

June 18, 2010

Ms. Monica Stevenson Attention: MCC Strategic Framework U.S. Department of Health and Human Services 200 Independence Avenue, S.W., Room 736-E Washington D.C. 20201

Re: Comments regarding HHS's proposed Strategic Framework on Multiple Chronic Conditions, 2010-2015

Dear Ms. Stevenson:

The Consortium for Citizens with Disabilities (CCD) appreciates this opportunity to comment on the proposed strategic framework on multiple chronic conditions detailed in the draft "Strategic Framework 2010-2015 Optimum Health & Quality of Life for Individuals with Multiple Chronic Conditions" (May 2010). CCD is a coalition of national consumer, service provider, and professional organizations which advocate on behalf of persons with disabilities and chronic conditions and their families.

Persons with disabilities and chronic illnesses often have health care needs of greater amount, duration and scope than the rest of the population. Many people have multiple conditions, contributing to endless variation in the complexity and severity of individuals in need of health and long-term services and supports.

The fact is that reform of our nation's health care system involves more than just covering more people for the acute care services they may need when they become ill or injured, and we strongly endorse the development and implementation of a strategic framework for the U.S. Department of Health and Human Services to improve the health status of individuals with concurrent multiple chronic conditions.

The framework must address not only primary prevention initiatives but must also include secondary and tertiary prevention. Such services are often long-term and ongoing in nature and they seek to maximize health status, full function and participation in society, employment, independent living, and the pursuit of fulfilling and meaningful lives. **CCD's overarching** 

concern is that the framework consider a spectrum of conditions, and not only diseases traditionally thought of as chronic diseases. Although we agree that the examples you have set forth in your draft are chronic conditions, we are also cognizant that there are an entire range of disabilities to be considered, from developmental disabilities to spinal cord injuries.

When co-occurring disorders are present the complexity and challenge to the individual, family, and professionals significantly increase. Combine severe, multiple and chronic disorders, including mental disorders and learning disorders, and the result can be highly disabling.

Please see our comments below regarding the four goals included in the strategic framework.

## Goal 1: Provide better tools and information to healthcare and social service workers who deliver care to individuals with MCC

It is unacceptable that many healthcare professionals feel uncomfortable with key chronic care competencies, as stated in the framework. Patients with chronic conditions must have access to trained, qualified, and appropriately credentialed health care personnel; these professionals should understand disability and function to help plan and coordinate care with the rehabilitation team as an alternative to gatekeeper case managers with no experience with disability.

Practitioners should also receive ongoing best practices training and receive up to date guidelines for treating an array of conditions. However, it is important that evidence-based guidelines are not the only measure used to identify standard treatments. In treating and managing disabilities and multiple chronic conditions, lack of evidence does not mean lack of efficacy. Consensus-based guidelines within the field must also be considered when developing best practices in chronic disease management.

## Goal 2: Maximize the use of proven self-care management and other services by individuals with MCC

People with multiple chronic conditions 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. An appropriate health care system is one that ensures services are patient-centered and consumer-directed to the maximum extent possible and one that enables families to provide care for family members with disabilities of any age in the most appropriate setting. We support mechanisms that provide a seamless continuum between health care services and long-term services and supports for people with disabilities and chronic illnesses. We support care models which emphasize home and community-based services and reduce the need for and cost of institution-based care. We also propose a new objective that addresses medical awareness and informed consumer and family involvement in medical decision making.

## Goal 3: Foster health care and public health system changes to improve the health of individuals with MCC

CCD is concerned that the current fragmented health care system contributes to substantial administrative waste and impedes the appropriate treatment of individuals with multiple chronic

conditions. An efficient health care system is one that actively manages and coordinates care for people with chronic conditions in order to improve quality and ensure the delivery of clinically effective services.

HHS should ensure new patient care models protect patients from being under-served; CCD supports the strategies described in the framework, which involve pilot testing new patient care models. CCD believes that patients would be well served by a comprehensive study of post-acute care bundling before any widespread implementation of models that bundle payments. The study must identify, among other things, the nature of protections needed for individuals under a system of bundled payments as well as the types of conditions to which bundling should or should not apply.

## Goal 4: Facilitate research to fill knowledge gaps about individuals with MCC

CCD applauds HHS for including strategies to assess the inclusion of patients with MCC in clinical trials, as well as objectives to better understand the epidemiology of MCC. The occurrence of multiple conditions must be documented and studied so that in the future these conditions can be better managed and prevented.

On behalf of the Consortium for Citizens with Disabilities (CCD), we thank you for the opportunity to comment on HHS's proposed Strategic Framework on Multiple Chronic Conditions, 2010-2015. We appreciate your work and look forward to working with you as you move forward.

Sincerely,

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