

President's 2004 Proposed Budget

Centers for Medicare and Medicaid Services
New Freedom Demonstrations

RESPIRE

Respite care can take many forms, although its essential purpose is to provide community-based planned or emergency short-term relief to family caregivers from the demands of ongoing care. Care may be provided in the family home, in the respite provider's home, day programs, or in some cases, community-based or institutional facilities. Respite services might last from several hours to several days. Without respite, family caregivers who are forced to stay at home to provide care experience significant stress, loss of employment, financial burdens, and marital difficulties. Many caregivers report that it is not safe to leave their family member at home alone, they are unable to leave their family members with another relative, and they face barriers in accessing generic day care or companion services. To be effective, respite services should be responsive to individual needs and offer the opportunity for consumer direction.

Consumer direction is a concept that rests on the premise that individuals with a disability should (a) be able to make decisions about the care they receive, (b) have control over the nature of the services, and (c) determine how those services are delivered. Consumer direction is not one strategy, but reflects a continuum of approaches based on the level of decision-making, control, and autonomy allowed in a particular situation. Consumer direction in this context is more broadly defined than self-direction, which might require person centered planning, individualized budgets, participant protections, fiscal/employer agent service, brokerage services, and a quality assurance and improvement plan.

Choice is the overarching theme that has emerged from studies about consumer preferences in respite services. Families and individuals have expressed a desire to be able to choose from a variety of respite options that meet the needs of their families across time and as their circumstances change. Some caregivers prefer short but frequent respite services to attend to errands or other family members, or to take a night off. Families have identified the need for both in-home and out-of home respite. Caregivers consistently identify a need for both emergency and longer-term respite.

A number of different respite models are in practice, and their services (both planned and emergency) typically vary across four dimensions: purpose, duration, location, and provider:

- (1) **Purpose.** The purpose of respite lies in the intent to either (a) provide the family with relief from caregiving or (b) meet the needs of the individual with a disability (in this case respite occurs as a by-product, such as when a person participates in a recreational program).
- (2) **Duration.** Short-term respite usually provides relief for a few hours, while longer-term programs might provide care for a period of several days or more.
- (3) **Location.** The location of the respite service may be in-home, in a respite provider's home, in a community-based facility, or in an institutional setting.

- (4) **Provider.** Respite services might involve paid professional caregivers who have special training or a cooperative and informal system utilizing friends and relatives who are paid to provide respite.

Medicaid has a critical role to play in achieving community living and integration for individuals with a disability or long-term illness. A self-evaluation by HHS determined that the unmet support needs of family caregivers were one barrier to community living for individuals with a disability. When caregivers of an individual with a disability become overwhelmed with the demands of caregiving, the individual may be forced to leave his or her home for a less desirable, more restrictive environment. Respite services that provide a temporary relief for caregivers enable individuals with a disability to remain in the community.

DEMONSTRATION TO IMPROVE THE DIRECT SERVICE WORKFORCE SUMMARY

Background

The Centers for Medicare and Medicaid Services (CMS) has a critical role to play in achieving community integration for individuals with a disability or long-term illness. The success of initiatives to improve community supports hinge largely on the availability of an adequate community-based infrastructure, including well-trained direct service workers. Direct service workers include personal care attendants (PCAs), certain Assertive Community Treatment (ACT) team members, home health aides and others who support individuals with disabilities by assisting with activities of daily living (ADLs). The supply of these workers will be increasingly stressed as the demand for long-term care services rises and the supply of traditional caregivers falls.

Nationally, there is a well-documented shortage of personnel. Over the next ten years, the Bureau of Labor Statistics predicts a 39% growth in the direct service worker occupations. This is due partly to the aging baby boom generation that will need more access to direct service supports over that ten-year period. Though the need for direct service workers is expected to grow at this high rate, the general pool of workers in the United States is expected to remain stable. The goal of the Demonstration to Improve the Direct Service Workforce is to provide some funding to pilot potential workforce recruitment and retention strategies.

Demonstration

CMS has committed, under the New Freedom Initiative, to seek Congressional approval for demonstration funds. Congress appropriated \$6 million in funding from the FY 2003 research budget to begin a direct service worker demonstration. CMS anticipates being able to continue the demonstration with additional funding from the FY 2004 research budget, if adopted by Congress.

Many recruitment and retention strategies have been suggested by researchers and other professionals. This demonstration is intended provide funding to test some of the hypotheses. Due to the size of the demonstration, it will by necessity be geared to support practical projects of limited scope that can be expected to have direct impact on the workforce. CMS staff have collected ideas from the literature and through provider and consumer interviews. The following list represents a sampling of these project suggestions:

- Partner with an existing health insurance pool to provide health care benefits to workers,
- Implement a system to increase worker wages through hierarchy or performance based systems,
- Develop continued training/education programs that will enhance the skills of the current workforce and encourage current students to seek employment in the direct service worker field,
- Create time-off or leave based programs that will alleviate the strain and demand placed on workers within the rigorous direct service occupation,
- Address underserved linguistic groups, through hiring bilingual supervisors, developing written employment and marketing materials in the target language(s), and/or providing employees with English language classes, child care, tuition vouchers, health care, etc.,
- Provide culturally competent services that will resolve potential cultural boundaries which may discourage people of diverse backgrounds from becoming a direct service worker,
- Recruiting underserved populations such as college students, retirees, TANF recipients, or individuals with disabilities,
- Addressing rural transportation barriers by subsidizing direct service worker transportation costs.

Robert Wood Johnson Foundation Initiative

HHS is coordinating its work in this arena with the Robert Wood Johnson Foundation. The Robert Wood Johnson Foundation has co-sponsored with the Atlantic Philanthropies the “Better Jobs, Better Care” program. This initiative is focused on changes in policy and practice that will lead to increased recruitment and retention of direct service workers. The initiative has two parts: an applied research program to evaluate workplace innovations; and a demonstration program to test policy changes and practice interventions. Additional information about the “Better Jobs, Better Care” program may be found at www.futureofaging.org.

Every effort will be made by CMS to coordinate the Demonstration to Improve the Direct Service Workforce with the demonstration portion of the “Better Jobs, Better Care” program.

DEMONSTRATION OF COMMUNITY-BASED ALTERNATIVES TO PSYCHIATRIC RESIDENTIAL TREATMENT FACILITIES FOR CHILDREN

Background

Medicaid provides inpatient psychiatric services for children under age 21 in hospitals. The statute also extends these Medicaid benefits to children in psychiatric residential treatment facilities. However, psychiatric residential treatment facilities are not considered to meet the definition of hospital so they do not qualify as institutions against which States may measure 1915(c) waiver costs. Over the last decade, psychiatric residential treatment facilities have become the primary provider for children with serious emotional disturbances requiring an institutional level of care. However, since they are not recognized as hospitals, States have been unable to use the 1915(c) waiver authority to provide home and community-based alternatives to care, which would keep the children in their homes and with their families.

Demonstration

As part of Delivering on the Promise, CMS proposed to create an evaluated 10-year home and community-based services demonstration as an alternative to Medicaid funded psychiatric residential treatment facilities. The President's FY 2004 budget request included funding for this demonstration program and CMS expects that the corresponding authorizing legislation will also be submitted to Congress.

It is believed that extending home and community-based services (HCBS) as an alternative to residential treatment facilities would allow children to receive treatment in their own homes, surrounded by their families, at a cost per child which would be less than the cost of institutional care. The demonstration, while limiting federal financial exposure by capping the total demonstration participation, will allow CMS to develop reliable cost and utilization data. That data will be used to evaluate the impact of the provision of Medicaid services on the effectiveness of community placements for children with serious emotional disturbance. The data would also serve as a useful predictor of what would be expected if permanent authority is granted for the HCBS waiver as an alternative to psychiatric residential treatment centers.

1915(c) Waiver Authority v. Demonstration

The Demonstration of Community Based Alternatives to Psychiatric Residential Treatment Facilities for Children would test the use of 1915(c) waiver authority but there are several differences. Among them are that the Demonstration will last for 10 years and will not be renewed every 3 or 5 years; the Demonstration will be evaluated; the Demonstration is fixed cost and will have a national enrollment target; and the Demonstration will have a maintenance of effort requirement. Additionally, there may be specific participation requirements involving coordination and adequacy of State plan

services, and quality improvement and assurance, however, these design elements will be largely controlled by the legislation creating the demonstration.