the ACO Advisory Committee

Beneficiary participation is equally as important on advisory committees as at the level of the ACO's governing body. The advisory board should have a role in oversight, ensuring that beneficiaries and other advocates have the opportunity to review program data, identify relevant quality measures, and develop beneficiary education and outreach materials.[22] The advantages of advisory committees with these substantive roles are numerous.[23]

- Beneficiary feedback assists providers in implementing types and qualities of services and evaluating program effectiveness, and that feedback should represent diverse populations of beneficiaries, including people with various types of disabilities.
- Beneficiary involvement educates beneficiaries both substantively and in leadership skills and thus enhances their expertise and the role they contribute to the organization over time.[24]
- Partnering with beneficiaries in a meaningful way beyond mere information sharing and at the level of program and policy development, implementation, and oversight will allow Medicare ACOs to get early buy-in and build sustainable working partnerships with beneficiary communities.[25]
- Recognition of beneficiary perspectives and an oversight role creates transparency and accountability in policy and decisions that is critical to the legitimacy of limit-setting policies in health care organizations.[26]
- Active involvement of beneficiaries in organizational operations through advisory boards is more likely to engage other beneficiaries and to boost the overall credibility of the health care organization among all beneficiaries.

As in the case of formal governance, tokenism on an advisory board is defeating of the numerous benefits to be gained by involving beneficiaries. Limiting beneficiary involvement on an advisory board to one or a mere handful of beneficiaries deprives those representatives of natural allies and creates an inhospitable and potentially intimidating forum.[27]To be meaningful, the beneficiary role must truly make a difference in the operations, policies, outcomes and improvements of an organization.[28]In addition, the advisory boards should include leaders in the advocacy community including, in the case of people with disabilities, centers for independent living.[29] Finally, to ensure that Medicare ACOs actually comply with the requirement for a meaningful beneficiary voice in governance and advisory boards, we recommend that HHS-CMS build in governmental oversight mechanisms and penalties for noncompliance.

We appreciate this opportunity to comment on the proposed rule for the Medicare Shared Savings Program and ACOs and looking forward to working with you as you continue to implement important provisions of the ACA.

Sincerely,

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Endnotes

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