July 11, 2011

Edo Banach
Division of Program Alignment
Federal Coordinated Health Care Office
Centers for Medicare and Medicaid Services
U.S. Department of Health and Human Services
Washington, DC 20515

Re: Medicare and Medicaid Programs; Opportunities for Alignment (CMS–5507–NC)

Dear Mr. Banach:

The Consortium for Citizens with Disabilities (CCD) Health Task Force appreciates the Federal Coordinated Health Care Office's efforts to align care for individuals that are eligible for both Medicare and Medicaid, particularly those beneficiaries with disabilities and chronic conditions. CCD is a coalition of national disability organizations working together to advocate for national public policy that ensures the self determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

CCD believes that efforts to align care should result in beneficiaries able to access the benefits that they need more easily. In addition, an improved process would result in smoother transitions between settings of care, particularly from institutions and into the home and community setting. Finally, any process to better align care for dual eligibles must focus on the quality of care that beneficiaries receive, to ensure that quality is not sacrificed in the name of efficiency.

To the extent that care coordination for dual eligibles is premised on patient-centered care, patient engagement, performance measurement, and meaningful patient and stakeholder involvement, CCD sees significant value in these efforts. We also support appropriate emphasis on beneficiary choice, beneficiary engagement, and the documentation of grievances and complaints as an indicator of the patient experience under an aligned system.

In the remainder of this letter, we recommend principles for coordinating care of beneficiaries eligible for Medicare and Medicaid, particularly those beneficiaries with disabilities and chronic conditions.

CCD Principles for Coordinating Care for Individuals with Disabilities

Comprehensiveness: People with disabilities and their families must have access to benefits that provide a comprehensive array of health, rehabilitation, assistive device, and support services across all service categories and sites of service delivery.

In the request for comment, CMS identifies multiple categories of benefits to align for dual eligibles, including: Behavioral Health, Durable Medical Equipment, Home Health, Nursing Home – Hospital Transfers, Skilled Therapies, and Prescription Drugs.

CCD strongly believes that no beneficiary should lose access to benefits through the alignment process. Where Medicare and Medicaid have conflicting coverage policies, alignment of these policies should not result in fewer beneficiaries having access to the appropriate services in a timely manner. Likewise, the alignment of policies under Medicare and Medicaid should not restrict access to needed services and devices.

For example, currently CMS defines "durable medical equipment" under Medicare with a phrase that has been misinterpreted for years, i.e., that DME is "used in the patient's home." This misinterpretation of the Medicare statutory provisions restricts Medicare coverage of wheelchairs and other mobility devices to only those that are medically necessary within the four walls of the person's home. Oftentimes, if Medicare denies based on an item not being reasonable and necessary because it can be used outside of the home, Medicaid will deny the item to the dual eligible as well.

However, Medicaid does not apply the same "in the home" interpretation to individuals eligible for Medicaid alone, thus resulting in beneficiaries that are only eligible for Medicaid – as opposed to Medicaid *and* Medicare – often having better coverage of DME than dual eligibles. CCD recommends that CMS align coverage for DME to improve access to assistive technologies for the most vulnerable and to allow dual eligibles to access the equipment they need to remain independent, live outside of institutions and prevent costly secondary conditions, consistent with Medicaid efforts to transition individuals into their home and communities.

For people with relatively high cost conditions such as brain injury, severe stroke, spinal cord injury, major traumas, severe mental and psychiatric illness, and developmental disabilities, the potential for greater coordination and increased efficiency to produce cost savings is greatest. If appropriately structured, the alignment process may improve access to 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, the alignment may result in limited services and generally stint on patient care to reduce costs. If this is the path taken during the alignment process, these new care coordination models will fail to achieve their promise and will only result in financial savings to payers at the expense of patients.

Appropriateness: People with disabilities and their families must be assured that comprehensive health, rehabilitation, and long term support services are provided on the basis of individual need, preference, and choice.

The alignment process should include a "person-centered" planning process where the care needs of beneficiaries are fully considered. During and after alignment, it should be demonstrated that beneficiaries with disabilities can access a sufficient network of providers, suppliers, and a wide range of community-based nonprofit service organizations with experience serving people with disabilities and chronic conditions. CMS should place special emphasis on demonstrating capacity for those services that may extend beyond traditional acute care medical services.

For millions of beneficiaries with disabilities and chronic conditions - especially for those that are dually eligible - 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 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.[1] 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. 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.

Quality: People with disabilities and their families must have access to health care that is effective, high quality and well coordinated, with a minimum of administrative waste.

CCD believes that provider participation in any new care coordination or delivery model must be explicitly contingent upon the achievement of good outcomes with quality and outcome measures. As new delivery and care coordination models take shape, 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 also living at

[1] "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 *HSR: Health Services Research* 46(2), pp. 479-490.

home as independently and actively as possible? Has this person 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 Medicare and Medicaid are truly going to improve quality and health outcomes while saving money for the dual eligible population with disabilities and chronic conditions.

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

CCD also strongly encourages CMS to focus on direct measures of a patient's experience with their care. There are measurement tools that are tailored to the post-acute care environment, including a 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 provider performance with respect to people with disabilities and chronic conditions.

In addition, through the alignment process, states should work with stakeholders to develop a series of metrics for plan performance. Such performance standards should include measures addressing:

- Beneficiary access to "person-centered" planning and care;
- Access to services, including those specific to persons with disabilities;
- Quality of care;
- Choice or providers, suppliers, and medical devices and products;
- Network adequacy, including architectural and programmatic accessibility; and
- Grievance and appeal procedures to make challenges to health plan decisions timely, meaningful, and easy to pursue.

Also, repeatedly clinic staff report Medicaid-only recipients' needs are served more promptly because of the administrative burdens required to serve dually eligible persons. For dual eligibles, there is burdensome paperwork required to verify that Medicare will not cover a needed item or service as a prerequisite for gaining Medicaid coverage or reimbursement of the same. For example, Medicare does not cover adult diapers, or products needed to prevent skin, (ointments, chucks, air mattresses), which can lead to life-threatening bed-sores and greatly increased costs to the system (e.g., hospitalization, institutional care, etc.) CCD recommends that the alignment process reduce the administrative burden so that there are less timely obstacles to needed care.

Continuity: People with disabilities of all ages and their families must have access to health care that responds to their needs over their lifetimes, and provides continuity of care that helps treat and prevent chronic conditions.

Adults and children with disabilities often need long-term services and supports that enable them to live as independently as possible. A health care system that supports continuity of care:

- includes mechanisms to assure timely and quality care between health care settings and provider systems, as well as a seamless continuum between health care services and long term services and supports for people with disabilities and chronic illnesses;
- emphasizes home and community based services and, by doing so, reduces the need for and cost of institution-based care; and
- enables families to provide care for family members with disabilities of any age in the most appropriate setting.

The alignment process should advance the appropriate use of home and community based services, as opposed to institutionalization. CCD recommends the Federal Coordinated Health Care Office work with the Office on Disability and with staff of the Community Living Initiative to coordinate these efforts.

CCD appreciates the opportunity to comment on efforts to align care for beneficiaries with disabilities who are eligible for Medicare and Medicaid. Please do not hesitate to contact a co-chair with questions.

Sincerely,

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