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# Respite Care: *State Policy Trends and Model Programs*

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# Respite Care: *State Policy Trends and Model Programs*

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## INTRODUCTION

The vast majority of care in the United States for individuals with disabilities or in need of supervision is provided by unpaid family and friends of the care recipient. One study, looking only at caregivers of adults, put their number at 25.8 million in 1997, providing on average 17.9 hours of care per week, at an economic value of \$196 billion (Arno, Levine, and Memmott, 1999). Another study estimates that 52 million individuals serve as informal caregivers annually (U.S. Department of Health and Human services [USDHHS], 1998).

As a society, we value informal caregiving for three very different reasons:

- 1) Because of the intrinsic merits of family and friendship bonds.
- 2) Because informal care can mean the difference between an individual living in an institution and living at home.
- 3) Because professional (formal) services can become costly for individuals with disabilities or chronic diseases.

Government policy increasingly has recognized that the public sector has a role to play in sustaining private caregiving and that formal services can be used to support informal care. One of the most important examples is respite care, the temporary relief of the primary caregiver through substitution of his/her services.

The purpose of this Policy Brief is to describe respite care, document its importance, and delineate state options for supporting its use. This paper provides background, defines respite care, explains its significance and describes state options for supporting respite (focusing on key aspects of policy design and challenges for programs). It also features three very different “best practice programs” – a

stand-alone respite program offering diverse service options to adult care recipients, a “lifespan respite” program that promotes the creation of community-based networks facilitating access to respite for all families and individuals, and a support program for caregivers of the

cognitively impaired that includes respite as part of a spectrum of services. Finally, some summary conclusions are presented.

## BACKGROUND

### ***What Is Respite Care?***

Respite care services, as defined in this Policy Brief, are short-term services to a care recipient designed to provide relief to an informal primary caregiver. The first state respite programs, along with other caregiver support services, were created in the 1970s, with a wave of programs following in the 1980s. New programs continue to appear up to the present.

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As noted by the Family Caregiver Alliance (FCA) in a 1999 study of 33 caregiver support programs in 15 key states (Feinberg and Pilisuk, 1999), some programs describe as respite anything that enhances the caregiver's quality of life. For example, within the rubric of respite, states have included the education of informal caregivers, cash subsidies or transportation services for caregivers. To maintain conceptual clarity and comparability across programs, this Policy Brief will employ the narrower definition laid out above.

Respite is used primarily for two kinds of situations:

- ◆ 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 eventuality.

While caregiver respite is the topic of this Policy Brief, it is important to be aware of the use of respite to promote child welfare. In both situations, the underlying values include support and preservation of family or caregiving relationships. In addition, non-categorical respite programs now simultaneously serve individuals and families in both situations.

The primary purposes of caregiver respite are to decrease the individual and family stresses associated with caregiving, and to postpone the need for institutionalization of the care recipient. To meet these purposes, respite generally takes one of two forms:

- 1) Brief, regularly scheduled episodes of respite (e.g. three hours weekly of home

care) to allow caregivers to perform routine chores and/or have a break from caregiving.

- 2) Sporadic, longer periods of respite (e.g. several consecutive days in an institution) allowing caregivers to leave town for business or vacation, go into the hospital, or attend to some other emergency.

### ***Importance of Respite Services***

Although informal caregiving has important potential benefits for the caregiver, the care recipient, and society, it can be stressful for all parties involved and difficult to sustain. A large body of literature has documented the strains on mental and physical health that can accompany caregiving (e.g. Pearlin et al., 1990). At a societal level, sustaining informal caregiving is likely to become increasingly

challenging as the population ages, increasing the number of people needing long-term care (LTC) and raising the age of the caregiving population. Some see an additional challenge for informal caregiving in the growing number of women participating in the workforce full-time

(Smith et al., 2000). However, others see no indication that the growth of the female workforce has significantly reduced informal caregiving (Stone, 1999).

Given the challenges of caregiving, it is not surprising that caregivers of individuals with Alzheimer's disease cite respite care as one of the services they need most (McConnell and Riggs, 1994). In their 1999 study FCA found this view mirrored in the perspectives of state program administrators, who described respite as one of the most beneficial caregiver support services. Indeed, respite was the most common element in the caregiver support programs reviewed for the study (Feinberg and Pilisuk, 1999).

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Early research on the effects of respite was unable to establish measurable gains aside from client<sup>1</sup> satisfaction. However, improvements in research design led to a significant body of literature showing that respite can mitigate the emotional distress often associated with caregiving and can even delay institutionalization of the care recipient (Cox, 1998; Cox, 1997; Kosloski and Montgomery, 1995; Knight, Lutzky, and Macofsky-Urban, 1993; Deimling, 1991; Montgomery and Borgatta, 1989). Not only do most individuals prefer to stay at home, but delayed institutionalization has a monetary benefit as well. A recent study reports that if institutionalization of individuals with Alzheimer’s disease could be delayed even one month, it would mean a savings of \$1.2 billion annually (Leon, Cheng, and Neumann, 1998).

Respite by itself is unlikely to address adequately a state’s needs for caregiver support. While research suggests that respite leads to improvements in the mental health and quality of life of caregivers, it also shows that there remains a high prevalence of stress and depression among caregivers. Furthermore, no one form of caregiver support suits all situations. Studies demonstrate great diversity among caregiving situations, including differing family relationships, caregiver resources and stressors, care recipient needs and caregiving responsibilities. Diverse policy options are the appropriate response to the resulting diversity of needs. State program administrators participating in the FCA study also emphasized that caregiver

<sup>1</sup> “Clients” and “consumers” both describe those who employ respite services and refer to both care recipients and caregivers.

support programs should offer a broad array of services (Feinberg and Pilisuk, 1999).

STATE STRATEGIES FOR PROMOTING RESPITE

**Overview**

This Policy Brief focuses on four elements that are fundamental in defining a respite program (Feinberg and Pilisuk, 1999; Fox-Grage, 2001; Maslow, 2001):

***“Respite by itself is unlikely to address adequately a state’s needs for caregiver support.”***

- 1) What is the conception of respite embodied in the program?
- 2) How is the program funded?
- 3) What is the scope of the program?
- 4) What are the program’s services and the mode of service delivery?

Other (generally more operational) program elements are also important, although space does not allow us to fully address them. These include whether a program is legislatively mandated, the process for eligibility determination, the amount/limit of benefits, the mechanism for setting reimbursement rates, the approach to service planning, how the program is administered and the method of outreach.

In considering alternative program designs, key tradeoffs and challenges emerge:

- 1) Most caregivers do not seek help until caregiving burden is high (Braithwaite, 1998). This means that programs are not providing the assistance that may be needed at earlier stages and that can help to preempt problems.
- 2) Respite programs are generally dependent on the market to provide services. These services may be scarce, particularly in times when providers have other employment options. Additionally,

providers may prefer to save services for longer-term or private-pay clients.

- 3) Program budgets may be insufficient to meet the need in the target population.
- 4) Target populations may leave some caregivers without services. Multiple programs for different populations can cause some clients to fall through the cracks.
- 5) Flexibility is key for meeting the needs of a diverse population whose circumstances can change quickly. However, requirements meant to achieve accountability or consistency can undercut flexibility. Creating institutional mechanisms for exceptions – e.g. a process for petitions – simultaneously promotes flexibility and accountability. Service diversity is an approach to flexibility that is also consistent with accountability.
- 6) Caregivers and care recipients often feel it important to have control over providers who enter their homes, touch their bodies and/or help them meet basic needs. The challenge is that increasing consumer control can mean a decrease of the control exercised by vendors/vendor agencies, program personnel and other state agents. Consumer control is also a consideration beyond the individual provider-client relationship. Many programs proactively involve clients in service planning. Consumers as a group can be involved in overall program direction, advocacy, fundraising, and quality assurance activities. Consumer control and flexibility are increasingly issues of concern for experts. (For more information on this issue, see the Policy Brief entitled “Paying Family Members to Provide Care:

Policy Considerations for States,” by Larry Polivka.)

### ***The Conception of Respite***

Respite programs vary on a number of conceptual dimensions, including the definition of respite, its goals and objectives, how respite fits into the larger LTC continuum, and who the client is. While the way in which a program is conceptualized does not always translate into the decisions of a front-line administrator, often it does guide daily implementation, how the program is evaluated and how it evolves.

***Definition of respite:*** As noted in the background section, programs vary in their definition of what respite is, ranging from the narrow definition used in this issue brief to the broad definitions of programs such as Florida’s Home Care Program for the Elderly, which provides cash subsidies to caregivers as a form of respite. These definitional differences can both reflect and lead to different conceptions of program mission.

***Purpose of respite:*** The primary objectives of respite are commonly understood to be:

- ♦ Caregiver relief.
- ♦ Delayed institutionalization.

However, some state programs explicitly define additional – generally more operational –

objectives, such as:

- ♦ Providing services that are adequate for the care recipient’s needs.
- ♦ Attending to the same needs that the primary caregiver would meet.
- ♦ Providing services in a home-like setting.
- ♦ Assuring the care recipient’s safety.

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The delineation of these goals creates a new set of considerations or standards for the design of respite services. For example, the Wisconsin Alzheimer's Family Caregiver Support program has the objective of providing services in a home-like setting. The program offers respite only in the care recipient's home, the home of the provider, or in free-standing facilities that exist primarily for the provision of respite.

Respite's two primary objectives – caregiver relief and delayed institutionalization – can often work in concert but can also be in conflict when a care recipient's physical or mental condition deteriorates dramatically. How program administrators understand the tension between these two goals and their relative importance can affect program implementation.

***Where does respite fit in the LTC continuum?*** The line between respite and other forms of LTC may be understood differently in different contexts. Within New Jersey, for example, respite is offered to the general disabled and frail adult population through the New Jersey Statewide Respite Care Program, a stand-alone respite program, and as one of eight services through the Medicaid waiver program. In the context of the stand-alone program, all services provided are understood to be respite. The waiver program, however, is designed to provide a range of home and community-based services. When a program provides multiple home care visits per week, which of these visits is respite? In this context, respite is generally understood as something outside of the standard service plan, e.g. a full day of in-home or institutional care provided because of a caregiver emergency, vacation or illness (Silberberg and Caruso, 2001-a; Silberberg and Caruso, 2001-b).

***Who is the client?*** Another conceptual difference among programs is the person(s) perceived as the client, potentially affecting whose needs are given primacy. Is it the care

recipient, i.e. the person who has the disease or disability and who will actually be attended to by the respite provider? Or is it the caregiver, given that the primary purpose of respite is to provide caregivers with temporary relief? Some programs define the client as the care recipient, others as the caregiver, and still others as both.

### ***Program Funding***

Both volume and type of funding are important considerations in the design of a respite program. Funding affects the program's capacity to meet the needs of the target population and how broadly that population can be defined. It also affects the resources available to staff to conduct outreach and their willingness to do so, as staff may be reluctant to advertise a program that is fully subscribed (Silberberg and Caruso, 2001-a). By limiting outreach, funding restrictions can limit a program's ability to reach clients at an earlier stage of disease or disability.

While developing a funding base is in large part a question of political viability, funding options also have implications for program design. Most obviously, federal funding sources allow for leveraging of state resources, but also come with requirements, e.g. pertaining to eligibility or administration. Different funding sources also embody different conceptions of respite.

***Federal Funds:*** Medicaid is an important source of matching federal funds, primarily through the Home and Community-Based Service Waiver Program (HCBS), which was designed to offset the bias of the traditional Medicaid program towards institutionalization. This is not a caregiver support program; the care recipient must be the primary beneficiary. However, as respite benefits both the care recipient and the family, it is an acceptable program component. In fact, most states with HCBS waivers do include respite as a service (Smith et al, 2000).

The Older Americans Act has also been a source of funds for respite care. A key development is the establishment of the National Family Caregiver Support Program through the Older Americans Act Amendments of 2000. The National Family Caregiver Support Program was modeled on caregiver support programs in states like Wisconsin, New Jersey, and California (Takamura, 2001). (For more information, see the Policy Brief entitled “Federal and State Policy in Family Caregiving: Recent Victories But Uncertain Future,” by Wendy Fox-Grage, Barbara Coleman, and Robert B. Blancato.)

The Developmental Disabilities Act Amendments of 2000 sustained existing dollars for support, training, and advocacy for respite and created a new program, the Families of Children with Disabilities Support Act, which was funded at \$10 million and will allow for support of state initiatives.

Other federal programs support respite care as well, including programs to prevent child abuse (such as the new Family Resource and Supports Grants Program), Maternal and Child Health Block Grants, Mental Health Block Grants, and Title XX Social Service Block Grants (which has been cut significantly in recent years).

**State and local funds:** The FCA survey found that almost half of the funding for the surveyed programs they studied came from state sources, and about half of the programs received state funds only. While the most common source of state support was general funds, other sources were important too, including casino tax revenues and tobacco settlement funds. Local sources, e.g. property taxes, also provided revenues (NGA, 2001).

**Client contributions or cost-share:** Programs may require some sort of client contribution, sometimes on a sliding scale. While some see collection of client contributions as a difficult administrative task, others view cost-share as a way to expand the population that can be served and the services that can be provided (Silberberg and Caruso, 2001-a, 2001-b).

### ***Program Scope***

Program scope has three dimensions:

- ♦ Program domain (e.g. respite, caregiver support, LTC).
- ♦ The ways in which the program promotes respite.
- ♦ Population served.

One common question pertains to all these elements, i.e. how broad or narrow is the program? Broader programs tackle more aspects of a problem, make it easier for consumers to navigate the system, make it less likely that services and clients will fall through the cracks, and promote synergies among services. However, they can also be difficult to forge and to enact. Furthermore, some argue that specialized programs do a better job of meeting the needs of their clientele.

**Program domain:** Respite care can be provided on its own or as part of a larger package of supports. That larger package can take a variety of forms; a basic distinction is that between a caregiver support program and a LTC program. In the FCA study (Feinberg and Pilisuk, 1999), key informants differed as to whether caregiver support programs should stand on their own or be part of larger LTC programs, with more respondents favoring the latter approach. Even those who favored the former approach, however, saw a need for coordination between caregiver support and long-term initiatives. A program that is initially narrowly defined can also be

incrementally expanded, although this approach may lead to fragmentation.

**Respite-related activities:** The primary role of government in promoting respite has been through financing respite services and, via program advertising, bringing these services to the awareness of potential users. However, the public sector can assist with respite use in a number of additional ways.

A comprehensive approach to promoting respite is that of the Oregon Lifespan Respite Program, which supports local networks that increase access to respite. A network recruits and screens respite care providers (paid and unpaid); identifies training opportunities for respite care providers and helps establish new ones; helps clients to define their needs; connects clients with respite services and financing options; identifies, coordinates, and develops community resources for care; and assists with quality assurance and evaluation.

**Population served:** Eligibility criteria are key in defining the target population for the respite program. In the FCA study (Feinberg and Pilisuk, 1999), it was far more common for eligibility criteria to refer to the care recipient than the caregiver, although a few did take into account caregiver income. Care recipient age, diagnosis, disability level, and income were common elements of eligibility determination. Most programs were not diagnosis-specific; those that were tended to be for individuals with dementia or developmental disabilities. Some programs had no definition of caregiver, while others specified a relationship to the care recipient (e.g. family member as opposed to family friend or other adult) or defined the nature of the involvement (e.g. daily or 24-hour).

## Services

Respite can be delivered in a variety of contexts by a variety of provider types and through a variety of contractual arrangements. Diversity on any of these dimensions has the advantage of promoting both flexibility and consumer control, allowing the client to choose what suits him/her best.

**Where is care provided?** Common forms of respite include in-home care, day care and traditional institutional care, e.g. a nursing facility. Other options exist as well, e.g. freestanding respite facilities or group homes. A study of the New Jersey Statewide Respite Care Program, which allows consumers to choose from an array of respite services, confirms the

importance of having a diversity of options (Silberberg and Caruso, 2001-a). While most clients of the program used home-based care, almost one-in-five used day care and a similar percentage used facility-based care. Moreover, type of service used was correlated to care recipient diagnosis, suggesting that different service types are more appropriate for different kinds of consumers.

**Who provides the care?** Respite services can be delivered by a variety of providers, differing by their professional training (ranging from companions to nurses) and their relationship to the care recipient (volunteers, family and friends, or paid professionals). While some state programs offer a variety of provider options, others may offer only one. For example, New York's Alzheimer's Disease Community Assistance Program and Florida's Respite For Elders Living in Everyday Families use volunteer providers only.

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Currently, a major issue is whether family members should be paid to provide respite services. Half of the state programs surveyed by the FCA pay family (Feinberg and Pilisuk, 1999). Under the Medicaid waiver program, a family member can be paid to provide respite if that individual is not legally responsible for the care recipient. (Even then, the family member can be paid under special circumstances.) Proponents of family pay believe that it promotes consumer control by expanding options; results in better quality care; is a good solution to the challenge of finding respite

workers; allows care recipients to be cared for by people they trust; increases care recipient satisfaction; and provides people with a job who may have had to leave their previous employment because of caregiving responsibilities. Others

worry that paying family members leads to expenditures for care that would otherwise have been free, can result in conflicts between care recipients and caregivers, and creates the possibility for family members to exploit care recipients. Some believe that family members should be hired (Feinberg and Pilisuk, 1999) but should be held to the same quality standards (training, certification, background checks) as other providers (Smith et al, 2000).

**Who employs the provider?** Another issue currently of great salience is whether respite services should be provided through an agency or direct pay/independent provider model. Under the former model, an agency contracts with the payer to provide services. These agencies most commonly include home care agencies, adult day care centers or institutional facilities. In an individual provider model, the care recipient or the primary caregiver directly employs the respite provider – hiring, training, supervising and paying him or her (although hybrid arrangements can be created, for

example, having a third party handle the finances). The goal of this approach is to allow consumers to direct and control their own care and to lower the per unit costs of care by cutting administrative expenses. The FCA study found that 90 percent of programs used contract agencies, and half used independent providers (Feinberg and Pilisuk, 1999).

The experience of the California Caregiver Resource Centers (CRCs) sheds some light on the choice between the direct pay and

independent provider models, as the program offers both options to respite clients. A 1996 study of the CRCs (Feinberg and Whitlatch) found that two-thirds of the clients preferred the direct pay approach. While many expected older caregivers to favor agency-based care, and while

those using direct pay were on average younger, even caregivers 65 years of age and older were as likely to use direct pay as agency-based care. Both groups were highly satisfied with the services they received, indicated that respite had improved their quality of life and said that their care recipients would not be better off in a nursing home. The direct pay model also met its goals of decreasing costs and increasing the control of caregivers. However, agency users preferred not to be responsible for arrangements themselves.

The Oklahoma Respite Resource Network promotes consumer control by combining service diversity, the family pay option and direct pay. Financially eligible families receive a voucher, the amount of which is determined by household income level. For three months from the date of issuance, families can use these vouchers to purchase the respite care that suits them, including paying professionals, family or friends. When

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a voucher has been completed, it is sent to the state Department of Human Services, which pays the service vendors.

### THREE MODEL RESPITE PROGRAMS

The three respite programs described in more detail here illustrate the design elements discussed above and provide a holistic picture of how a program works. These programs were selected for four reasons:

- ◆ First, they are among the five cited by FCA (Feinberg and Pilisuk, 1999) for meeting its defined criteria. (The criteria were statutory recognition of the term caregiver, a range of support services and respite options, designation of either the caregiver/family or both caregiver/family and care recipient as client, involvement of caregivers in service and care planning with service options, a broad-based target population in terms of age and disease/disability, eligibility for middle-income families, data collection on numbers served, and budget growth.)
- ◆ Second, other states and the federal government have looked to these programs as prototypes.
- ◆ Third, the programs represent a broad range of approaches to respite promotion.
- ◆ Fourth, they illustrate many of the issues discussed above.

These programs should be seen as sources of ideas for other states, not as cookie-cutter templates. Each program has its own challenges, as well as its benefits, and each state needs to adopt the approach that best suits its circumstances.

### ***Profile: New Jersey Statewide Respite Care Program***

The New Jersey Statewide Respite Care Program (SRCP) contrasts with the FCA's other model programs in its focus on respite services (based on Silberberg and Caruso, 2001-a; Feinberg and Pilisuk, 1999; conversation with Peri Nearon, August 8, 2001). Operational since April of 1988, the SRCP has historically been financed by state

casino revenue funds, with a supplement from a client cost-share based on a sliding scale, and some small in-kind contributions from the local administering agencies (which contract with the state to run the program). Recently, funds were added from the tobacco settlement. In calendar year 2000, total program expenditures were approximately \$6.28 million, and 2,822 clients were served. (Expenditure figures are approximate since client cost share and in-kind donations are not fully captured.)

SRCP has a broad target population, serving functionally impaired adult care recipients (18 or over) and their caregivers. Income eligibility requirements are designed to serve low-income care recipients whose assets make them ineligible for Medicaid HCBS. However, Medicaid-eligible individuals may receive care through the program if they need something they cannot receive through Medicaid.

Both caregivers and care recipients are considered clients.

A hallmark of SRCP is its diversity of respite services, including paid and volunteer companions, home health aides, private duty nursing, medical or social adult day health services, camperships (a camp setting for the younger disabled providing recreational and social opportunities), care in licensed medical facilities and other options. Service limits are set through a cost cap.

Program clients are involved in service planning and some counties survey clients for satisfaction. Flexibility is created by allowing for non-standard services, providing emergency respite, having a process by which clients can petition for exemptions to some program restrictions/requirements, and allowing counties to use cost-share funds as desired within broad guidelines.

Even a respite-only program like SRCP does more than provide respite. In the process of funding respite services and linking clients to

these services, SRCP also provides needs assessment, care coordination, and information and referral. Furthermore, the program now offers caregiver training (not included in the budget figures provided) and has taken advantage of the synergies with respite, providing extra respite to enable caregivers to participate in the training.

Program challenges have included the difficulty of finding providers and budget restrictions (NOTE: the budget has recently increased). Program administrators feel that additional funds would benefit the program by allowing for a higher cost cap, a larger client volume, and increased staffing.

### ***Profile California Caregiver Resource Centers***

The California Caregiver Resource Centers (CRCs) grew out of the efforts of the country's first grassroots program for caregivers of adults with cognitive impairment (based on Feinberg and Pilisuk, 1999; <http://www.dmh.ca.gov/SpecialPrograms/Caregivers/caregive-overview.asp>; and <http://www.caregiver.org/crcC.html>; email communication with Lynn Friss Feinberg, August 10, 2001). This grassroots effort became a pilot for the state's CRC program, which was established in 1984 and targets the same population. The CRCs provide information and referral, assessment and care planning, counseling, support groups and psychoeducational groups, legal help, caregiver education and respite care. In support of the CRCs' work, the state also funds a Statewide Resource Consultant. The Consultant operates a clearinghouse, conducts applied research and policy development, carries out educational programs, and provides technical assistance and data support to the CRCs. The CRCs were a model for the National Family Caregiver Support Program.

Funding for the CRCs comes from state general funds and client contributions. In fiscal year 1999-2000, the state appropriation was \$9,247,000 (additional funds came from

client contributions) and 12,348 clients were served. Approximately 1,700 clients received respite, and total respite costs were \$2.59 million of which 10 percent came from client cost-share.

One of the important features of the CRC program is its wide range of respite choices, including the option to use independent providers, as described earlier. The program also actively seeks to provide families with the skills and support they need to take control of their own services. Another program strength from the point of view of its administrators is the diversity of supports it provides. Administrators describe as ongoing challenges the need for more respite funding, the challenges of providing consistent service statewide and the fact that the program only targets caregivers of the cognitively impaired.

The CRCs have developed a number of outcome measures, and preliminary analysis shows some key gains over a six-month period. Caregiver competency and confidence increased, as did their knowledge of brain diseases/disorders. In addition, although caregiver reactions to problematic behavior by care recipients remained the same, the number of incidents of such behavior decreased.

### ***Profile Oregon Lifespan Respite***

One of the recent innovations in respite has been non-categorical respite access programs. "Lifespan Respite" promotes the creation of community-based networks that facilitate access to respite for all families and individuals. The primary impetus for these programs is the fragmentation produced by having different programs serve different populations and the difficulties this creates for those attempting to obtain services. However, the networks address other problems as well, including the difficulties of finding providers and providing consumers with pertinent information about them, and consumers' need for supports beyond respite.

Oregon's Lifespan Respite Program, established in 1997, is the oldest non-categorical respite access program in the country, supporting caregivers who provide ongoing care to any individual with special needs. Oregon's program serves as the model for initiatives in a number of other states (Feinberg and Pilisuk, 1999, and Bowers, 2001).

In Oregon, the state provides start-up and ongoing funding to local networks, as well as technical assistance and resource coordination. The network partners include caregivers, providers, federal and state government agencies, Native American tribes, faith-based organizations, non-profit organizations and others. Each local network is run by a leadership council, which must be comprised of at least 51 percent caregivers, in order to create consumer control.

In 1997 (the first program year), each participating community received approximately \$15,000 from the state to develop its network. Each network is currently budgeted to receive state funds of \$30,000 to \$50,000 for biannual (2001-3) ongoing operating costs. Networks augment program funding through donations, agency agreements, and solicitation of grants.

Each network maintains a database of trained in-home providers, volunteers and facilities that provide respite services. The network helps families connect to payment options and providers. It also gives them information on providers' skill levels and backgrounds and provides referrals to related resources. Networks go beyond meeting the needs of individual consumers by identifying gaps in the services available in their communities, recruiting and training providers, sharing resources and generally working to increase community caregiving capacity.

Program administrators do note some challenges. First, potential users of respite

services are often slow to seek help. Second, and related, the general community may not always be aware of the importance of respite and of coordinating services. Third, it takes

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time to build a strong network that can respond rapidly to the needs of families. Fourth, the networks can steer families to payment options but these programs may not have adequate resources to serve them. A variant of Lifespan Respite – Oklahoma's Respite Resource Network program – attempts to address the latter problem to some extent by centrally pooling respite funds.

In addition to the Oklahoma program, Lifespan Respite programs similar to Oregon's are found in Nebraska and Wisconsin. Several other states currently are piloting Lifespan programs, have legislation pending or are in the program design stage. The National Respite Coalition has recently drafted legislation, entitled the National Lifespan Respite Bill, that would support the creation of respite access programs in all states.

#### CONCLUSIONS

Respite is a central element of most caregiver support programs, mirroring its perceived importance among consumers and program administrators. Over the last decade a body of research has developed that supports these perceptions, providing evidence that respite mitigates caregiver distress and helps to delay institutionalization – its two major goals.

Challenges for respite include developing a sufficient budget, bringing clients into the program at an earlier stage, obtaining service providers, serving all caregivers, creating flexibility and weighing different claims for control.

With the advent of the National Family Caregiver Support Program, a new—albeit limited—opportunity exists for funding respite programs, supplementing the other sources currently available. In designing respite programs, a number of key elements must be determined, in particular, program conception, funding sources, the scope of the program and the nature of services and how they are provided.

As policymakers increasingly seek to promote flexibility and consumer direction, paying family members to provide respite and direct employment of providers have gained attention as modes of service delivery, sparking debate. The Lifespan Respite model is another important trend in respite care, creating a coordinated system serving all populations, and engaging the state in supporting respite in ways beyond public financing (including addressing the problem of provider scarcity). The model can also be fashioned to promote consumer governance and can be used to pool funds, enhancing its capacity to promote respite as a key component in caregiver support.

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