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February 18, 2008

Department of Health & Human Services
Centers for Medicare & Medicaid Services
Attention: CMS-2229-P
P.O. Box 8016
Baltimore, MD 21244-8016

RE: CMS-2229-P Medicaid Program; Self-Directed Personal Assistance Services Program State Plan Option (Cash and Counseling)

The Association for Home & Hospice Care of North Carolina is the largest and one of the oldest state associations in the nation representing the nurses, social workers, therapists and aides that serve more than 200,000 Medicare/Medicaid beneficiaries across the state. Thank you for the opportunity to review the Consumer Directed Personal Assistance Services (PAS) Proposed Rule. Please accept the following comments and recommendations.

General Comments ~
We recognize the value of preferences and choice, as they are foundations of person-centered care. A Self-Directed Personal Assistance Services (PAS) Medicaid option may be a viable alternative for some Medicaid recipients, such as a young disabled individual (i.e., spinal cord injury individual who is medically stable, with good cognition, and financially savvy). We also recognize the value of appropriate regulated oversight that offers support and protection to agencies and the consumers they serve.

Literature contends that an individual self-directing his/her preferences and needs leads to increased satisfaction, but may not lead to lower overall costs. Specifically, creating a new or adding to the existing oversight infrastructure will add additional costs to the programs.

Thoughtful and balanced consideration is warranted on this issue. Specifically addressing the following:

- **Federal Comparability** ~ It is critical that the proposed Medicaid option does not create obstacles and barriers to care. Specifically, individuals who chose the agency model for their personal care should not be put at a disadvantage by having stricter criteria or more burdensome requirements than those offered to consumers directing his/her own care. The Federal comparability requirements should not be waived between agency PCS and family/private arranged PCS.

- **Viability of the Home Care Infrastructure** ~ The majority of the Medicaid recipients would not be appropriate for consumer directed care; and the migration of those for whom the self-directed option is appropriate, would further stress the viability of the home care infrastructure. The challenge is the creation of a model that sustains a viable traditional provider base for those who could not self-direct as well as for those who are appropriate for self-direction and choose it. The sustaining of traditional models is especially important in rural areas or difficult to serve areas. If these agencies cannot remain viable, then the option for traditional use consumers would no longer exist.

- **Critical Mass** ~ The majority of agencies currently providing personal care services (PCS) under the Medicaid option provide it at or above their margin, i.e., at a loss. And many struggle to maintain a sufficient critical mass to break even on the program. Decreasing the number of eligibles in the program will have a direct correlation to increased agency costs and the need for States to increase the in-home aide rates in the traditional models. Providers may not be able to accept patients where they are operating at a loss. This would limit access, especially in rural communities, and force patients into a more expensive option, such as a skilled nursing facility (SNF) or would delay hospital discharges.

- **Migration to Private Pay** ~ We have seen a migration of agencies to serving predominately or only private pay clients due to the low Medicaid reimbursement rates and the cuts in service hours. As an agency's critical mass drops, the agency's costs increase forcing the agency to make business decisions that create access issues for Medicaid recipients and prematurely force beneficiaries into more costly alternatives.

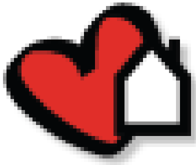
Specific comments to the proposed regulations are attached. Thank you for the opportunity to comment on this proposed rule. We appreciate CMS' continued open dialogue through the teleconferences and *Open Door* forums. As related to the Consumer Directed Care proposed rule, careful consideration is warranted due to the seriousness and extent of the changes. Providers may not be able to accept patients where they are operating at a loss. This would limit access, especially in rural communities, and force patients into a more expensive option, such as a skilled nursing facility (SNF) or would delay hospital discharges.

Should you require clarifications on any of our comments please contact Tracy Colvard, Director of Government Relations & Public Policy via phone at 919-848-3450, or via email at tracycolvard@homeandhospicecare.org.

Sincerely,

Timothy R. Rogers
Chief Executive Officer
Board Member, National Association for Home Care & Hospice

ATCH: CMS-2229-P Comments



Association for Home & Hospice Care of North Carolina's Comments On CMS-2229-P: Medicaid Program, Self-Directed Personal Assistance Services Program State Plan Option (Cash and Counseling)

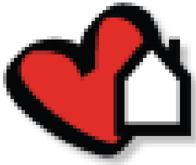
The Association for Home & Hospice Care of North Carolina (AHHC) is a thirty-six year old non-profit trade association that advocates for in-home care. Our State has required home care licensure since 1990 - ensuring standards of care statewide. We also have polices in place in our Medicaid Personal Care Program that require uniform assessment and assignment of service needs based on national standards – so that decisions regarding the amount of personal care hours a patient might receive for care a month are fairly determined and applied for all patients.

Our association has a long history of supporting patients and families and seeking alternatives to institutionalization. We recognize the value of patient centered care and consumer choice and consumer involvement in need assessment, care planning and delivery. **We strongly support that in all models of care that there are mechanisms in place that ensure the consumer receives the services that are needed to be able to remain independently at home while minimizing the opportunity for fraud, abuse, neglect and overspending.**

We also request that as CMS moves forward that they do so with thoughtful consideration and that they formulate policies and programs that do not harm existing infrastructures of traditional care – many rural, non-profit and health department based. Therefore, our comments will be related to these issues.

441.454 -Use of Cash ~

Compliance with IRS employer requirements is a laborious task for agencies. Allowing consumers, directing his/her own care; the option to be responsible for these reporting requirements puts the consumer at risk with the IRS. **The states using the financial manager option adds an additional administrative layer and costs associated with monitoring these activities.** We also do not believe that it is wise for CMS to allow so many hours in a cash model that the amount of hours received by the patient is to meet a desired "paycheck" of a family member or friend versus hours truly needed to deliver care. For example, our newspaper recently ran a story about an individual currently in North Carolina's Community Alternatives Program for the **Mentally Retarded and Developmentally Disabled.** The father is receiving payment for 105 hours a week of care for his son with Cerebral Palsy. That amount of hours seems questionable as the father appears to only be assisting with activities of daily living. The State agency has made the decision to cut the father's hours to 50 hours a week in order to prevent caregiver burnout. We estimate that this father has received over a half a million dollars over the 12 years of caring for his son. That level of expense cannot be sustained by State Medicaid programs. It seems obvious that the amount of hours met the father's "paycheck need" but probably exceeded hours needed to deliver personal care. **The concern is that it took the State twelve years to act on this. Without proper oversights, these same issues will be repeated in other cash models.**



441.456/460 -Voluntary and involuntary disenrollment and participant living arrangement
No additional comments

441.462 – Statewideness, comparability, and limitations on numbers served ~

We believe that the implementation should be gradual and the numbers limited in order to both independently study the impact of the program and impacts on health outcomes. CMS should start with patients currently residing in rest homes and nursing homes as an incentive for States to save money and deinstitutionalize people. As this support other CMS initiatives, such as Money Follows the Person.

Current PCS policies in individual states need to be changed to "level the playing field" between the proposed model and traditional models for consumers. For example, current NC policies do not allow agencies to employ family members and do not allow aides to transport clients to medical appointments. Policy changes such as this would ensure comparability of services for consumers who don't want the responsibility of the employment issues but would like to use a family member and have transportation as a benefit through an agency. **Again, the amount of hours available for care should also be comparable.**

441.464 - State Assurances ~

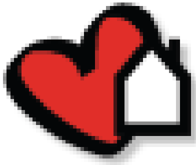
Because the public should expect the federal and state governments to ensure the same level of assurances for public dollars spent on consumer directed care as they do for traditional models of care, CMS should require the following:

- Mechanisms for reporting caregiver abuse and neglect for consumers who direct their own care. These mechanisms already exist for agency care.
- Background checks and drug screening of caregivers
- Competency verification by a licensed heath professional for certain specified levels of care
- Compliance to Board of Nursing standards where required
- Independent audit of both care delivery and health outcomes

441.466 -Assessment of Need ~

The proposed 15 minute time allowed explaining the option of Consumer Directed Care is too brief.

Need assessment should be standardized for all patients seeking PCS regardless of the model chosen for care delivery. Need assessment should be performed by registered nurses as functional limitations are closely aligned with medical conditions and disease. Need assessment should be based on the KATZ scale and the amount of assistance needed should be based on a national standard such as the MDS.



441.470/472 - Service Budget Elements ~

The service budget should not exceed what is currently available to clients in traditional care models. It should be based on a uniform assessment. Agency directed care has state utilization and quality assurance controls in place to monitor the care to ensure that the recipient is receiving the care that is being billed for and that it meets defined quality standards. NC agencies also have to provide cost reports to Medicaid to justify their costs. Consumer directed care should have those same oversights of the service budget. And, service budgets must be comparable.

441.474 -Outcome Measurement ~

We applaud that the proposed rule at 441.464(a) requires the states to develop outcomes beyond consumer satisfaction. We encourage the development of outcome measures that prevent deterioration or worsening of health conditions, or premature institutionalization.

441.476 -Risk Management ~

Workers in consumer directed should be protected by Worker's Compensation and have access to unemployment insurance. Since the consumer would not be bound to provide these benefits, what would the worker, who was injured on the job, do to pay for injuries sustained on the job. This will add additional costs to the State in ensuring worker protections. Will privately hired consumer directed employees be aware of these limitations on their employment?

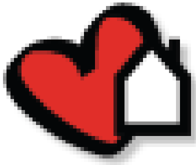
441.478 - **Qualifications of providers of personal assistance ~**

Because the public should expect the federal and state governments to ensure the same level of assurances for public dollars spent on consumer directed care as they do for traditional models of care, CMS should require the following:

- Mechanisms for reporting caregiver abuse and neglect for consumers who direct their own care. These mechanisms already exist for agency care.
- Background checks and drug screening of caregivers
- Competency verification by a licensed heath professional for certain specified levels of care
- Compliance to Board of Nursing standards where required

441.480 - **Use of a Representative ~**

A mechanism needs to be in place to ensure that the needs of the consumer are met rather than the needs of the representative. There should never be financial gain for the representation of the consumer.



441.482- Permissible Purchases ~

Although we see the value of flexibility in how the money is used in consumer directed care, strict oversight guidelines must relate the purchases back to an assessed need. Purchases must be restricted to those that relate to the medical condition of the client. Individuals in traditional models of care should have access to the same purchase options.

441.484 - Financial Management Services ~

Careful consideration should be given to whether or not this adds considerable more administrative costs to State Medicaid budgets. Will the costs to the State's increase because of additional oversight needed such as hiring case managers, counselors, fiscal intermediaries, etc.

Should you require clarifications on any of our comments please contact Tracy Colvard, Director of Government Relations & Public Policy via phone at 919-848-3450, or via email at tracycolvard@homeandhospicecare.org.