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A D A P T

FREE OUR PEOPLE

**Nancy-Ann Min DeParle, Administrator
Health Care Financing Administration
Dept of Health and Human Services
Washington, D.C. 20201**

August 11, 1998

ADAPT appreciates your July 22, 1998 response to our letter on the institutionally biased long term care system in the United States.

ADAPT response will follow the format of your letter by addressing your written answers to our concerns one by one.

Response 1

ADAPT believes the letter to the State Medicaid Directors by Sally Richardson was a positive step in directing States to comply with the ADA's "most integrated setting" mandate. Though a good first step ADAPT believes that the State's have ignored and continue to ignore the "most integrated setting" mandate of the ADA as it relates to nursing homes, ICF-MR/RC facilities and home and community services. ADAPT believes HCFA can promulgate regulations directing States to update their self-evaluation to take the "most integrated setting" into consideration. Your statement that regulations issued by the US Department of Justice are sufficient will only lead to litigation that could be avoided if HCFA would give States direction.

ADAPT again demands that you issue regulations implementing "the most integrated setting" mandate as it relates to long term care services.

Response 2

ADAPT believes that any series of town meetings should have as its purpose some public policy purpose. People with disabilities have for years been advocating for a change in the institutionally biased long term care system with no action occurring. ADAPT needs your assurance that these meetings have as its end purpose to make fundamental changes in the institutionally biased long term care system. Will you give us that assurance?

ADAPT believes that, if these series of town meetings occur, to adequately "listen" to people with disabilities there must be at least 8 "listening sessions". Locations should be Atlanta, Boston, Chicago, Dallas, Denver, Kansas City, New York City and San Francisco. Stipends should be available so low income people from rural and surrounding areas can attend. Disability organizations in each area should have a significant role in outreaching and putting on these "listening sessions".

Response 3

ADAPT believes that UCSF contract is only the first step in reviewing the institutionally biased long term care system. HCFA has ignored these issues for years and must take affirmative steps to change the institutionally biased long term care system. ADAPT wants HCFA to identify the recommendations in the UCSF report that it will implement and a timetable for their completion.

ADAPT has communicated to President Clinton our disbelief in what HCFA did to the "Date Certain" concept. This demonstration, as now configured, has no relation to what ADAPT had proposed or what Chris Jennings understood. Though ADAPT member Bob Kafka agreed to be one of the reviewers of the proposals he is doing so as an individual not representing ADAPT. ADAPT wants to make it clear to HCFA that the \$2 million dollars that Senator Specter directed HCFA to use for innovative consumer-directed attendant service programs was to be taken from existing appropriations. The money used for "Date Certain" must not be confused with this \$2 million dollars.

ADAPT demands that HCFA allocate \$2 million dollars for innovative consumer-directed attendant service programs. ADAPT again recommends that there is a need for a composite of "best practices" in the delivery of consumer-directed attendant service programs that can be disseminated to progressive providers as well as the home health industry. Will HCFA develop an RFP for the above purpose?

Response 4

ADAPT has worked well with HCFA in the past and will continue to do so if HCFA commits to changing the institutionally biased long term care system. Technical assistance on how to change the institutionally biased long term care system is helpful but unless HCFA takes regulatory actions the system cannot change.

Please respond by September 9, 1998.

For an Institution Free America

M.W. Kubejger

Stephanie Thomas

Bob Kafka

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