June 6, 2011

Donald M. Berwick, MD, MPP
Administrator
Centers for Medicare and Medicaid Services
U.S. Department of Health and Human Services
Washington, DC 20515

RE: Medicare Shared Savings Program – Accountable Care Organizations
Response to Notice of Proposed Rulemaking
RIN 0938-AQ22
File Code CMS-1345-P

Dear Dr. Berwick:

The undersigned members of the Consortium for Citizens with Disabilities (CCD) Health Task Force appreciate the opportunity to comment on the Proposed Rule for the Medicare Shared Savings Program – ACOs, which was published in the Federal Register, March 31, 2011, vol. 76, no. 67, pages 19528 to 19654. CCD is a coalition of approximately 100 national disability-related organizations working together to advocate for national public policy that ensures the self determination, independence, employment, integration and inclusion of children and adults with disabilities in all aspects of society.

*The Promise of ACOs:* CCD believes that better integration of health care providers and the services they provide can lead to reductions in unnecessary cost, inefficiency, and duplication of effort in the health care delivery system. We also believe that quality improvement can be the end result of such an environment, if ACOs are structured and regulated appropriately.

To the extent that ACOs are premised on patient-centered care, patient engagement, performance measurement, and meaningful patient and stakeholder involvement, CCD sees significant value in these arrangements. We also support the proposed rule’s emphasis on beneficiary choice, beneficiary engagement, the right of beneficiaries to opt out of these demonstrations, and the documentation of grievances and complaints as an indicator of the patient experience under ACOs.

*ACOs and the Disability-Chronic Illness Population:* The ACOs described in the proposed rule are based on a strong foundation of primary care and for many Medicare beneficiaries, this is the appropriate focus. But for millions of Medicare beneficiaries
with disabilities and chronic conditions - especially dually eligible and beneficiaries covered under Title II of the Social Security Act - an emphasis on primary care may miss some of the critical needs for specialty care and other services routinely provided under the current program by a variety of professionals in a number of different settings.

This is potentially problematic in that chronic conditions are responsible for nearly half of all annual health care expenditures for persons not in nursing homes or other institutions.\footnote{“Patient-centered care categorization of U.S. health care expenditures,” by Dr. Conway, Kate Goodrich, M.D., M.H.S., Dr. Machlin, and others in the April 2011 \textit{HSR: Health Services Research} 46(2), pp. 479-490.} In addition, more than a third of hospital-based expenditures are for the care of patients with these conditions, according to the 2007 Medical Expenditure Panel Survey (MEPS).

For instance, persons with conditions such as spinal cord injury, brain injury, Multiple Sclerosis, end stage renal disease, or serious mental illness may not interact routinely with a primary care professional as defined under the proposed rule. A person with Multiple Sclerosis may have a neurologist as their primary contact with the health system. A person with spinal cord or brain injury may primarily engage the health system through a physical medicine and rehabilitation physician known as a “physiatrist.” A person with ESRD may interact most frequently with a nephrologist and a person with serious mental illness may use a psychiatrist or other mental health professional as their primary contact with the health system.

\textbf{ACO’s Financial Incentives:} Whether ACOs will accommodate the needs of these types of individuals is a topic of serious debate within the disability and rehabilitation community. The main concern centers on the profit motive of the ACO. In fact, CCD has concerns with any system where health care providers are financially rewarded for keeping costs down. People with disabilities, chronic health conditions, or anyone who requires specialized or complex care is at risk of losing access to appropriate medical technology, rehabilitation devices, rehabilitation therapies and other specialized services if access is tied to profit motivation. This includes a loss of access to high quality providers/suppliers of these services and devices, including rehabilitation care provided at the appropriate level to meet the needs of the individual patient.

Therefore, it is fundamental that providers in ACOs should not be permitted to share in savings achieved through the denial of high quality patient care. ACOs must not merely be a new mechanism to pay providers, but must be a new way of delivering health care that provides access to quality care across the acute and post-acute care continuum. Therefore, in the final ACO rule, CMS should ensure that mechanisms are in place that monitor the status of beneficiaries covered under Title II of the Social Security Act and dually eligible Medicare populations under ACOs and take immediate steps to correct deficiencies in treatment of this subgroup. In addition, CMS should work through the Center for Medicare and Medicaid Innovation (CMMI) to examine specific health care delivery models that focus on subgroups of Medicare beneficiaries and implement these models as expeditiously as possible.
Protecting Against Under-Serving Patients: CCD believes that provider participation in any shared savings in any new delivery model must be explicitly contingent upon the achievement of good outcomes with quality and outcome measures. As new delivery models take shape through the Centers for Medicare and Medicaid Services (CMS) or the Center for Medicare and Medicaid Innovation (CMMI), they should have at their foundation the achievement of patient-centered outcomes. Primary and acute care outcome measures are necessary in this regard, but they are not sufficient, at least for the population of people with disabilities and chronic conditions. Outcome measures for this population must include measures based on function, not simply primary health care status.

For instance, a person who experiences a traumatic injury or surgical operation may achieve completely acceptable primary care outcomes (e.g. blood pressure, blood sugar, heart rate, and cholesterol) six months later, but the real indicator of a successful outcome is the level of function and independence the person enjoys. Is the person not only “healthy,” but living at home as independently and actively as possible, having returned to work and normal activities, or is that person significantly compromised in terms of their function, living in a nursing home, unemployed and out of the mainstream of community activities? Measures to assess functional status of this kind will need to be employed if ACOs are truly going to improve quality and outcomes while saving money for the population of people with disabilities and chronic conditions.

CCD understands the potential changes in provider behavior that can spring from ACOs depending on how ACOs are structured. For people with relatively high cost conditions such as brain injury, severe stroke, spinal cord injury, major multiple trauma, severe mental illness and developmental disabilities, the potential for greater coordination and increased efficiency to produce cost savings is greatest. However, one way to manage the cost of patients with significant health needs is to simply deny care or divert the patient to the least costly setting whether or not it is in the patient’s best interests from a medical and functional perspective.

If appropriately structured, ACOs may incentivize provider networks to provide early and intensive services (i.e., inpatient hospital rehabilitation, intensive mental health services) as well as primary and specialty services throughout the post-acute care continuum at sufficient intensity and duration to minimize long term costs downstream. However, if inappropriately structured, ACO’s may seek to avoid certain high cost patients, limit services to reduce costs, and generally stint on patient care. If this is the path taken by ACOs, these new delivery models will fail to achieve their promise and will only result in financial rewards to ACO provider participants at the expense of patients.

Opt Out Provision as a Safety Valve: Given these concerns and genuine questions about which path ACOs are likely to take with patients with disabilities and chronic conditions, CCD supports an opt out provision in all ACOs, allowing patients assigned to ACOs to have the ability to opt out of an ACO if they feel their needs are not being met. The ability of patients to access providers outside of their ACO is a major step in this
direction, but CMS should provide an opt out provision to all ACO patients while it studies the relative merits of this mechanism.

The reason CMS should continue to study the opt out mechanism is because CCD recognizes that it has the potential to be manipulated by ACOs and may even decrease the likelihood that these patients will be able to take advantage of the principal concept behind ACOs, better coordination of care. It may even serve as a disincentive for ACOs to strive to meet the needs of this population, assuming that these individuals will be removed from the ACO over time. An opt out provision for certain beneficiaries could be an important safety valve to ensure quality care for this population. CMS should monitor this provision very closely as ACOs are implemented and take steps to correct problems as they develop.

*Meaningful Quality Measures for People with Disabilities:* Of course, CMS and ACOs alike will only really know whether they are under-serving persons with disabilities and chronic conditions if they are measuring quality indicators that are relevant to this population. Of the 65 quality measures listed in the proposed rule, strikingly few of them have any relevance to people with disabilities. In fact, none of the measures account for the functional status of the patient or measure functional improvement in response to care provided. In addition, none of the measures seek to assess the level of independence achieved by the patient compared to a previous state.

We encourage CMS to actively seek guidance on an ongoing basis from the disability and rehabilitation research field to identify appropriate measures for ACOs to adopt that will measure meaningful outcomes for people with disabilities and chronic conditions, particularly measures to assess functional status and independence. There are a variety of measurement tools in this area that should be considered.

In addition, there are some existing measures that relate to certain aspects of care for people with certain disabilities that we encourage CMS to consider. For instance, the National Quality Forum is working on a variety of post-acute care measures and has already adopted measures for:

1. Antidepressant medication management;
2. Initiation and engagement of alcohol and other drug dependence treatment;
3. Medication management in the elderly;

While more specific measures are developed to identify the level of function and independence the patient achieves after an episode of ACO care, CCD strongly encourages CMS to focus on direct measures of the ACO patients’ experience with their care. In addition to the ACAHPS cited above, there are other measurement tools that are tailored to the post-acute care environment, including tool known as “uSPEQ” developed by CARF, the Rehabilitation Accreditation Commission. uSPEQ is a psychometrically balanced comparative analysis of the consumer experience in the areas of informed
choice, access, respect, participation and satisfaction. Measures such as this would serve a fundamental purpose in assessing ACO performance with respect to people with disabilities and chronic conditions, especially while more specific functional and independence measures are being developed.

**CCD’s Specific Recommendations on ACOs:**

Given the factors and analysis cited above, CCD offers the following specific recommendations to CMS to adopt in the final rule on ACO’s:

- **Interim Final Rule:** CMS should issue an Interim Final Rule rather than a final rule after due consideration of the many public comments expected on this NPRM. There are simply too many major changes being contemplated to issue a final rule. As a potential major driver of health care delivery in the future, it is critical that CMS issues regulations that structure ACOs appropriately from the outset and, therefore, an Interim Final Rule would allow CMS to continue to refine the final rule in the future.

- **Beneficiaries covered under Title II of the Social Security Act and Dual Eligible Population:** CMS should recognize the specific challenges of serving beneficiaries covered under Title II of the Social Security Act and dually eligible populations through the primary-care based ACO model and take meaningful steps to track, report, and hold accountable ACOs that do not adequately meet the needs of these beneficiaries.

- **Quality Measures Relevant to People with Disabilities and Chronic Conditions:** CMS has identified 5 key domains within the dimensions of improved care and improved health that the agency proposes will serve as the basis for assessing, benchmarking, rewarding, and improving ACO quality performance. CMS should establish a separate domain for functional status and design measures to quantify this important outcome. If ACOs are not required to measure functional and independence outcomes, CMS will never know whether savings have been achieved at the expense of patient care.

- **Measurement of Beneficiary Experience:** CCD strongly supports the regulation’s requirement for implementation of a beneficiary care experience survey. Such a survey should be tailored to the patient’s use of the health system. For instance, a person who undergoes extensive rehabilitation should be provided with a survey that is tailored to the post-acute care experience. Similarly, a patient who has undergone extensive mental health services should receive a survey that is relevant to that experience.

- **Tailored Delivery Models:** CMS should work through CMMI to implement new health care delivery models that are specifically tailored to certain subgroups of beneficiaries with disabilities and chronic conditions (e.g., brain injury, end stage renal disease, major stroke, etc.).
- **Assignment to ACO’s:** CMS should ensure that the assignment methodology which delegates beneficiaries to primary care providers (defined as general practice, family practice, internal medicine, and geriatric medicine physicians) does not miss large numbers of people with disabilities and chronic conditions who may rely on a specialist as their primary contact with the health system.

- **Opt Out Provision:** CCD believes CMS should mandate that ACOs provide an opportunity for participants to opt out of ACOs if they believe their needs are not being met. This is an important safety valve that CMS should continue to monitor and refine as data becomes available on the impact of this opt out mechanism, in order to prevent unintended consequences.

- **Quality and Savings:** ACOs that do not maintain or improve quality outcomes for all beneficiary groups, including people with disabilities and chronic conditions, or that achieve savings through the inappropriate denial of care—or the diversion of a patient to less than optimal care—should not be able to share in savings. (For instance, if an ACO routinely diverts patients requiring intensive inpatient hospital rehabilitation to skilled nursing or other less intensive settings, the ACO should not be permitted to share in savings.)

- **Avoiding At-Risk Beneficiaries:** CCD strongly supports the provisions in the proposed rule that would impose on ACOs a requirement to put forth a Corrective Action Plan (CAP) in the event CMS detects ACO behavior that suggests an avoidance of at-risk beneficiaries. CCD also supports the proposal to prohibit the ACO from sharing in savings while under a CAP and the ultimate sanction of termination as an ACO if the ACO does not adhere to the CAP.

- **Individualized Care Plan:** CCD strongly supports the requirement to have systems in place to identify high-risk individuals and processes to develop individualized care plans for targeted populations.

- **Network Adequacy:** CCD believes that ACOs should be required to ensure there are a sufficient number and diversity of providers and suppliers in their ACO networks. For patients with disabilities and multiple chronic conditions, it is imperative that providers across the continuum of care, such as rehabilitation, habilitation and mental health providers, be active participants in ACOs. CCD requests that CMS clarify that post-acute care providers may participate in an ACO Shared Savings Program. We also believe that CMS should require acute care hospitals participating in ACOs to establish processes and procedures that ensure communication with patients informing them of their post-acute care service options prior to discharge.

- **Quality Providers and Suppliers:** CCD believes that arrangements with specialists and specialty care settings should be sufficient to meet the needs of all
ACO participants and that ACO providers and suppliers are appropriately credentialed through certification, accreditation and state licensure.

- **Community Stakeholders:** CCD strongly supports the requirement for ACOs to establish partnerships with community stakeholders. We also recommend that the requirement that the ACO produce a written description of how it will partner with community stakeholders be included in its compliance plan.

- **Consumer Participation in ACO Governing Body:** CCD supports the inclusion of community stakeholders on the governing bodies of ACOs and encourages CMS to specifically include robust consumer representation on these boards. If these new delivery systems are to in fact be “patient-centered,” it will be important that governing bodies include patients and the providers who serve them.

- **Care Coordination:** CCD strongly supports the requirement that as part of the application process, a mechanism must be in place and described to CMS for the coordination of patient care. An ACO should be required to describe in its initial assessment process how it will develop a care coordination plan, how often and in what manner reviews will take place, and the process for modifying the care coordination plan in response to those reviews. We also urge that the application include the methods used to monitor and manage tests, referrals, and medical procedures—including medication management. CCD strongly believes that the continuum of care includes more than the provider-hospital system, and that post-acute care be represented in a care coordination plan to further the goal of improving quality care and reduce acute care costs by considering the on-going functional (i.e., rehabilitation) needs of persons with disabilities or chronic conditions.

We thank you for the opportunity to comment on this important proposed rule and encourage you to contact us to further discuss any of these issues.

For more information, please do not hesitate to contact any of the co-chairs below.

Sincerely,

ACCSES
American Association of People with Disabilities
American Association on Health and Disability
American Medical Rehabilitation Providers Association
American Music Therapy Association
American Therapeutic Recreation Association
Autism Society
Association of University Centers on Disabilities
Bazelon Center for Mental Health Law
Brain Injury Association of America
Disability Rights Education and Defense Fund
Easter Seals
Epilepsy Foundation
Health & Disability Advocates
National Alliance on Mental Illness
National Association for the Advancement of Orthotics and Prosthetics
National Association of State Head Injury Administrators
National Council for Community Behavioral Healthcare
National Disability Rights Network
National Multiple Sclerosis Society
The Arc of the United States
United Spinal Association