July 2, 2012

Barbara Edwards, Director
Disabled & Elderly Health Programs Group
Center for Medicaid, SHIP and Survey & Certification
Centers for Medicare and Medicaid Services
Department of Health and Human Services
ATTN: CMS-2249-P2
P.O. Box 8016
Baltimore, MD 21244

RE: Medicaid Program; State Plan Home and Community-Based Services;
5-Year Period for Waivers, Provider Payment Reassignment and
Setting Requirement for Community First Choice; CMS-2249-P2

Dear Ms. Edwards,

The National Center on Caregiving, Family Caregiver Alliance; the National Alliance on Caregiving; and the National Family Caregivers Association appreciate the opportunity to comment on the proposed rule to implement the State Plan Home and Community-Based Services (HCBS) Option/Benefit under Section 1915(i) of the Social Security Act, setting requirements under multiple Medicaid HCBS authorities and the five year period for waivers including individuals who are eligible for both Medicare and Medicaid.

All three organizations listed above represent informal caregivers of older and disabled adults through direct services, research and advocacy efforts over many decades. All organizations are national in scope and touch millions of caregivers each year directly or through educational programs, web events or visits. Our work acknowledges that informal caregivers – family members and friends – form the backbone of the long term services and support system in the U.S. All organizations work towards shared goals of recognizing and supporting informal caregivers across health and social service systems and the promotion of person and family-centered plans of care.

We commend the movement of long term services and supports away from institutional care to providing those services in the community reflecting the preference for older and disabled adults and their families. For many, living with their families in the community also represents the best and most preferred option. We recognize the complexities represented by formal and informal supports in the community environment and commend CMS for the inclusion of caregiver assessment in the proposed regulatory text of 1915(i).
We would like to comment on two sections in the proposed regulations that speak to the recognition of supports provided by informal caregivers and to the assessment of those who provide those services.

**Section 441.662 – Independent Assessment**

We support an assessment that includes, if appropriate, the family – a spouse, partner, adult child(ren), guardian, authorized representative or other individuals. This is particularly true when the client has a cognitive impairment, the presence of which should also be addressed during an assessment process. We commend the inclusion in regulatory text of a caregiver assessment “when unpaid caregivers will be relied upon to implement the service plan”.

Informal caregivers provide critical care and social supports that enable older and disabled adults stay in the community. But many face increased stress, suffer health problems linked to care demands like back injuries or feel overwhelmed with care needs for which they have received little training or instruction. Informal caregivers need to be assessed for their own needs so they may be linked with support services, education program, respite, wellness classes and other services that can extend their capacity to care.

**Section 441.665 – Person-Centered Service Plan**

We support the development of a person-centered service plan that has a focus on needs and choice. In the proposed regulations under Person-Centered Service Plan, it states that the plan must include the “services and supports (paid and unpaid) that will assist the individual to achieve identified goals, and the providers of those services and supports, including natural supports.” If appropriate, the informal caregiver(s) should be included as part of the care team and those supports provided should be noted in the care plan. This also speaks to the need for an assessment of informal caregiver needs so they may also be addressed within the care plan.

Later under this section it is noted, “Natural supports cannot supplant needed paid services unless the natural supports are unpaid supports that are provided voluntarily to the individual in lieu of State plan HCBS.” We agree to the voluntary nature of the support but also caution as to the tone of assessment or interview questions in this area. This may be an area where clarification about language and interview skills might be needed.

**Conclusion**

The National Center on Caregiving, Family Caregiver Alliance; the National Alliance on Caregiving; and the National Family Caregivers Association appreciates the opportunity to comment on these important proposed regulations regarding assessment of informal caregivers and inclusion of informal caregivers within the Person-Center Service Plan. Family Caregiver Alliance (FCA), in particular, would be happy to provide information specific to assessment of informal caregivers if needed in the future. FCA has significant expertise in this area developed over years of system development experience and research.
Thank you in advance for your consideration of our comments. If you have questions, please feel free to contact Kathleen Kelly, Executive Director, National Center on Caregiving, Family Caregiver Alliance at (415) 434-3388, X 309 or kkelly@caregiver.org.

Sincerely,

Kathleen Kelly  
Executive Director  
National Center on Caregiving  
Family Caregiver Alliance

Gail Hunt  
CEO  
National Alliance for Caregiving

John A. Schall  
President and CEO  
National Family Caregivers Association