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Defining Respite Care

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Defining Respite Care

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Summary

This technical assistance document is the first in a series of papers that examines issues pertaining to respite services as part of the Medicaid program. By reviewing the prevalent definitions of respite in the published literature and federal documents, we seek a consistent view of respite services that can be used in the development of administrative policies to support respite for Medicaid HCBS beneficiaries and their informal caregivers. To stimulate discussion, we address policy implications and recommendations.

Major Points

- The contribution of family care to older adults and people with disabilities is estimated to be \$257 billion annually.
- The availability of Medicaid-financed intervention services like respite may help to sustain informal caregivers and prevent or postpone costly nursing facility placements of the persons for whom they provide care.
- The lack of consensus regarding respite services may result in lack of access for potential beneficiaries, non-coordination of benefits, and underutilization of services, with the possible outcome of over-burdened caregivers relinquishing their responsibilities to governmental and institutional facilities.
- A more consistent definition of respite care would benefit both the delivery of outcome-based services and policy analysis.
- Examination of the legislation that introduced respite into the HCBS waiver reveals what appears to be an intentionally broad, open-ended representation of respite services. There appears to be agreement in both federal and published literature that its primary intent is to provide the effect of delivering relief or a rejuvenating benefit to the caregiver.
- Policymakers have traditionally designed entitlement programs for persons with disabilities that are allocated based upon the exclusive needs of that person. Respite introduces complexities because it is a service that benefits the welfare of the entire family. This is a significant policy shift towards family versus individual outcomes.
- Eligibility for respite services should include assessment of caregivers' capacity for providing a range of supportive activities beyond help with activities of daily living measured by the "functional needs" of the person receiving support.
- Consumer-directed or direct pay programs, where Medicaid beneficiaries control the budget and selection of their supportive service and service provider, could improve informal caregivers' access and use of respite.

Background

Since 1970, State Medicaid agencies have been required to provide coverage for home care services for those individuals eligible for nursing home care. Since then the home care and supportive services provided through Medicaid have evolved to enable states to offer a wide range of service options. Part of this expansion in coverage has been provided under the 1915(c) waiver authority. These waiver programs, mandated in section 1915(c) of the Social Security Act (SSA), enable states to provide long-term home and community-based services (HCBS) not always covered through the state's Medicaid State Plan, as long as provision of these services enables the individual with disabilities to remain in the community at a cost no greater than what would alternatively be required for nursing facility care. Services covered under waiver programs include: case management, homemaker, home health aide, personal care, adult day health, habilitation and respite care.¹

Long-term care benefits are a substantial expense for state and federal funding programs. Medicaid spending for long-term care of older adults and people with disabilities has continued to grow, from \$33.8 billion in fiscal year 1991 to \$75.3 billion in fiscal year 2001. Over this same time, HCBS waivers grew from 5 percent to 19 percent of total expenditures. Since 1992, the number of HCBS waivers increased by almost 70 percent to 263 in June 2002, and the number of beneficiaries, as of 1999, had nearly tripled to almost 700,000.²

Offsetting this substantial growth in Medicaid support for long-term care, the U.S. Department of Health and Human Services documented that about 64 percent of direct care for people with disabilities is provided by informal caregivers, rather than being derived from paid sources. Among elderly persons needing assistance with activities of daily living, 95 percent have family members involved in their care.³ It is estimated that the cost to replace the entire population of informal caregivers would total \$257 billion annually.⁴

From an economic perspective, it behooves state and federal agencies to provide support to informal caregivers by alleviating some of the physical and emotional strain that they experience as an outcome of providing in-home care services. The availability of Medicaid-financed intervention services may help to sustain informal caregivers and prevent or postpone costly nursing facility placements of the persons for whom they provide care.⁵ Caregiver support services could prevent adverse health consequences for caregivers that would necessitate them utilizing Medicaid or other services.

¹ U.S. Department of Health and Human Services (2000).

² U.S. General Accounting Office (2003).

³ U.S. Department of Health and Human Services (2001).

⁴ Arno (2002).

⁵ Kosloski & Montgomery (1995); Hasselkus & Brown (1983); Smyer & Chang (1999); Brody, Saperstein & Lawton (1989).

types and amounts of respite offered, service models, and staffing patterns.”⁹ Despite new respite programs funded by many states and the National Family Caregiver Support Program, divergent funding and terminology still confound consumers and program administrators today.

This assessment is substantiated by states in written grant proposals made to CMS in 2003, requesting funds to study the feasibility of providing respite support to Medicaid beneficiaries. States cited the following issues in developing Medicaid funding programs for respite services:

- The current provision of respite services through the state is “neither cost-efficient nor consumer friendly.”
- Because there is “no universal federal respite program available as a Medicaid benefit or an alternative funding source, state respite services have been provided through local levy funds or system specific grants, with significant variation in respite services.”
- The current care system for providing respite is “clearly fragmented among various agencies of State and local government.”
- Families using currently available respite services “report that there is no clear centralized source of information about respite and other family support services,” with the outcome that they are “confused by the system about where to turn when seeking help.”
- Formal respite providers within the varied existing programs “have a wide and uneven range of skills to provide the service. Training requirements are uneven across programs, as is the quality of the care.”

In order for respite programs to deliver services to persons with disabilities of all ages and their in-home caregivers, these issues will need resolution. Problems such as these, largely based in a lack of consensus regarding respite services, may result in a number of administrative issues, including lack of access for potential beneficiaries, non-coordination of benefits, and underutilization of services, with the possible outcome of over-burdened caregivers relinquishing their responsibilities to governmental and institutional facilities.

Respite Defined in Federal Documents

Examination of the legislation that introduced respite into the HCBS waiver reveals what appears to be an intentionally broad, open-ended representation of the respite services. Historically, in 1981, with the enactment of Section 1915(c) in Title XIX: Grants to States for Medical Assistance Programs of the Social Security Act (SSA), Congress authorized states the option of funding home- and community-based services to individuals who would otherwise be eligible for long-term facilities-based assistance. The limits of these services are not clearly bounded within the waiver legislation. Respite is

⁹ Brody, Saperstein & Lawton (1989), p. 43.

specifically named as a covered service in the SSA, along with “such other services requested by the states as the Secretary may approve,” with the caveat that these services are necessary to avoid institutionalization and are cost-neutral.¹⁰ The only specific qualifier for respite services in the SSA Section 1915(c) is that “except as provided under paragraph (2)(D), the Secretary may not restrict the number of hours or days of respite care in any period which a state may provide under a waiver under this subsection.”¹¹ An electronic search of the SSA revealed no other definitions of respite, other than in Sections 1813(a)(4)(A)(ii) and 1861(dd)(1)(G), referring to hospice care.

In an interpretation of the statute, found in the Code of Federal Regulations for Public Health, there again is a list of covered HCBS that includes respite. Broadly, according to the CFR, HCBS “means services, not otherwise furnished under the State's Medicaid plan, that are furnished under a waiver granted under the provisions of part 441, subpart G of this chapter.” Again the definition of specific services, including respite, is left open such that “[t]hese services may consist of any or all of the services listed in paragraph (b) of this section, as those services are defined by the agency and approved by CMS.”¹²

Another source reviewed in this analysis for definitional boundaries was the standardized Medicaid HCBS waiver application, initially introduced by CMS in the early 1990s to facilitate states’ waiver requests. In the June 1995 version of the Section 1915(c) Home and Community-Based Services Waiver Application, respite is included several times in lists of commonly requested home- and community-based services for state programs. In Appendix B of the form, respite is defined as “services provided to individuals unable to care for themselves; furnished on a short-term basis because of the absence or need for relief of those persons normally providing care.” However, that definition becomes less restrictive when the applicant is offered the option to specify “Other” respite services descriptions that may qualify outside of the “standard” definition.¹³

The application does offer suggested locations for covered respite services, including an individual’s home, foster home, Medicaid certified nursing facility (NF), Intermediate Care Facility/Mental Retardation (ICF/MR), or licensed respite care facility. But again, the door is left open for other acceptable locations with the selection option of “Other community care residential facility approved by the State that is not a private residence.”¹⁴

Another definition of respite, applied specifically to people with mental and developmental disabilities, was offered in 1972 by the U.S. Department of Health, Education and Welfare (HEW) Social and Rehabilitation Services, Rehabilitation Services Administration, Division of Mental Retardation as:

¹⁰ U.S. Department of Health and Human Services (2000), p.13.

¹¹ Social Security Act, (2003).

¹² 42CFR440.180, p. 246.

¹³ CMS (1995), p. 16.

¹⁴ Ibid., p. 17.

Appropriate services, in a variety of settings, provided for the care of the mentally retarded person through temporary separation from his family, in or outside the home, for short, specified periods of time on a regular or intermittent basis, for the purpose of relieving the family of his care in order to: 1) meet planned or emergency needs; 2) to restore or maintain his physical and mental well-being; 3) initiate training procedures in or out of the home.¹⁵

Another more detailed definition comes from an Administration on Aging (AOA) Fact Sheet, which cites respite as a specific component of services put into place through the enactment of the Older Americans Act Amendments of 2000 (Public Law 106-501), establishing the National Caregiver Support Program. Respite is described as, “for example...provided in a home, an adult day-care or over a weekend in a nursing home or an assisted living.” The Fact Sheet adds that “[r]espite can cover a wide range of services based upon the unique needs of the caregiver,” with examples being medical or social adult day-care and/or a short-term stay in a nursing home or assisted living facility, a home health aide or home health companion, a private duty nurse or adult foster care.” Additionally, the idea that respite provides an opportunity for the caregiver to “rejuvenate him or herself” is emphasized.¹⁶

Finally, some definitional guidelines for respite can be found in the President’s 2004 Proposed Budget, in a section targeted at CMS funding. In proposals for National Demonstration Grants for adult and children’s respite programs supporting the New Freedom Initiative, the following explanation of respite was offered:

Respite 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 may last from several hours to several days.

Consumer Direction and Respite

Adding to the definition of respite, within the text of the President’s 2004 Proposed Budget, it is noted that the effectiveness of respite is contingent upon its responsiveness to individual needs, emphasizing the importance of employing “consumer direction.” Consumer direction is defined as a concept based on the premise that individuals with disabilities should: be able to make decisions about the care they receive; have control over the nature of the services; and, determine how those services are delivered.

The suggestion to employ the consumer directed model for determination and distribution of benefits for respite services, contained within a document generated by the

¹⁵ Parham, Hart & Terraciano (1983), p. 1.

¹⁶ Administration on Aging (2004).

Respite, one of a range of support services that may be offered to sustain families in their caregiving role, is included as a Medicaid benefit that states can offer to eligible individuals through HCBS waivers. Respite has been documented as one of the critical services required by families that provide long-term in-home care for relatives with disabilities.⁶ Almost every state with an HCBS program approved by the Centers for Medicare & Medicaid Services (CMS) offers respite services. These states face the challenge of defining how those services will be delivered to recipients.

This paper, part of a series of papers examining issues pertaining to respite services that are part of the Medicaid program, reviews the prevalent definitions of respite in published scholarly and professional literature, and federal documents. The goal is to determine whether there is a consistent view of respite services that can be used in the development of administrative policies to support respite for Medicaid HCBS beneficiaries and their informal caregivers. Policy implications and recommendations will be addressed.

Why Define Respite?

In general terms, *respite* refers to an opportunity for rest, cessation or reprieve from the ordinary duties of life. In the context of long-term care, with some variation in approach, it describes a service that provides a caregiver with temporary, intermittent, and substitute support services. Its goal is to provide the caregiver with relief from the daily responsibility of attending to the individual with disabilities and to enable the caregiver to attend to a more normalized routine and responsibilities.

While these general definitions are informative, they may not adequately serve the needs of federal agencies, states, and caregivers in the development of policies and funding practices necessary to effectively deliver respite services. To streamline waiver application approval processes and maximize the benefits delivered to recipients, a more consistent view of what comprises respite may be required.

There has been a substantial level of discussion concerning issues arising from the broad range of options that can be classified under the umbrella of respite.⁷ For instance, questions regarding whether adult day care or homemaker services qualify as respite is an ongoing issue. The ambiguity associated with defining this concept has been identified as a possible contributor to an observed inconsistency in funding and policy development for respite services to families whose members provide long-term in-home health care.⁸ Reports published 15 years ago, that cited significant policy issues resulting from a lack of clarity in defining respite, still ring true today. Brody and her colleagues noted that respite “programs are diverse, varying from one another not only in sources of funding but also in the definition of respite, target population(s), eligibility criteria, auspices,

⁶ Starkey & Sarli (1989); Gwyther (1986); Chan & Sigafos (2000); Montgomery, Marquis, Schaefer & Kosloski (2002).

⁷ Smyer & Chang (1999); Montgomery & Prothero (1986).

⁸ Butler & Friesen (1988); Vladek (2004).

executive branch of the federal government, could be viewed as an indication of support for a very broad and inclusive view of respite. Viewed in concert with the open-ended representation of respite in the SSA, the possibility appears to exist for consideration of the adoption of the consumer directed model by CMS.

The Presidents 2004 Budget Proposal also notes that respite services typically vary across the following four dimensions:

- *Purpose:* Lies in the intent to either (a) provide the family with relief from caregiving, or (b) meet the individual needs of the individual with a disability (as a by-product, as during a recreational program for the disabled individual);
- *Duration:* Can be short- or long-term;
- *Location:* May be in-home, in a respite provider's home, in a community-based facility, or an institutional setting; and,
- *Provider:* Might involve paid professional caregivers with training or a cooperative and informal system utilizing friends and relatives who are paid¹⁷

Summary of Federal Definitions

Federal documents present a view of respite that can be organized in the following categories:

- *Purpose/Activity:* Within the SSA statute, the CFR and the standardized HCBS waiver application, respite is positioned as primarily serving the needs of the individual with dependencies and/or disabilities. However, the standard HCBS waiver expands the purpose of respite to include consideration for the "relief of those persons normally providing care," thereby introducing the caregiver into the realm of consideration. In the HEW, AOA and President's 2004 Budget Proposal, there is recognition that the purpose of respite includes the perpetuation of the caregiver's well-being. References are made to provision of services "based on caregiver need," intended for "relief to family caregivers" and providing the opportunity for the caregiver to "rejuvenate" as primary goals. The President's 2004 Proposed Budget, which is a document directly associated with CMS operations, notes that the purpose of respite is to "provide the family with relief" either directly, or indirectly as a "by-product" or outcome of meeting the needs of the person with a disability. It also introduces "consumer direction" as a guide for determining services.
- *Duration:* In all of the documents that offer definitions of respite, it is described as having a short-term or temporary duration, without any stipulation on how long each occurrence should last. HEW expands the definition to include either "regular or intermittent" occurrences, while the Presidents 2004 Proposed Budget specifies that both "planned or emergency needs" qualify as respite. The SSA and CFR do not provide any definitive duration specifications.

¹⁷ CMS (2003).

- *Location:* The site where respite may be provided, noted in all documents that offer a specification or example, includes a broad spectrum of possibilities ranging from the home of the individual to a number of different community and/or institutional settings. The SSA and CFR do not provide location specifications.

Respite Defined in Published Literature

In comparison to definitions provided in federal documents and legislation, the published literature offers a much richer and more detailed description of respite. Many of these descriptions arise from case studies of organizations that have provided respite services either through private or state programs. However, some of the most recent literature advances explanations and definitions of respite that are evoked from a theoretical base within the social sciences.

Across most of the published literature, respite care is defined as occurring in two forms:

- Informal respite services, where family and friends provide caregiver relief, including activities such as custodial supervision, companionship, personal care, meal preparation, household chores, financial aid, transportation and help in dealing with bureaucratic forms and services.¹⁸
- Formal respite services are those delivered by paid professional and paraprofessional caregivers.

The literature also identifies two primary situations where respite is appropriate:

- When a family member or friend is providing care for an individual with disabilities, chronic illness or other special needs.
- When a child is at risk of abuse or neglect, and temporary relief of a parent or guardian is primarily intended to prevent that occurrence.

Although in this review only respite for persons with disabilities is examined, in both instances the primary intent is to provide support and preservation of family or caregiving relationships.¹⁹

Respite received legitimization as a formal service for people with disabilities in the mid to late 1970s when it was the topic of research reported in several articles published in the scientific literature.²⁰ The development of respite services, also occurring in the 1970s, has been attributed to the beginning of the deinstitutionalization movement for persons with mental and developmental disabilities. Starting in the later 1980s and

¹⁸ Lidoff (1983).

¹⁹ Family Caregiver Alliance (2001).

²⁰ Toner (1993).

early 1990s, interest grew in developing respite opportunities specifically for the caregivers of older adults. This movement is marked by the publication of a number of program guides for “translating models into practice” for the caregivers of the functionally impaired elderly.²¹ Also around this time, adult day-care programs began to be established, and these facilities have evolved into an accepted option for current respite care.

Over the last twenty years, respite care has gained recognition as an important, if not critical component of home- and community-based long-term care. In efforts to make respite care accessible, planners of early programs grappled with the problem of establishing guidelines that were transferable across the numerous funding organizations sponsoring these services. Because of this diversity in funding, as well as an identified need to meet divergent needs of various target populations, a variety of models were developed.

As interest in the development of these formalized programs grew, it became apparent that a common understanding of the services comprising respite would be useful. Some early definitions of respite, which persist in current literature, describe the service in relation to the location at which it occurs, with the two major categories being in-home and out-of-home respite. In a national study conducted by the Foundation for Long-Term Care in 1987, five major types of location-based respite care were identified:

- In-home respite (provided by respite, home care and general community agencies);
- Respite provided in community settings (adult day care, freestanding respite facilities);
- Institutions caring for the elderly (senior housing, adult homes and nursing homes);
- Hospitals (VA and community); and,
- Combination groups of the above.²²

Currently a much more extensive list of options is considered, including respite camps and mobile respite. However, respite care continues to often be defined by its location.

A more recent study that described respite based upon location employed the sub-categories of “single component programs (in-home respite, adult day service programs, and overnight respite), and “multicomponent programs” (a range of services from brief in-home to extensive out-of-home services; case management, counseling and support groups were sometimes part of this package) as a models for service delivery.²³

As illustrated in the list of services above, respite programs may vary from very narrowly defined models like the location-based model, to very broad definitions that

²¹ Klein (1986).

²² Hegeman (1993).

²³ Zarit, Gaugler & Jarrott (1999).

may include such elements as caregiver training, patient transportation and cash subsidies. A study by the Family Caregiver Alliance (1999) found that some respite programs describe respite as anything that enhances the caregiver's quality of life.

Other models have been identified that reflect this type of broad view. The Institute on Aging, University of Washington, identified four nonrestrictive elements of respite services:

- *Purpose:* To provide a rest for the caregiver;
- *Time:* In all cases respite is temporary relief. The actual amount of time may vary from a few hours to several weeks;
- *Place:* Relief may be offered through institutional placement, in-home services, or community-based day programs; and ,
- *Activity:* Respite may simply involve the presence of a companion or worker to ensure safety of the recipient, performance of household tasks, personal care, medical services, or social activities.²⁴

These program elements are almost identical to the four dimensions of respite presented in the previously described President's 2004 Proposed Budget directed at CMS operations.

Recent published literature has shown a growing trend in conceptualizing respite as involving the entire caregiver network as well as the beneficiary. This idea was circulated in published literature as early as 1976 regarding geriatric day-care programs, when it was suggested that "the family is an important corollary consumer of geriatric day-care services" and that "the family is also a day-care client and must be treated as such in program planning and service delivery."²⁵ This consideration of the *caregiver as client* is reflected in the positioning of respite as "caregiver interventions," which can be divided into two major groups: (a) those aimed at reducing the objective amount of care provided by caregivers (respite interventions to enhance the competence of the care receiver), and (b) those aimed at improving the caregiver's well-being and coping skills (e.g., psycho-educational interventions, support groups).²⁶

Additional literature provides evidence for placing a focus on the caregiver network as the beneficiary of respite, and from a policy perspective, caregiver assessment as a measure of need and program success.²⁷ Researchers propose that "no assessment is complete unless it takes into account the patient's family caregiver network,"²⁸ "characteristics of the elder [care recipient], the caregiver, and the provider are all associated with patterns of respite use,"²⁹ and "[r]espite service, simply and directly,

²⁴ Montgomery & Prothero (1986).

²⁵ Rathbone-McCuan (1976), p. 517.

²⁶) Sorensen, Piquart, Habil & Duberstein (2002), p. 357.

²⁷ Lidoff (1985); Klein (1986); Montgomery & Prothero (1986); Feinberg & Whitlach (1996).

²⁸ Dobrof, Zodikoff, Ebenstein, & Phillips (2002), p. 24.

²⁹ Montgomery, Marquis, Schaefer & Kosloski (2002), p. 59.

seeks to support the integrity of the family unit.”³⁰ For instance, the California Caregiver Resource Centers Uniform Assessment Tool uses the Adapted Zarit Interview to identify self-assessed stress levels of the caregiver, feelings of social isolation and information gaps experienced by the caregiver.

Reflecting this caregiver focus, in 1984, California enacted legislation for the provision of Caregiver Resource Centers to address the needs of families caring for persons with adult-onset cognitive impairment. In addition to services described previously, this program offered respite in the form of the “Caregiver-Focused Respite Weekend,” where the caregiver, and not the person with disabilities, spent time in a retreat, with activities ranging from training and support, to unstructured rest and relaxation. Other respite services included “emergency respite,” provided when the caregiver had unanticipated medical or personal demands. Respite transportation subsidies were also made available so that patients could be transported to day programs.³¹

In addition to research promoting migration towards a view of respite that identifies the primary goal of caregiver relief, another perspective obtaining greater recognition is the assessment of respite based upon measurement of “outcomes.” As early as 1985, proposals have been made to conceptualize respite as the outcome of a number of formal and informal services, rather than as a service itself.³² Findings from several studies evaluating caregiver satisfaction with respite services noted that though caregivers reported being satisfied with the respite provided, user satisfaction did not necessarily correlate with perceived reductions in levels of burden or stress.³³ Study results appear to indicate that in order for respite to be truly effective in providing relief to caregivers, a broad spectrum of unique caregiver needs must be addressed through provision of a wide range of service options. This research may serve to advance the notion of redefining respite as an outcome and taking caregivers’ experiences and the entire caregiver network into account, rather than simply measuring the consumption of respite as a service.³⁴

Conclusions

The primary goal of this review was to identify and compare how respite is defined in federal documents and published literature to determine whether there is a common definition that can be applied in HCBS waiver applications. This is important from two perspectives: the consumer and the program administrator. It is important to consumers because defining the service enables beneficiaries to more clearly conceptualize the service and to better understand its relevance to their situation, thereby encouraging usage. A lack of knowledge can serve as an obstacle in subscribing to this kind of support service, with underutilization as a potential result. From the

³⁰ Starkey & Sarli (1989), p. 324.

³¹ Feinberg & Kelly (1995).

³² Lidoff (1985).

³³ Cox (1997).

³⁴ Chappell, Reid & Dow (2001).

policymakers' perspective, understanding the components of the service can facilitate the administrative process of distribution of services, and it can also help in the control of a subsidized service to prevent an over-extension and costly excessive demand.

It is important to note that even among programs within the same state, respite is often defined and delivered differently. This makes data collection and analysis, including comparisons of program expenditures and caseloads, a challenge. It is difficult to compare data from a program that defines respite as in-home or adult day health services to another program in the same state that defines respite as including homemakers, chore services, and personal care.³⁵

In terms of defining respite, this analysis has revealed that it is a complex entity for which boundaries may be difficult to determine. There does appear to be agreement in both federal and published literature that its primary intent is to provide the effect of delivering relief or a rejuvenating benefit to the caregiver. Determining how this effect is accomplished is complicated by the general acknowledgment that every caregiver family has unique needs, life styles and endurance levels that will find "relief" in different ways. Given this view, it may be more useful to position respite within a delivery system model based upon outcome within the caregiver unit, as opposed to attempting to derive a service-oriented definition.

This analysis found a diverse range of definitions of respite in the documents reviewed. Respite is described, particularly in research and professional reports, as an intervention for in-home providers of long-term care that spans a broad range of support options. In these publications, respite is frequently described through case studies, with detailed outlines of various program components and services delivered. Conversely, definitions of respite services in the federal documents reviewed here, when provided at all, were found to most often be quite succinct, but non-restrictive.

It is this nonrestrictive attribute that may provide insight into the federal perspective on respite. While the legislative documents (i.e., SSA and CFR) provide little in the way of detailed description, subsequent federal documents (i.e., in particular the President's 2004 Proposed Budget) offer a very broad, flexible view of respite, similar to that presented in research and professional literature. When these legislative and executive documents are viewed together as a continuum of a developing perspective, the legislative documents provide an open framework that establishes respite as an HCBS benefit, and the executive-level Budget Proposal may be seen as expanding this open view to align with a "consumer direction" model that could include a broad range of potential respite options. Proceeding with this line of interpretation, under SSA legislation for HCBS respite waivers, the Secretary of CMS may be viewed as being endowed with primarily exclusionary power to deny state-proposed services that fall outside of the consumer direction model, but given this broad framework denials would be few and far between. For example, using the criteria of "rejuvenation" of the caregiver as a qualifier, the Secretary of CMS would likely rule that daily day-care for an individual that enables a caregiver to attend work would not qualify as respite.

³⁵ Newman (2005).

According to the literature, this fluid definition of respite, based on the caregiver's unique life style and needs, is one that is most meaningful for caregiver families and networks.³⁶ Extending this idea of respite customized to caregiver needs and looking at outcomes based upon this model, it has been observed that "the diversity of caregivers and their caregiving contexts is now well-established by a large body of research, and there is reason to believe that this diversity in caregiving will be reflected in patterns of service utilization."³⁷ The value in positioning services based upon a consumer direction model is illustrated in a study of respite caregivers that found over 60% of caregivers defined "a break" in ways that policymakers, professionals and researchers did not.³⁸

For the most part, respite services have been operationalized by measuring the type and frequency of specific services received by the caregiver. Recent research offers that this service framework may not accurately reflect the true nature and benefit of respite. Instead, a more meaningful and realistic approach may be to view respite as an outcome, measured in terms of caregiver burden or well-being, and to develop assessment tools that will enable federal gatekeepers to distribute funds for respite and other caregiver support services based upon such criteria.

Evidence supporting caregiver assessment arises from studies that have shown that the caregiver is most often the major initial barrier to the use of formal respite services.³⁹ Reasons for this include that caregivers may feel that using such services indicates a failure or inadequacy on their part to cope with the situation, and that caregivers may have difficulty in locating services that meet their unique needs when they are most needed.⁴⁰ In some cases, when respite services are not well administered, the service itself can become the source of stress. This can occur if the family has to worry about the quality of care that a beneficiary receives from an untrained formal respite care worker or if the caregiver does not have access to all of the services that are required to deliver relief. For example, the respite program may support out-of-home day-care, but does not provide transportation for the disabled individual to get to the facility.⁴¹

Other more complex, policy-related reasons for underutilization have been documented as arising from obstructive eligibility criteria, where benefits are approved only with the occurrence or imminent risk of out-of-home placement.⁴² Families that do not consider institutionalization as an option may never attain this eligibility criteria. The result is that many caregivers only turn to respite in desperation when the burden of caregiving is extreme. In these cases, after respite meets the short-term critical need, institutionalization is often seen as the ultimate solution. Recognition of these stressors

³⁶ Feinberg & Kelly (1995); Brody, Saperstein & Lawton (1989); Starkey & Sarli (1989).

³⁷ Montgomery (2002), p. 35.

³⁸ Chappell, Reid & Dow (2001).

³⁹ Gwyther (1986).

⁴⁰ Chappell, Reid & Dow (2001); Brody, Saperstein & Lawton (1989).

⁴¹ Chan & Sigafos (2001).

⁴² Castellani (1986).

and their effects on utilization of the service suggest that assessment based upon the entire informal caregiver system should be employed at all stages of the respite program.

Other factors, representing a narrowly defined service view of respite, can contribute to underutilization of respite programs, including:

- Services to families are fragmented and uncoordinated (i.e., different funding agencies);
- Services are often not designed to help families stay together (out-of-home promoted vs. in-home assistance) and to meet caregivers individualized needs (i.e., making available evening or weekend respite for working caregivers);
- Services are too often provided outside the home without secondary supports to enable families to use these services (e.g., transportation); and,
- Services are often only made available after serious damage has been done rather than to prevent such damage.⁴³

Researchers suggest that professionally focused respite services may be a disincentive to caregiver use of respite.⁴⁴ One solution may be to adopt a more family-focused approach to respite that is informed by theory, which will enhance practice and move it in the direction best able to meet family need.

In summary, a more successful program approach could be defined by including the following three fundamental conditions:

- The existence of an adequate supply of high-quality services that match the number of families needing them;
- Services available to families in a manner that allow access when they are most needed, and facilitates prevention of further problems; and
- Services that are consistent and reliable over time, with families and program staff able to feel secure that respite care services will be continuously available and not dependent on short-term grants or projects.⁴⁵

Emerging Policy Issues

Economic Benefit versus Social Responsibility

Rather than being promoted as a service necessary for the well-being of family caregivers, respite has largely been advanced as a service that saves public dollars while benefiting family members. Respite may need to be repositioned, based upon societal values, as a basic necessity much as is food or medicine, that is required to provide standard levels of care for individuals with disabilities living in the community.

⁴³ Cohen & Warren (1985).

⁴⁴ Starkey & Sarli (1989).

⁴⁵ Butler & Friesen (1988), p. 32.

Considerations need to be made for evaluating the relative costs and benefits for family members versus the costs and benefits for public services.⁴⁶

Target Population

Policymakers have traditionally designed entitlement programs for persons with disabilities that are allocated based upon the exclusive needs of that person. Respite introduces complexities from a policy perspective because it has been positioned as a service that benefits the welfare of the entire family. The primary focus of respite, the rejuvenation, relief and strengthening of the caregiver network, requires a significant policy shift towards family versus individual outcomes. Mechanisms need to be developed that enable program administrators to measure the success of outcomes that include respite and other service interventions so that there can be accountability for resources used.

Caregiver Assessment

Medicaid HCBS waivers frequently employ functional level of the person with impairments as the indicator for eligibility of respite. Most assessment tools ascertain eligibility of applicants based exclusively upon the need of the person with disabilities. Eligibility criteria focused on activities of daily living excludes consideration of caregivers' capacity for providing support in a wider range of activities.⁴⁷ Given the focus on family burden and well-being that respite introduces, new assessment mechanisms are required that consider the characteristics of the individual family beneficiary over time. Additional research is required to better assess those families that would benefit from respite.

Service Definition

Research has shown that caregivers need a broad range of respite options and other caregiver support services, as their level of burden can be greatly affected by the amount, types, and quality of formal supportive services received. This demand for diversity in services raises policy issues for respite: families' preferences for either in-home or out-of-home respite may not be met by available resources; rate-setting procedures and regulations on use of facilities may restrict selections; and, liability issues raise costs and restrict options. As the demand for respite services increases, policymakers will need to resolve the question regarding eligible services and locations.

Funding

Funding for respite services has been fragmented across state, federal and private sources. This situation has contributed to obstacles that families may encounter in accessing the services that they need at a time when they are required. Federal funds are seen by some as a primary source of support for these services. Demand for cash subsidies, vouchers, and other mechanisms that empower families may emerge as solution.

Best Practices

⁴⁶ Montgomery (1995); Butler & Friesen (1988).

⁴⁷ Reinhard (2004).

There are currently only a few places where states can turn to obtain information on how to develop and administer respite programs that will both serve caregiver families and address constituency concerns. Although research has begun to explore some theoretical frameworks around respite that may contribute to policy development, much work remains to be done in providing guidelines for establishing best practice programs. Operationalization procedures need to be developed that will enable administrators to manage programs efficiently and effectively.

Legislation

Development of model programs will be motivated by support from legislation such as the *Lifespan Respite Care Act of 2003* that would authorize grant funds for Lifespan Respite Programs to help families to access respite. Three states have enacted legislation to implement Lifespan Respite Programs (OR, NE, WI), which establish state and local infrastructures for developing, providing, coordinating and improving access to respite. Oklahoma has also implemented a Lifespan Respite Program, and Maryland has established a statewide family caregiving council that develops plans to provide lifespan respite.

Underutilization

Respite programs and funding may be at risk if underutilization occurs. However, research shows that respite is a service that is greatly desired by caregivers. Underutilization may result from a number of policy-related factors, the most prevalent reason being lack of awareness of respite services; other reasons include difficulty in accessing services, eligibility factors, facility availability, and others. Policymakers need to investigate underutilization factors and develop procedures that enable caregiver families to access funding for services as needed.

Consumer direction

Underutilization of respite services has been, in part, attributed to difficulty in access and a lack of choice in in-home respite options. It has been proposed that consumer-directed or direct pay programs, where Medicaid beneficiaries control the budget and selection of their supportive service, could improve informal caregivers' access and use of respite. In relation to agency-based services, caregiver families pay lower rates for direct pay respite services and can therefore obtain more service at lower cost. Additionally, a direct pay model, where families hire and supervise their own aides, places greater control and choice of service in their hands.

Workforce Reliability

The term "crisis" is currently being used to describe existing problems with attracting and retaining long-term care workers. The lack of a well-trained, well-qualified workforce for respite care can have negative effects on family caregivers. The inability to recruit and retain home care workers places more pressure on informal family caregivers to provide care and creates anxiety for those who are trying to arrange for formal care. Policymakers and providers need concrete examples of programs that successfully link workforce development and long-term care quality improvement so that investments can be validated. To this end, the Robert Wood Johnson Foundation and The Atlantic

Philanthropics have joined together to fund a \$15 million demonstration and research program. Another policy issue affecting the long-term care workforce pool is whether states are willing to amend nurse practice acts to allow certain tasks to be delegated to respite workers, such as administering medication⁴⁸.

Summary

The primary goal of respite appears, as noted in literature from federal documents, scholarly literature and stakeholder associations, appears to be to provide for the rejuvenation, relief and strengthening of the caregiver network. Eligibility for respite services should include assessment of caregivers' capacity for providing a range of supportive activities beyond help with activities of daily living measured by the "functional needs" of the person receiving support. To meet the need of each unique caregiver system, a wide range of options may be required. Therefore, a policy shift towards family versus individual outcomes should be examined.

This technical assistance document was prepared to generate discussion about defining respite care to improve both the delivery of outcome-based services and policy analysis. The authors invite comment that can further productive discussions.

Comments can be directed to Susan Reinhard at sreinhard@ifh.rutgers.edu.

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⁴⁸ Stone (2004); Stone (2001).

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