

**Planned and Crisis Respite for Families with Children:
Results of a Collaborative Study**

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Executive Summary

Introduction

The Child Welfare League of America (CWLA), the ARCH National Respite Network and Resource Center (ARCH), and Casey Family Programs (CFP) National Center for Resource Family Support collaborated to lay the groundwork for the development of best practice standards for planned and crisis respite services. This work involved surveying CWLA and ARCH agencies about the planned and crisis respite services they provide, convening focus groups to discuss respite service issues, and studying the efforts of four jurisdictions to deliver respite care. For this project, respite is defined as temporary relief for primary caregivers. Respite services provide short-term care to children and adults with special needs, chronic illnesses, or those at risk of abuse and neglect. Planned respite is scheduled short-term care. Crisis respite is emergency care provided to children when the family is in crisis (Delapp, Denniston, Kelly, & Vivian, 1998). This report describes the survey's findings; documents approaches to funding, administering, and delivering planned and crisis respite services to families, as described in the case studies; and makes preliminary recommendations on expanding and enhancing these services to support families and caregivers nationwide.¹

Two Surveys on Respite Care Services

The first step in developing best practice standards is to gather information on the kinds of planned and crisis respite services available, how these services are provided, and the availability of these services in comparison to the need. CWLA and ARCH surveyed their respective members about planned and crisis respite care services.

CWLA members are primarily public and private nonprofit agencies that provide child welfare services. ARCH agencies provide mainly respite care.

- Compared with ARCH agencies, the 74 CWLA agencies responding to the survey reported serving a higher percentage of resource families and clients with a history or risk of abuse and neglect.
- Conversely, ARCH agencies responding to the survey reported serving more birth families and clients with developmental disabilities, mental retardation, or autism.
- Service providers in CWLA agencies were more often foster parents or paid staff members, while providers in ARCH agencies were more often paid staff members or private contractors.
- Recruitment of providers and compensation to providers reflected the different types of service providers used by CWLA and ARCH agencies.

¹ These include foster families, adoptive families, and kinship caregivers, who may be caring for relative children in either formal or informal arrangements. It should be noted that in this report the term "resource families" is used to refer to foster families, adoptive families, and kinship caregivers and to distinguish them from birth families. The term "families," without any modifier, includes both birth and resource families.

- Funding sources of CWLA and ARCH agencies also varied, with ARCH agencies receiving half of their funding from user fees and the United Way, and CWLA agencies receiving half of their funding from public sources.

Although the differences between CWLA and ARCH agencies highlight the variety of programs providing respite services around the country, there are also striking similarities.

- The majority of programs in both agencies provide planned respite care rather than crisis respite.
- Most families receiving services were in the low to lower-middle income range.
- The vast majority of families sought respite services voluntarily.
- More than half of the programs served families speaking a primary language other than English; yet few programs translated materials into other languages.
- Respite was generally available 24 hours a day, across all jurisdictions, and in large service areas.
- Respite was provided in numerous settings, but the most common locations for providing respite were the family's home and the respite provider's home.
- Fewer families and children received crisis respite than planned respite, yet there was a clear need for both planned and crisis respite services.
- The costs for CWLA and ARCH agencies to provide planned respite were similar, about \$10 per hour, which is less costly in both financial and social terms than placing children in out-of-home care. The national average (non-specialized) foster care maintenance payment was \$4,832 per year in 1998 (Child Welfare League of America, 1999) while ARCH estimates that providing 12 hours of respite each month costs \$1,422.88 per year.

The surveys provide new information about the nature and availability of planned and crisis respite nationally. The survey results not only reflect the similarities and differences in CWLA's and ARCH's members, but reveal common themes across providers and programs—all focused on meeting the needs of families in their communities.

Site Studies: Four Approaches

To obtain an in-depth look at how planned and crisis respite services are delivered around the country, four states or communities were interviewed. These sites use different approaches to meet the respite needs of families in their state or community.

Sites ranged from a single community respite network to a statewide respite coalition. Respite networks or coalitions varied in their focus—from addressing specific respite issues to supporting a respite voucher system to serving as a respite resource for the state. Each site attempted to tackle funding challenges in ways that fit its needs, by blending funding, contracting with the state public agency, or seeking funding from public funds or from funds designated to serve special populations.

Common elements were identified among the four sites. Whether formally or informally, each site organized a respite network or coalition to better meet the respite needs of families. All sites

mentioned funding as a challenge—either maintaining current funding, seeking new funding, or developing fiscal strategies to share funding between various sources. No matter how each community or state organized the delivery of respite services, its focus was on meeting the respite needs of families.

Although the type of families served varies by site, in general, adoptive, kinship, and birth families could access respite services. One site did not serve foster families. Foster families in the other three sites could access services only if respite providers were licensed foster parents. Two sites did not provide respite as an adoption subsidy item. One site did not provide respite for children whose birth families were receiving protective services.

Practice and Policies Issues in Respite Care for Families

A review of the literature and results from the surveys, focus groups, and site studies revealed numerous program and practice issues that may create challenges for families in need of planned and crisis respite services. Families may fail to take advantage of respite because they do not trust respite agencies or providers. Other families may want to use respite but find there is a shortage of respite providers or the type of respite service offered does not match their needs.

Resource families, which include foster families, adoptive families, and kinship caregivers, face some of the same barriers. Because of their involvement with the child welfare system, they may be even more restricted in their ability to access needed respite services. Regulations may limit the number of children in a respite provider's home. The pool of respite providers may be further depleted as providers become licensed foster parents. Cost plays a role, as foster care maintenance rates are not adequate to pay for respite. Resource families may also distrust agencies and providers, or fear being judged by them.

Funding for respite can come from various sources, depending on the particular need or population of the consumers. Funding sources used to provide respite services to families include the Community Based Family Resource and Support Program, Promoting Safe and Stable Families (Title IV-B, Subpart 2), Adoption Assistance, foster care programs, and the National Family Caregiver Support Program. Funding is aimed at strengthening families, reducing child abuse and neglect, facilitating adoption of children with special needs, and providing respite for foster families, relatives raising children, and family caregivers of older individuals. Each funding source has its own requirements and the availability of funds varies between and within states.

Recommendations

This inquiry into the current state of such programs reveals that, while the overall goal of family support is being addressed for some families, available services are insufficient to meet the needs of families. The following recommendations are offered as next steps in building a responsive and workable system of respite care.

- Address the concerns that families have regarding agencies and providers, such as lack of trust, fear of being judged, and other emotional barriers.

- Develop and promulgate best practice standards of respite and crisis care services, such as providing clear definitions of respite and crisis care, encouraging family involvement in the service plan, and ensuring safety of care.
- Conduct research on existing respite programs that can inform cost-benefit analyses for using respite to prevent child abuse and neglect, retain foster and kinship care homes, support the adoption of children with special needs, and prevent adoption dissolution.
- Educate families, child welfare workers, public and private agencies, the general public, and legislators about the benefits of respite for resource families and as a component in the prevention of child abuse and neglect.
- Support state and national efforts to legislate the creation and maintenance of lifespan respite networks. “Lifespan respite is a coordinated system of accessible, community-bases respite care services for caregivers and individuals regardless of age, race, ethnicity, special need, or situation.” (Kagan, 2001, p. 1)

This inquiry has confirmed the need for a comprehensive approach to planned and crisis respite care, including a national and state legislative strategy, additional research, a broad effort to educate child welfare professionals and the public about the value of respite for families, program and funding models, clear guidelines for practice, and practice tools. Such an effort will benefit families in the most tangible way: providing relief, support, and the respite resources needed to successfully care for children.

Introduction

Project Description

In 2001, the Child Welfare League of America (CWLA) and the ARCH National Respite Network and Resource Center (ARCH) launched an initiative to jointly develop Standards of Respite and Crisis Care for children and their families. CWLA and ARCH approached the Casey Family Programs (CFP) National Center for Resource Family Support, which has been interested in this area of service, especially as it applies to foster care, kinship care, and adoption.

CWLA, ARCH, and CFP collaborated to lay the groundwork for developing standards for respite and crisis care services. This work involved

- surveying public and voluntary child welfare agencies and respite care providers about providing respite and crisis care to birth, foster, kinship, and adoptive families;
- holding focus groups with key stakeholders on available respite services, unmet needs, and wishes for the future;
- identifying and studying three to four jurisdictions that have developed promising approaches in delivering respite and crisis care to families; and
- producing a report that describes the survey findings; documents promising approaches to funding, administering, and delivering respite and crisis care services to families, as described in the case studies; and makes preliminary recommendations regarding the expansion and enhancement of these services to support families and caregivers nationwide.

Information for this report is derived from mail and e-mail surveys of ARCH and CWLA members, as described in Section III, from case studies of four jurisdictions as described in Section IV, and from focus groups on respite care conducted by both organizations. ARCH led a focus group at its National Respite and Crisis Care Networking Conference in Sacramento, California, on August 23, 2001. This diverse group of agency representatives, providers, and consumers of respite services responded to a series of questions about the respite services available to families in their areas. CWLA conducted a focus group of foster parents and caseworkers at the Foster Family Treatment Association Conference in Atlanta, Georgia, on July 17, 2001. The responses of both focus groups are referenced in this report. There was no formal involvement of children or youth in the surveys, case studies, or focus groups; their participation will be included in future projects.

In addition to these surveys, the National Resource Center for Foster Care and Permanency Planning conducted a telephone survey during the summer of 2001, contacting foster care administrators in 45 states about the management of foster care services in those states. Some information from that survey is included in the discussion of respite.

Background

The deinstitutionalization movement of the late 1960s catalyzed a change in caring for people with disabilities. Children and adults who previously might have been placed in hospitals and other care facilities due to serious mental or physical conditions remained in their homes. Parents and other family members became primary caregivers, often with little or no assistance. Their loved ones needed round-the-clock care, and caregivers had no opportunity to do anything other than provide that care. Respite care programs emerged in response to the need for providing support to these families and caregivers (Edgar & Uhl, 1994).

In the 1970s, as the issue of child abuse and neglect rose in prominence, another type of respite appeared—crisis nurseries. These were designed to prevent abuse and neglect by providing temporary child care for young children at risk, while offering an array of support services to the families and caregivers of these children (Edgar & Uhl, 1994).

Since then, respite programs have grown to provide services for a wide variety of caregivers. Some groups serve specific populations of individuals with disabilities to support their families. Other agencies providing respite respond to the needs of multiple populations, and have either expanded their services or sought to coordinate with other groups to serve clients. The National Respite Coalition, formed in 1994, is working toward a vision of lifespan respite, defined as

a coordinated system of accessible, community-based respite care services for caregivers and individuals regardless of age, race, ethnicity, special need or situation...Special needs may include any disability, any chronic or terminal physical, emotional, cognitive or mental health condition requiring ongoing care and supervision, including Alzheimer's disease and related disorders, developmental disabilities, children with special medical needs, and any other condition determined by the state. Crisis respite may also be used to provide a temporary safe haven for the care recipient in the event of an emergency brought on by domestic violence, substance abuse, or a housing, health, or job crisis (Kagan, 2001, p. 1).

Respite services can improve family functioning, improve satisfaction with life, enhance the capacity to cope with stress, and improve attitudes toward the family member with a disability (Cohen & Warren, 1985). A recent evaluation study of families of children at risk of abuse or neglect found a significant decrease in child maltreatment reports and reduced stress in families using crisis respite services (Cowen, 1998).

Respite for Families with Children

ARCH differentiates respite/crisis care from child care or day care by describing respite as “temporary—it is child care offered for designated periods of time to allow a caregiver to tend to other family members, alleviate a work, job, health, or housing crisis; or to take a break from the stress of caring for a seriously ill child” (National Respite Coalition, 1998, p. 1). ARCH also

includes families of children with disabilities and other health care needs, and families under stress and at high risk of abuse or neglect as populations needing respite services.

Almost any family with children may be a candidate for planned or crisis respite care at some time. For many families, this need is addressed when parents vacation together, leaving children in the care of relatives or friends, or perhaps when children are sent to camp at the same time. Shorter respite is provided by baby-sitters when parents go out for an evening or by sending a child to sleep at a friend's house. For many families, however, these options are not available. Parents may not be able to take time off work or afford to pay for a vacation, camp for a child, or baby-sitting. Relatives may not be available to provide care. For families in which a child has special health care needs, parents may be unwilling or unable to ask others to care for the child.

Families with children may be nuclear, birth families with one or both parents plus the children, families in which one of the parents is a stepparent, and blended families. They may also be one of several types of families who provide care for children when their birthparents cannot or will not. These include foster families, adoptive families, and kinship caregivers (who may care for the relative children in either formal or informal arrangements). In this report, the term "resource families" is used to refer to all of these families, and to distinguish them from birth families. The term "families," without any modifier, includes both birth and resource families.

Why do families need planned and crisis respite services?

- All families need support and assistance from time to time. Some families may be particularly at risk due to financial, housing, and social stressors; substance abuse; mental illness; poor parenting skills; and domestic violence. Crisis respite provides a safe haven for children in families experiencing such challenges (Edwards-Sutton, 1995; Hardin, 1994).
- Without adequate family supports, children with disabilities are three to four times more likely to be victims of neglect, physical abuse, emotional abuse, or sexual abuse than children without disabilities (Sullivan & Knutson, 2000). Several studies cited by Kagan (2000) point to the value of respite as a service that reduces the risk of abuse and neglect, helps families avoid child protective services involvement and out-of-home placements, and improves family relationships.
 - A high percentage of the 581,000 children in foster care have behavioral or emotional disorders, developmental disabilities, learning disabilities, chronic and acute health problems, and other disabilities (Barbell & Freundlich, 2001).
 - More than 125,000 children with special needs are waiting to be adopted in the United States (U.S. Department of Health and Human Services, 2001b), and more than 167,000 children with public child welfare agency involvement were adopted in fiscal years 1995–1999 (U.S. Department of Health and Human Services, 2001a). Many children with special needs have physical, health, emotional, or behavioral problems; 88% of families adopting children from foster care receive subsidies to help meet these needs (U.S. Department of Health and Human Services, 2001b).
- An estimated 151,000 children in foster care in the United States are in formal placements with grandparents and other relatives (U.S. Department of Health and Human Services, 2001b). According to the National Survey of Families, in 1997, 1.3 million children were

living with relatives in private kinship relationships that are not formalized by the child welfare system. Another 300,000 children were placed with kin by a public agency but were not taken into state custody (Ehrle, Geen, & Clark, 2001). Children being cared for by kinship caregivers are often affected by conditions such as the developmental, behavioral, and physical effects of prenatal substance exposure; the effects of parental abuse or neglect; weakened immune systems; physical disabilities; and attention deficit hyperactivity disorder (ADHD) (Minkler, 2001).

- Grandparents caring for grandchildren are more likely to be living in poverty than those who are not. About one-third report their health status to be fair or poor (Kagan, 2000).

A variety of organizations in the fields of advocacy, medicine, and government support the need to provide respite services to families.

- Respite is an important component in the prevention of child abuse and neglect for all families. The Community-Based Family Resource and Support (CBFRS) program, established by Title II of the Child Abuse Prevention and Treatment Act (CAPTA) Amendments of 1996, includes respite in the list of services states are directed to develop to strengthen families and reduce the incidence of abuse and neglect (Denniston & Abdullah, 2001).
- The National Child Abuse Coalition (as cited in Kagan, 1998) states that planned and crisis respite care prevents child abuse by
 - minimizing the stress of working parents;
 - increasing the ability of parents to cope with the pressures of child care;
 - enhancing parent-child communication;
 - reducing family isolation;
 - improving family access to health and social services; and
 - offering family relief from the demands of daily child care.
- The American Academy of Child and Adolescent Psychiatry (2001), citing studies indicating that up to 80% of children in foster care have developmental delays or other mental health problems, calls for access to respite care for foster parents.
- The National Foster Parent Association (2001) “supports the development and implementation of respite care programs, with respite care providers being approved and reimbursed and compensated to care for children on a short-term, temporary basis. Respite care providers shall be support families for foster families, thus providing consistent care for foster youth. The National Foster Parent Association advocates that foster parents will receive at least two days of planned respite care per month for each child placed in their home.”
- ARCH’s position is that respite for foster parents is a preventive measure that “enhances the quality of care for the child, gives foster parents a deserved and necessary break, and ensures healthy and stable placements for all children.”
- The Public Policy Agenda of Generations United (2001) supports expanding and improving mental health and respite care services for grandparents and other relative caregivers (Barney, Levin, & Smith, 1994, p.3).

- The Children’s Defense Fund (2000) suggests that kinship caregivers can benefit from respite care programs that give caregivers, especially older grandparents, much needed rest from caregiving responsibilities.
- The Child Welfare League of America takes the position that agencies “should arrange for all foster parents to have access to respite care as needed” (1995, p. 104).
- Twenty-three states and the District of Columbia believe that respite is an important postadoption support component and specifically allow for respite as an adoption subsidy item (North American Council on Adoptable Children, 2001).
- Twenty-three states have statewide policies on providing respite care to foster families (Darer, 2001).

Despite this widespread support for the provision of respite services for families, families have limited opportunities to receive respite. This monograph describes the respite and crisis services available to birth, foster, kinship, and adoptive families; how these services are being provided; and the availability of services in comparison to the need for them.

Two Surveys on Respite Care Services

In the later half of 2001, CWLA and ARCH surveyed their members to gather information about respite services they provide. Both CWLA and ARCH are membership organizations, but with different member bases. CWLA members are public and private nonprofit agencies providing a wide range of child welfare services, of which respite is only one. In contrast, ARCH members provide respite care and may also offer other services.

CWLA first e-mailed its member agencies to ascertain whether they offer planned and crisis respite services. Detailed survey forms were mailed to the member agencies that indicated they provide respite and to the state public child welfare agencies that had not responded to the e-mail inquiry. Of the 161 surveys that were mailed or e-mailed to agencies, 74 agencies returned their surveys.² For the purpose of the survey, the following definition of planned and crisis respite was used:

Respite is temporary relief provided to primary caregivers in order to reduce stress, support family stability, prevent abuse and neglect, and minimize the need for out-of-home placement.

- Respite is provided to children with disabilities and other special needs, to children who have a chronic or terminal illness, and to those children at risk of abuse and neglect.
 - Families receiving respite can include intact families, foster and adoptive families, kinship families, and other caregivers.
 - Respite can be offered both in-home or in settings outside the home.
 - As a service to foster families, respite can help to reduce disrupted placements. (CWLA, 2001, p. 1)
-
- Planned respite services are and scheduled.
 - Crisis respite services are provided on an emergency basis.

The majority (59.7%) of programs responding to the CWLA survey stated that they offered both planned and crisis respite services by the definition provided; another 32.5% indicated that they offered only planned respite, and 5.2% offered only crisis respite.

ARCH has conducted a survey of planned and crisis respite programs annually since 1992. Its 2001 survey was sent to the 186 members of the ARCH National Respite Network. Fifty-five surveys were returned, representing respite programs in 29 states and Canada. Of these responding agencies, 54.7% offered planned respite only; 41.5% offered both planned and crisis respite; and 1.9% offered crisis respite only.

Administering Organization

Agencies responding to these two surveys differed significantly, reflecting the difference in membership between CWLA and ARCH. Compared with ARCH respondents, a higher

² One of the agencies responded for four different programs that provide respite.

percentage of CWLA respondents were public child, family, or adult service agencies (36% versus 4%) and family resource or support centers (13% versus 4%). Half of the ARCH agencies were private child, family, or adult service agencies (see Table 1).

TABLE 1.
Type of organization that administers the planned respite or crisis care services program

Administering Organization	CWLA Agencies	ARCH Agencies
Private child/family/adult service agency	40%	50%
Public child/family/adult service agency	36%	4%
Family resource/support center	13%	4%
Child or adult day care center	6%	2%
Mental health agency	6%	11%
Hospital/medical institution	3%	4%
Religious institution	3%	4%
Long term care agency	1%	2%
Other (primarily schools and agencies for person with developmental disabilities)	9%	20%

Consumer Description

The differences in responding agencies were reflected in different responses about the consumers of respite services.

- On average, 59.5% of families receiving respite from programs offered by CWLA member agencies in 2000 were headed by resource families (46% by foster parents; 9% by adoptive parents; 3% by grandparents; and 1.5% by other kin). This stands in marked contrast to the ARCH survey, in which only 15% of families served were identified as headed by resource families.
- Birthparents headed 34% of households receiving respite services from CWLA agencies and 73% of ARCH agencies.
- Families of all types with children (as opposed to families caring for adults who need respite) were the majority of consumers of respite services in both surveys.

Population Served by Respite Programs

- Although both groups served children with a range of disabilities, CWLA member agencies had a considerably higher percentage of clients with a history or risk of abuse or neglect. The largest percentage of clients in the ARCH sample had developmental disabilities, mental retardation, and autism (see Table 2).

TABLE 2.
Population served by planned respite or crisis care program

Population Served	CWLA Agencies	ARCH Agencies
History of abuse/neglect	83%	55%
Risk of abuse/neglect	75%	61%
Attention deficit disorder	73%	72%
Developmental disabilities	71%	93%
Mental illness	64%	64%
Physical disabilities	57%	78%
Mental retardation	53%	91%
Speech/language disabilities	51%	78%
Hearing impairments	44%	67%
Visual impairments	43%	63%
Autism	39%	94%
Medically fragile conditions	37%	51%
Chronic/terminal illness	36%	48%
HIV/AIDS	36%	31%
Substance abuse	34%	24%
Other	19%	23%
Adults with dementia	N/A	15%

- The most common conditions that made clients eligible for respite services from CWLA member agencies were risk of abuse or neglect (reported by 14% of responding agencies) and mental illness (13%), followed by developmental disabilities and history of abuse or neglect (both 9%). The low percentage of CWLA agencies identifying conditions for service eligibility may be because all children, regardless of condition, are eligible for their respite services.
- For ARCH member agencies, almost half (44%) listed developmental disabilities as a qualifying condition; one-third listed mental retardation, and more than one-quarter listed autism (see Table 3).

TABLE 3.
Condition to be eligible for planned respite or crisis care services

Qualifying Condition	CWLA Agencies	ARCH Agencies
Risk of abuse/neglect	14%	17%
Mental illness	13%	23%
Developmental disabilities	9%	44%
History of abuse/neglect	9%	13%
Mental retardation	6%	33%
Autism	5%	28%
Physical disabilities	5%	22%
Attention deficit disorder	5%	19%

Speech/language disabilities	5%	15%
Medically fragile conditions	5%	15%
Hearing impairments	4%	22%
Visual impairments	4%	19%
Chronic/terminal illness	4%	17%
HIV/AIDS	4%	7%
Other	4%	N/A
Substance abuse	3%	2%
Adults with dementia	N/A	6%

Family Income

- CWLA agencies served a slightly higher percentage of low-income families, although only two (2.6%) reported an income eligibility requirement. The majority of families using respite services from either CWLA or ARCH agencies fell below the \$35,000 income level. The ARCH survey report concluded that programs do not serve families from higher income levels because “it is likely that families in higher income categories are able to hire private nurses or other providers without going through respite agencies, as well as having strong personal networks and support systems to assist with respite needs” (ARCH National Respite Network and Resource Center, 2001, p. 8).

Ages of Consumers

- The majority of CWLA and ARCH agencies served children and youth up to age 19. Respite services from CWLA agencies are more readily available for children in the middle age ranges (4–12 years old) than for infants and teenagers. Only one-quarter of the respondents reported providing respite for young adults, who presumably have a disability or illness, although this was not specifically stated. A higher percentage of ARCH members served infants (87% versus 73%) and more than twice as many served young adults (56% versus 22%). Teenagers, however, were served at approximately the same rate. Almost one-half of ARCH respondents provide respite to adults and seniors, as well.

Primary Language of Consumers

- Both surveys found that more than half of the responding agencies provided services to families who do not speak English, with Spanish being the most frequently spoken language. Only 25% of ARCH members and 11% of CWLA members, however, had program materials available in language other than English.

How Families Learn About Services

- Only 3% of families served by ARCH agencies and 7% of families served by CWLA agencies are mandated to receive services to prevent abuse or neglect.
- Respondents to both surveys indicated that many families were referred by social service agencies (CWLA 46%; ARCH 42%) and, to a much lesser extent by medical professionals (CWLA 6%; ARCH 12%). Of families not referred for services, programs reported using a variety of methods to reach families:

- ◆ word of mouth;
- ◆ schools and early intervention programs;
- ◆ posters;
- ◆ public service announcements;
- ◆ newspaper advertisements; and
- ◆ other methods, such as community presentations or foster care program services (see Table 4).

TABLE 4.
How families learn about planned respite or crisis care services

How Families Learn About Service	CWLA Agencies	ARCH Agencies - method used	ARCH Agencies - families reached
Word of mouth	56%	74%	22%
Other methods such as community presentations, foster care program services	49%	N/A	N/A
Schools/early intervention programs	34%	57%	14%
Posters	17%	20%	1%
Public service announcements	17%	20%	1%
Newspaper advertisements	9%	20%	2%

- ARCH members, however, also indicated that they believed much lower percentages of their families actually learned about their services from some of these methods.
- Professional referrals and word of mouth, plus presentations directed specifically toward families, appear to be the most effective means of informing families about respite services.

Respite Program Description

Location of Service

- The sites at which services were offered were markedly different. Almost three-quarters of CWLA member agencies offered respite in the home of the provider, and 42% brought respite providers into the family’s home. These percentages were almost reversed among ARCH member agencies. In both groups, many agencies offered services in more than one setting (see Table 5).

TABLE 5.**Where respite and crisis services take place**

Location of respite/crisis services	CWLA Agencies	ARCH Agencies
Provider's home	73%	43%
Family's home	42%	68%
Residential facility	30%	24%
Day care center	22%	21%
Camp	17%	25%
Family resource/support center	14%	12%
Therapeutic child development center	8%	12%
Recreational facility	8%	19%
School	6%	12%
Hospital	4%	13%
Church	3%	6%
Other	22%	34% ³

Geographical Service Area

- CWLA and ARCH respite programs served geographical areas ranging from city, county, multicounty, state, and multistate. CWLA programs tended to serve larger geographical areas than ARCH programs. The majority of CWLA programs served a multicounty or state area while the majority of ARCH programs served a county or multicounty area.
- Respite services were available across urban, suburban, and rural jurisdictions, with more CWLA agencies serving urban populations (83% versus 65%). Service availability to suburban and rural jurisdictions was about the same (suburban: 73% CWLA versus 70% ARCH; rural: 71% CWLA versus 70% ARCH).

Program Service Hours

- The vast majority of agencies responding to both surveys indicated that they offered 24-hour care. This clearly differentiates them from child care services offered to families seeking regular temporary care during daytime hours and usually only during weekdays.

Direct Service Providers

- The two surveys describe different populations of individual direct service providers. More ARCH agencies employed paid staff members (64% versus 34%) or private contractors (34% versus 16%) who provide respite; whereas more CWLA agencies had foster parents that provide respite services (46% versus 5%). ARCH had slightly more volunteers who were not foster parents (6% versus 5%). Again, this reflects each organization's membership.

³ The majority of those who responded "other" indicated that respite was provided in community settings, such as taking care recipients shopping, to movies, or parks.

Compensation

- Reflecting the different population of service providers, compensation to non salaried staff varied between CWLA and ARCH agencies. Nonsalaried service providers in CWLA agencies received payment by billing the agency or through “other” methods, such as foster care payments. Nonsalaried service providers in ARCH agencies billed the agency or received direct payment from families (see Table 6).

TABLE 6.

How nonsalaried staff are compensated

Compensation to nonsalaried staff⁴	CWLA Agencies	ARCH Agencies
Bill the agency	61%	44%
Direct payment from families	21%	23%
Vouchers	6%	19%
Other (such as foster care payments)	23%	6%

Method of Recruitment

- Service providers were identified and recruited using the following methods:
 - ◆ materials and presentations at colleges;
 - ◆ materials and presentations at health care facilities;
 - ◆ materials and presentations at schools;
 - ◆ materials and presentations at social service agencies;
 - ◆ newspaper want ads;
 - ◆ posters in the community;
 - ◆ public service announcements; and
 - ◆ other recruitment methods aimed at groups (such as churches, community groups, and foster parents).

A higher percentage of ARCH agencies used newspaper ads and presentations at colleges and schools to recruit service providers. In contrast, a higher percentage of CWLA agencies used presentations at social service agencies, newspaper want ads, and other methods, such as obtaining referrals from foster parents and recruiting providers from the pool of current foster parents (see Table 7).

TABLE 7.

How service providers are identified and recruited

Recruitment of Service Providers	CWLA Agencies	ARCH Agencies
Other methods such as efforts aimed at churches, community groups, foster parents	57%	38%

⁴ The percentages do not total 100% because agencies could select more than one response.

Newspaper want ads	54%	77%
Social service agencies	49%	38%
Colleges	39%	75%
Schools	33%	60%
Posters	30%	38%
Health care facilities	27%	27%
Public service announcements	26%	27%

Differences in recruitment may be because a larger percentage of the ARCH providers were paid staff who are prepared to offer a level of medical care that is not necessary for most children served by CWLA agencies.

Fiscal Information

Funding Sources

- Funding for respite services is a patchwork of public and private money, much of it earmarked for specific populations or services. Answers to funding questions from the two survey groups indicate the extent to which funding sources can vary. ARCH member agencies, which served a higher percentage of individuals with disabilities, received more of their funds from health-related sources, including United Way agencies. Among ARCH agencies, about half of their funding source came from user fees and the United Way. CWLA agencies, however, reported that their largest funding was from state general funds (34%) with almost half of their funding from public sources (federal, state, county, and city) (see Table 8).

TABLE 8.
Percentage of planned respite or crisis care program funding from funding sources

Funding Sources	% of funding from this source	
	CWLA Agencies ⁵	ARCH Agencies
State general funds	34.0%	3.6%
City/county general funds	7.1%	13.8%
Private contributions, fund raiser, planned giving	7.4%	7.2%
Foundations	6.3%	6.1%
United Way/other local private funding	4.9%	31.1%
User fees	4.3%	20.1%
Social Services Block Grant/Federal Child Welfare Fund	4.2%	5.4%
Medicaid Waivers	3.8%	1.9%
Mental health funds	3.7%	4.2%

⁵ The sum does not total 100 because the total is a sum of averages

Promoting Safe and Stable Families Act	1.8%	0%
Community Based Family Resource and Support (CBFRS)	1.8%	.9%
Temporary Assistance for Needy Families (TANF)	.7%	.7%
Child Care Development Block Grant	.6%	.6%
Adoption Assistance/Opportunities Acts	.5%	<.1%
Profit-making business	.1%	<.1%
Tobacco settlement money	0%	<.1%
Maternal and Child Health Act	0%	2.3%
Other	10.0%	0%
“Unknown”	1.6%	2.2%

Program Cost

- The reported cost for CWLA agencies to provide respite and crisis care services, whether described in hourly or daily rates, varied widely.
 - ◆ The average cost of respite care was \$10.21 per hour.
 - ◆ The average cost of crisis care was \$15.43 per hour.
- The cost of respite and crisis care to ARCH agencies also varied.
 - ◆ The average hourly rate of pay for crisis care providers is \$8.71 per hour with a median of \$8.24 per hour.
 - ◆ The average rate of pay for planned respite providers is \$8.81 per hour. Added to the average administrative cost of \$1.21 for each hour of respite provided, the total average cost of providing respite is \$10.02 per hour.
 - ◆ Extrapolating from this hourly cost for planned respite care, ARCH estimates that it costs \$120.24 per month or \$1,422.88 per year to provide twelve hours of respite to an individual each month.
 - ◆ When used to prevent out-of-home placement due to child abuse or neglect, respite becomes a fiscal bargain compared to the national average (nonspecialized) foster care maintenance payment of \$402.67 per month, or \$4832.04 per year in 1998 (Child Welfare League of America, 1999).

Services Delivered

- The following two tables show total numbers served by planned and crisis respite care in 2000, as reported by respondents. CWLA’s and ARCH’s results indicate that while a greater number of families received planned respite than crisis care, many more hours of crisis care were provided per family. The large discrepancy between the hours of crisis care provided by CWLA agencies and by ARCH agencies may be because ARCH agencies have limited slots of crisis beds, whereas CWLA agencies that are involved with the child welfare system may have access to longer periods of crisis care (see Table 9).

TABLE 9.
Who is served planned respite care and crisis care

Planned Respite Care	CWLA Agencies	ARCH Agencies	TOTAL
Families served past week	1,064	1,987	3,051
Families served past year	3,187	9,242	12,429
Children and/or dependent adults served past year	7,906	10,305	18,211
Hours care provided	859,563	1,291,751	2,151,314
Hours care provided per family ⁶	270	140	173

Crisis Care	CWLA Agencies	ARCH Agencies	TOTAL
Families served past week	230	197	427
Families served past year	2,548	5,110	7,658
Children and/or dependent adults served past year	3,900	8,221	12,121
Hours care provided	2,087,354	298,785	2,386,139
Hours care provided per family	819	59	311

Need for Service

- Forty percent of CWLA agencies and 59% of ARCH agencies reported turning families away from planned respite care in 2000.
- Additionally, 23% of CWLA agencies and 59% of ARCH agencies stated that they have waiting lists for planned respite care.
- Thirty-six percent of responding CWLA agencies and 63% of ARCH agencies reported turning families away from crisis care services.
- In addition, 10% of CWLA agencies and 17% of ARCH agencies reported they have waiting lists for crisis care services.

⁶ This number was derived by dividing the hours of care provided by the number of families served in 2000.

Summary

The first step in developing of best practice standards was to gather information on the kinds of planned and crisis respite services available, how these services are provided, and the availability of respite in comparison with the need. To ascertain this information, CWLA and ARCH surveyed their respective members about planned and crisis respite care services.

CWLA members are primarily public and private nonprofit agencies that provide child welfare services. ARCH agencies mainly provide respite care. Compared with ARCH agencies, the 74 CWLA agencies responding to the survey reported serving a higher percentage of resource families and clients with a history or risk of abuse and neglect. Conversely, ARCH agencies responding to the survey reported serving more birth families and clients with developmental disabilities, mental retardation, or autism. Service providers in CWLA agencies were more often foster parents or paid staff members while providers in ARCH agencies were more often paid staff members or private contractors. Recruitment of providers and compensation to providers reflected the different types of service providers used by CWLA and ARCH agencies. Funding sources between CWLA and ARCH agencies also varied, with ARCH agencies receiving half of their funding from user fees and the United Way and CWLA agencies receiving half of their funding from public sources.

While the differences between CWLA and ARCH agencies highlight the variety of programs providing respite services around the country, there are also striking similarities. The majority of programs in both agencies provide planned respite care rather crisis respite. Most families receiving services were in the low to lower-middle income range. The vast majority of families sought respite services voluntarily. More than half of the programs served families speaking a language other than English, yet few programs translated materials to other languages. Respite was generally available 24 hours a day, across all jurisdictions, and in large service areas. Although respite was provided in numerous settings, the most common locations for providing respite were the family's own home and the respite provider's home. Fewer families and children received crisis care than planned respite, yet there was a clear need for both planned and crisis respite services. The costs for CWLA and ARCH agencies to provide planned respite were similar, about \$10 per hour, which is less costly in both financial and social terms than placing children in out-of-home care. The national average (nonspecialized) foster care maintenance payment is \$4,832 per year in 1998 (Child Welfare League of America, 1999) while ARCH estimates that providing twelve hours of respite each month costs \$1,423 per year.

The surveys provide new information regarding the nature and availability of planned and crisis respite nationally. The survey results not only reflected the similarities and differences in CWLA's and ARCH's membership, but revealed the common themes across providers and programs—all focused on meeting the needs of families in their communities.

Site Studies: Four Approaches

Respite services have evolved in response to the needs of various, often unique, populations. Beginning with specialized care for children with disabilities in the 1960's, respite providers gradually emerged to meet the needs of children at risk of abuse and neglect. In the 1970's, respite served medically fragile infants with conditions such as prenatal drug exposure, HIV/AIDS in the 1980's, and, in the 1990's children with serious emotional disturbances and adults with conditions like Alzheimer's. The most recent group to be identified as needing respite services is grandparents and other relatives raising kin.

As individual respite providers began caring for an increasingly diverse group of consumers, it became apparent that coordination and cooperation between small agencies would enable them to better meet consumer' needs, as well as access various funding opportunities emerging from federal, state, and local initiatives. The development of local networks is evolving into a national movement to create lifespan respite networks designed to provide a "coordinated system of accessible, community-based respite care services for caregivers and individuals regardless of age, race, ethnicity, special need, or situation" (Kagan, 2001, p.1). As the National Respite Coalition works for the passage of Federal Lifespan Respite Legislation, individual states and communities are addressing the need for comprehensive respite services through legislation, as well as through less formal coalitions of agencies, service providers, and consumers.

In this section we look at how four communities in different parts of the country are trying to address the respite needs of families. These programs represent a few of the many approaches being used to provide respite services to families with children. For a description of six states currently addressing Lifespan Respite on a statewide basis, see the state side-by-side comparison by the National Respite Coalition (2001).

Michigan: Blended Funding Provides a Range of Services

Individuals participating in the Michigan telephone site study included the directors of community respite centers, a county mental health respite coordinator, a funder, birthparents, and foster and adoptive parents. Geographically, they are in the southern portion of the state. Participants are members of the Michigan Respite Coalition, an informal workgroup seeking "to secure quality, accessible, planned and crisis respite services for all families and caregivers in need of such services in order to strengthen and stabilize families and enhance child and adult safety" (ARC of Michigan, 2001).

Respite services in Michigan, as in other states, are provided by a variety of organizations, each of which operates independently. Services available from each, therefore, depend on the organization's purpose, the population(s) it serves, the limitations imposed by state licensing requirements for some types of services, and by funding sources. For example, "child care centers" are not permitted to care for children on a 24-hour basis and a facility wishing to offer respite care for more than 24 hours would have to be licensed as a "child caring institution" (Michigan Department of Consumer & Industry Services, 2000).

Some providers focus strictly on the provision of planned respite for families with youth less than 18 years old who are developmentally delayed or severely emotionally impaired. Local Community Mental Health Boards set standards for determining qualifications for use of such services in their areas. Other independent agencies are free to determine their operating principles. There are two examples of such agencies.

- The Lansing Area Parents Respite Center, a private nonprofit organization, provides only planned respite services in the family's own home, in schools, and in its respite house. Serving a multicounty area with both urban and rural populations, it offers care during the day on weekdays and weekends, and planned overnight care for children through age 21 with a variety of disabilities. The vast majority (90%) of its clients are birth families, but it also serves foster and adoptive families and grandparents and other relatives caring for related children. Funding of services comes primarily from state general funds (see information on the Children's Trust Fund below) and from foundations.
- The Community Respite Center, a nonprofit private service agency, also provides planned respite services, but in a child day care facility. It offers day, evening, and weekend care, including overnight services, in an urban county. Its goal is to provide a continuum of services to meet the needs of families. One-third of its funding comes from regular child care user fees, a third is from annual contributions and gifts, and a third from grants. Child day care and respite care are provided in the same facility, requiring the Center to match the services it provides with the funding it is able to obtain. For example, children younger than age 16 with special needs are eligible for weekday respite care paid for by community programs; moneys from the Children's Trust Fund are used for overnight respite. Clients include a number of grandparents raising grandchildren, families whose children have special needs, and parents who are at risk themselves, often from substance abuse. Foster and adoptive families, as well as kinship caregivers, are served.

What these and other agencies in this area have in common is a reliance on blended funding from a variety of sources to facilitate the offering of different services, often under the same roof. Funders for just these two agencies include such diverse organizations as the Children's Trust Fund, United Way, private foundations, individual user fees, private contributions, city or county general funds, and TANF.

The use of creative blended funding has enabled organizations in Michigan to provide for a variety of clients. For example, several local YMCAs provide respite for grandparent caregivers during spring vacation, as well as day and weekly summer camps. The Macomb County Department of Senior Citizen Services receives funding from both the county budget and a local community foundation. (Minkler, 2001).

However, what all agencies have in common is a constant struggle to maintain funding and seek out new sources of support. Because there is no consistent way of accessing funds over time, agencies must sometimes scramble to make up for budget cuts that leave respite services, which are not mandated, unfunded. Funder's regulations may also be problematic; for example, money coming from the state's tobacco tax can only be used for children with serious emotional disturbance. Agencies have difficulty recruiting and retaining service providers because the rate

of pay they are able to provide is so low; participants in the site study expressed frustration at their inability to offer higher pay due to lack of funding.

The Michigan legislature established the Children's Trust Fund in 1982 as a nonprofit organization providing permanent funding for child abuse and neglect prevention, which is in turn funded by a check-off donation on the state income tax form. Other sources of financial support include direct tax deductible donations, fundraising, state and federal grants, and interest from the trust account. By law, half the funds collected through the tax check-off are allocated to local prevention programs across the state. Respite, both planned and crisis care, is included as a preventive measure. In addition to grants to the Lansing Area Parents Respite Center, this fund provides assistance to several organizations for the purpose of reducing stress in families in which children are at risk of abuse or neglect. To the extent that families meet the requirements of a grant, they would be entitled to participate in respite services (for example, any family caring for a developmentally disabled child could be eligible for respite provided by Lansing Area Parents Respite Center).

Respite is not an adoption subsidy item in Michigan, and no funds are provided for it. Resource and birth families have the same access to respite services for children with special needs. Although, there are licensing requirements covering respite for foster families and a lack of respite services for foster families. The Michigan Foster and Adoptive Parent Association runs a Family Resource and Support Center in Calhoun County that offers respite and day care services as a service to its resource families.

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Oklahoma: Using Vouchers to Support Family Choice

The Oklahoma Respite Resource Network (ORRN) is a collaboration of public and private agencies supporting families and caregivers by increasing the availability of respite care in the state. It is coordinated by the Oklahoma Areawide Services Information System (OASIS), a free statewide information and referral service that uses a computerized database to help the people locate resources for a variety of social services and health care needs.

Started in February 1998 with a pilot project involving 15 families in one county, ORRN served 1,200 families statewide in fiscal year 2002 and has more than \$1 million in funding from nine major funding sources. The majority of funds come from state agencies within the OK Department of Human Services and from Community-Based Family Resource and Support (CBFRS) funds through the State Department of Health, with additional grants from private foundations and state agencies and associations. ORRN has “no officers, no budget, and no bylaws” (Oklahoma Respite Resource Network, 2001 p. 2). Funding is used to support a voucher system that allows qualifying caregivers to manage their own respite needs.

The only qualification standard for accessing ORRN funding is an income limitation; families earning over \$60,000 per year or those receiving particular types of waiver services or assistance payments from the Developmental Disabilities Services Division (DDSD) or Aging Services Division cannot participate. An exception to the income limitation is for certain caregivers whose funding comes through Aging Services, including grandparents raising grandchildren; there is no limitation for these families.

Application is through OASIS, which then sends it to the appropriate funding source for a determination of eligibility for services. Approval depends on funding availability and may take two months or more. Each funding agency can establish its own eligibility criteria based on income, age, disability, or geographical location. Families with the following needs are supported:

- adoptive parents of a child who was formerly in the custody of the Department of Human Services (DHS) and who needs health and behavioral supports;
- parents of a child participating in the DHS SSI-Disabled Children’s Program;
- caregivers providing care for a person with a developmental disability who is not receiving DHS Developmental Disabilities Services Division waiver services or the Family Support Assistance payment;
- caregivers with a family member age 60 or older who is not receiving Advantage waiver services;
- caregivers with a family member with an acquired brain injury, such as, multiple sclerosis, stroke, dementia, shaken baby syndrome, closed-head trauma;
- grandparents raising a grandchild;
- families with children being served through a mental health center that is contracted with the Department of Mental Health Substance Abuse Services;
- two-parent families with children under age 18 who have a disability;
- caregivers caring for a family member or domestic partner with a catastrophic illness; and
- gap funding is available through two grants, so that no one is left behind (Oklahoma Respite Resource Network, 2001, p. 13).

Once approved, the caregiver is issued vouchers for \$300 or \$400 per quarter (depending on income). These vouchers are used by the caregiver to purchase respite services in any way they

choose, negotiating with any selected provider for an hourly, daily, or weekly rate of payment. Providers must be at least 18-years-old, and can be anyone except a spouse, parent of a minor, legal guardian, or family member who lives in the same house as the person needing respite. After services are provided, the voucher is completed and returned to DHS, which then issues a check to the provider.

Participants in our telephone site visit with Oklahoma were representatives of OASIS, several divisions within DHS, the parent of a child with disabilities, and a grandparent raising a grandchild. All were uniformly enthusiastic about the voucher system as it is being used by ORRN for many reasons, including that

- families are the experts in the care of their own members and are best able to select and train providers with whom they feel comfortable;
- families have developed their own support systems and respite resources over time. By providing for the funding of these services, families do not have to turn the care of their loved ones over to strangers;
- families feel empowered by the process;
- families are able to negotiate their own payment rates, resulting in lower costs;
- DHS is relieved of the responsibilities of certification, licensing, training, and running background checks; and
- there are no liability issues for DHS because families are responsible for hiring, training, and firing providers.

In addition to administering the voucher system, OASIS maintains a registry of respite providers, who are listed on the basis of information they provide. Listing does not constitute a recommendation. Families who use the registry are responsible for evaluating providers themselves.

Adoptive families and informal kinship caregivers are treated the same as any other families in this system, and grandparents caring for grandchildren do not have to adhere to the general income limitation. Foster parents, however, cannot participate in the voucher program. State policy requires foster parents wishing to use alternate short-term care to identify a caregiver, who must then be approved with a background check by DHS. Even informal babysitting arrangements must be documented, although a background check is not necessary (Oklahoma Department of Human Services, n.d.).

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Arizona: A Community Network Start-Up

Approximately 15 agencies in the Tucson, Arizona, area offer respite services. Each runs a program that serves a particular population, and services are dependent on whatever regulations and policies may be required by its funding source(s). However, a group of respite providers in Tucson is actively working toward developing a community-wide respite network. They have approached the effort systematically, meeting monthly to address specific issues and determine action steps. The agencies have taken particular care to identify both practice and policy challenges that they face in developing a program that will effectively meet the needs of their community. The list of challenges to be addressed may be instructive to other groups working toward community collaboration in the provision of respite services. Identified challenges include:

- defining what respite is;
- funding;
- building a sufficient pool of providers;
- getting everyone (agencies, providers, and consumers) to the table;
- sharing information, providers, or resources;
- meeting the needs of diverse client populations;
- requiring different skill requirements of providers depending on the clients served;
- following various regulations depending on agency connection, funding, and legal status;
- resolving insurance liability issues (such as child safety, loss and damage, provider protection, and agency protection);
- changing community perception that families are doing well enough on their own;
- overcoming family reluctance to use respite services;
- setting standards;
- arranging payment for services;
- determining which agency provides what services;
- meeting licensing standards;
- obtaining Department of Developmental Disabilities certification;
- improving provider to client ratios; and
- providing sibling care.

Having established their identity as the Community Respite Care Network, members are now addressing these issues in a variety of ways.

Members of the collaboration agreed to define respite as “planned or unplanned short term care for special needs children/adults for the purpose of temporary relief to the primary caretaker and/or the child/adult in need of care. Relief may be provided in the caretaker’s home or out of their home” (S. Abagnale, personal communication, November 8, 2001).

Surveys have been distributed for completion by providers, to determine current services available, and by consumers, to determine both current use of services and need for additional services.

The National Foster Parent Association (NFPA) presented a workshop on the development of a respite program to network members.

Subgroups have been assigned to do specific work around marketing, funding, recruitment, and management, with information-gathering the first step to be undertaken by each group.

As this group moves forward with its planning, it hopes to learn from the experiences of respite networks in other states by seeking out contacts and resources, such as manuals and guidelines.

The long-term vision of the Network is to

- work toward common minimal standards of care for the community;
- pursue collaborative funding opportunities;
- explore ways for the agency representatives and members to work together (including marketing, recruitment, training, and shared families);
- examine the feasibility of the Network developing its own pool of respite families who can work with multiple populations;
- promote cooperation and coordination of services; and
- reduce duplication of efforts.

Foster families in Arizona are eligible for six days per year of respite care, which must be provided by licensed foster families. Twelve days of respite is available to special needs adoptive families as a subsidy item.

The use of respite as a child abuse preventive measure for families involved with the child welfare system is not currently supported by state programs. Arizona does not provide respite services to children whose birth families are receiving protective services, which includes “families who are unable to provide child care for a portion of a 24-hour day due to a crisis situation of domestic violence or homelessness; a physical, mental, emotional, or medical condition; or participation in a drug treatment or drug rehabilitation program; or court ordered community service” (State Plan, 2001, Appendix 2). Services to these families are considered “child care” rather than “respite care” and are funded through the Child Care and Development Fund (CCDF). Senate Bill 1435, introduced to the Arizona State Senate in early 2001, called for the establishment of a program that would provide up to two weeks free respite for parents, guardians, and custodians “who need temporary assistance from child protective services and who have not been the subject of a substantiated report (p. 7).” This interesting approach to providing respite as a child abuse preventive measure did not win approval.

Only one of the 15 agencies in the Tucson area offers crisis respite services. Insufficient funding is considered to be part of the reason for this, as crisis care in this community is seen as requiring a center-based facility as opposed to care in the home of either the client or the provider.

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Florida: A Businesslike Approach

The Florida Respite Coalition is a nonprofit formed in the fall of 1997 to address the needs of families in the state for respite care. During its first four years the Coalition has expanded its base to 300 members and contracted with the Department of Children and Families to develop a statewide lifespan community-based respite care system. The Coalition recently hired a full-time Executive Director and is planning to bring five regional coordinators and a director of development on board in 2002. They will be governed by a 21-member board. The mission of the Coalition is to “ensure that each caregiver in need of respite will have access to available, affordable, and quality respite care services” (Varnadore, 2001, p. 3).

Under the leadership of its Executive Director, the Coalition has developed a business plan that seeks to address the terms of its contract with the state to

measure the need for respite care, identify populations respite care programs currently serve, address service gap areas, and design a system that will:

- Support respite care providers
- Foster additional development of respite care programs
- Build capacity to meet identified need and projected growth
- Provide financial assistance to respite care providers
- Develop a statewide provider directory
- Develop quality assurance standards
- Provide technical assistance to respite care providers
- Provide information and resources to families
- Provide respite options to families
- Provide continuous training to families and providers
- Ensure emergency respite is available (Varnadore, 2001, pp. 3–4)

The Coalition sees its primary work over the next three years as completing its transition from a grassroots volunteer organization to one capable of taking on a full-range of professional business functions, including needs identification, public relations and marketing, lobbying, developing an integrated management information system, developing standards of care, developing and maintaining relationships with the insurance and health industries, funding, fiscal management and oversight, technical assistance, and advocacy. The Coalition will not be involved in the provision of respite services, but will serve as an outreach, educational, and resource coordinator for the entire state.

Like all of the groups we contacted, the Florida Coalition defines funding as one of its major challenges. What makes this group different is its approach to overcoming the challenge and incorporating fragmented funding sources into a coordinated system that enables regional groups to access appropriate funds to meet the needs of their populations. By making passage of funded federal and state lifespan respite bills one of its top priorities, the Coalition hopes to become the

primary funding mechanism for legislative respite care dollars. In addition, it plans to work politically and legislatively to identify and consolidate funds earmarked for respite. The Coalition believes it will then be able to leverage these state and federal funds for match to local communities, as well as to approach foundations, corporations, and other funders for additional revenue.

A second area the Coalition envisions creating is a comprehensive information and referral system supported by a management information system that uses technology, such as a statewide toll-free telephone number and an online resource database that will provide families, caregivers, providers, and the general public access to respite services throughout the state, as well as information on training, funding, volunteer opportunities, legislative awareness, general respite information, parent support groups, and scheduled board and focus group meetings.

The Coalition is also interested in integrating standards of care and a provider training program. Both standards and training would address the need to provide competent, safe, and when appropriate, medically correct care; liability issues for providers, for the state, and for the Coalition; and the desire of some constituencies to provide consumer-directed care. Florida is already facing challenges in coordination between standards and training requirements, such as recently mandated medication administration training that is neither funded nor regulated by the state. The Coalition is proposing a proactive approach, planning to develop its own standards by the conclusion of its second year instead of waiting for other organizations to impose requirements that will be difficult to implement.

Unlike Oklahoma, which welcomes consumer-directed management of respite as an opportunity to bypass regulatory and liability issues, Florida is eager to establish regulations that protect consumers of respite, as well as providers and the Coalition. One issue it is struggling with is how to handle respite provided by volunteers, who could not be regulated in the same manner as those receiving funds through the Coalition. They also want to identify and respect families providing care on an informal basis, and do not want to ignore them when creating training and accreditation, but believe they would have to make a disclaimer about not ensuring quality of care. One solution they are considering is to include volunteer organizations in their database, but identify them with a disclaimer about liability.

The Coalition's current contract is funded under CBFRS (see Section III) on a cost reimbursement basis. The only other funding they receive is from membership fees. At the end of the current contract, the Coalition envisions negotiating a new that will enable it to be paid on a unit basis for resource and referral services and to seek other funding streams.

Respite for foster parents is governed by legislation that requires respite providers to attend training similar to that required of foster parents. Foster families are permitted 12 days of respite per year. Many foster families provide respite for one another. Respite is not available through adoption subsidy in Florida.

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Summary

Four communities were interviewed for a more in-depth look at how planned and crisis respite services are delivered around the country. These sites are using various approaches to meet the respite needs of families in their state or community.

Sites ranged from a single community respite network to a statewide respite coalition. Respite networks or coalitions varied in their focus—from addressing specific respite issues, to supporting a respite voucher system, to serving as a respite resource for the state. Each site has attempted to tackle funding challenges in ways that fit their needs: blending funding, contracting with the state public agency, seeking funding from public funds or from funds designated to serve special populations.

There were some common elements between the four sites. Whether formally or informally, each site organized a respite network or coalition to better meet the respite needs of families. Funding was a challenge mentioned by all sites—either maintaining current funding, seeking new funding, or developing fiscal strategies to share funding between various sources. No matter how each community or state organized the delivery of respite services, their focus was on meeting the respite needs of families.

Although the type of families served varies by site, in general, adoptive, kinship, and birth families could access respite services. One site did not serve foster families. Foster families in the other three sites could access services only if respite providers were licensed foster parents. Two sites did not provide respite as an adoption subsidy item. One site did not provide respite for children whose birth families were receiving protective services.

Practice and Policy Issues in Planned and Crisis Respite for Families

The following issues were identified from a brief review of the literature, results of the CWLA and ARCH surveys, focus groups, and site studies.

Barriers for Families

Although families often need the break that respite care can provide, some families fail to take advantage of respite opportunities that may be available to them.

Lack of Trust

Lack of trust in the agencies, institutions, and providers involved in the provision of respite services is often cited as a primary reason for failure to take advantage of existing respite care resources:

A family's previous experience may affect their level of trust. For example, it has been suggested that parents of children with serious emotional disturbances may distrust the human service system because of a traditional bias toward blaming the family for the child's problems (Sturtevant & Elliott, 1994).

Shortage of Providers

A common thread in the surveys, focus groups, and literature on respite care is the insufficient pool of competent respite care providers. In some cases, agencies do not share information about respite because the shortage of providers prevents them from helping families take advantage of respite allowed by policy. Respite care, like other child care work, is generally low-paid and undervalued by funders. It is difficult to find individuals who are willing to do this work for the little compensation provided, and families are sometimes uncomfortable turning over their children to those who are willing to work for so little. When trained medical care or the ability to handle children with behavioral problems or emotional disturbance is needed, it may become even more difficult to find a provider with the training necessary to provide appropriate care.

Location of Service Delivery

A participant in our Florida site study brought an additional barrier to accessing respite care to our attention: some respite services are only available in the family's own home. This has the unintended consequence of forcing the family members to leave their home and possibly have to spend money for food or entertainment in order to take advantage of respite. This becomes an economic issue for families. It is also a matter of preference for families who might wish to have an evening or weekend at home without the burden of caregiving and who may want to give the individual requiring care the opportunity to experience a different environment. On the other hand, participants in the Oklahoma site believed respite care should be provided in the family's own home so that the child experiences the least disruption. Families may have their own preferences that may not match the type of respite service that is offered.

In a focus group conducted at the ARCH National Respite and Crisis Care Networking Conference in Sacramento, California on August 23, 2001, the following responses were given to the question, “What barriers exist for families trying to access respite care?”

- Knowing about it; awareness
- Finding providers
- Number of respite slots available
- Limited funding—most dollars come from state agencies
- Fear that children will be removed; stigma; “looks bad”
- Lack of trust
- Guilt
- Perception that respite agency is connected with child protective services
- Limits of the agency (for example, agency services physically disabled, but family seeking respite for mental health needs)
- Geography—where the respite providers are located
- Ages of children
- Number of children; sibling groups
- Timeframes—too short or too long
- Level of disability of the children
- Paperwork to register—families too overwhelmed to go through lengthy process; literacy; language barriers; repetitiveness; lack of interagency coordination
- Confidentiality

Barriers Specific to Resource Families

Children who are in the care and custody of a state or local child welfare agency are the responsibility of that agency, no matter where the child resides. Agencies control, to the extent they are able, the quality of care these children receive by screening caregivers, running criminal and child abuse background checks, assessing the home environment, setting training and other requirements, and certifying or licensing homes before children can be placed in them. This applies to kinship caregivers as well as to nonrelative foster families, although some rules may be relaxed when the caregiver is a relative. Rules may also vary depending on whether the relative is receiving a foster care payment. It is reasonable, therefore, that agencies regulate the safety of the same children when they are in the care of respite providers.

Of states with specific policies on respite for resource families,

- five require all respite providers to be licensed foster parents;
- five more have licensing requirements but permit other individuals who know the child well to provide respite;
- two include licensed respite providers or child day care providers;
- three require background checks;
- one uses agencies under contract;

- only two have no licensing or approval process; and
- even in states without statewide policies, licensing is required in four (Darer, 2001).

Unfortunately, this need for regulation may inhibit the ability of foster parents and formal kinship caregivers to take advantage of respite services. Foster homes are in short supply throughout the country. In 1999 there were approximately 133,000 homes available for more than 500,000 children in out-of-home care (Casey Family Programs National Center for Resource Family Support, 2002). When families interested in providing respite care are required to complete the same licensing process as foster families, they may be discouraged by the lengthy training process and the requirements for background checks, fingerprinting, and other steps in the approval process.

Even in states in which foster parents provide respite for one another on an informal basis, regulations may be problematic. Many states limit the total number of children who can be cared for in a foster home. If the selected respite provider has no spaces left for additional children, even on a temporary respite basis, the foster family seeking respite may not be permitted to use that provider. Clearly, it is not sufficient for a state to only have a policy in place entitling resource families to respite care. There must also be funding, availability of services, ready access, and ease of use for resource families to turn the policy into practice. The National Resource Center for Foster Care and Permanency Planning (2001) suggests that as organizations develop respite networks, they take foster care regulations and other state-approved licensing guidelines into account up-front. In this way, they can have a pool of respite care providers that already meet the requirements to provide respite for children in foster care.

Once licensed, respite homes may become foster care homes, thus removing them from the pool of respite providers. In fact, some states take advantage of the fact that providing respite care may also be a path to foster parenting. A foster parent recruitment effort in the state of Washington targeted families who could foster children with disabilities. Some responders, not ready to commit to foster care, were interested in providing respite care as a means of gaining experience and gauging their ability to provide longer-term care. Further investigation revealed that a large percentage of foster parents had, in fact, been introduced to caring for children with disabilities by providing respite services. Agency staff developed a continuum of services that provided both “existing foster families with respite care and...prospective foster parents with short-term experience in caring for a child with special needs” (Siegel & Roberts, 1989, p. 552).

While some states cover payments for respite services through direct payments to providers or reimbursement through the resource families, some have the expectation that respite services will be paid for out of the existing foster care maintenance rate or adoption subsidy. Even if funds are built into these payments for the purpose of paying for respite, resource families may be less likely to apply non earmarked funds for respite, since they have other expenses related to the care of the child. Some reimbursement rates for respite care, while identified specifically for that purpose, are quite low, making it difficult for resource families to find quality caregivers willing to accept the rate offered. Some examples of rates allowed by states for foster care respite are: Hawaii, \$20 per day; Louisiana, \$25 per day; and Wyoming, \$14.50 per day (Darer, 2001). These rates do not compare very favorably with ARCH’s estimate that the cost of planned respite care averages \$8.81 per hour, not including administrative costs.

Other barriers frequently identified by resource families is the lack of trust in respite providers and programs, and the possibility of facing stigma for using respite.

- In a review of respite programs for grandparents and kinship caregivers, difficulty trusting respite caregivers was identified as a common challenge (Meisel, 1999).
- Adoptive parents, too, may fear that accepting respite points to an inability to care for their child, or be afraid that respite providers will not be able to manage behaviors or care for special needs (Goldsmith, 1994).
- The U.S. Department of Health and Human Services (1994b) identified several factors involving trust that kept foster parents from accessing respite services. Foster parents feared that: respite providers were evaluating their performance as foster parents; respite providers could not adequately care for the children in foster care; and the use of respite care would demonstrate their own inability to cope with the demands of foster caregiving.
- Resource families' fears about being judged if they use respite may not be completely unfounded. As an example, one state representative, responding to the National Resource Center for Foster Care and Permanency Planning telephone survey (Darer, 2001) expressed the opinion that respite might allow foster families to treat foster children differently than biological children, such as by not taking them on family vacations.

Barney, Levin, and Smith (1994) pointed out additional concerns that foster parents may have about taking advantage of respite services:

- feeling that, since being a foster parent is voluntary, they should not “need” respite;
- afraid that use of respite services would be a sign that they are not fit to be foster parents;
- worry about handling paperwork;
- fear of damaging their status, having children removed from their homes, or losing their licenses if a problem occurs during a respite stay; and
- concern that respite providers may undo progress made in a child's behaviors.

Funding and Policy Issues

Funding for respite services that can be accessed by families comes from many different sources. Most of these funds come with restrictions on either eligibility requirements or specific services provided. The problem for an individual family, agency, or provider is to locate a funding source that will pay for the particular services needed.

The four sites contacted for our study all cited funding as a major concern, and all demonstrated considerable effort in locating funding and matching it to the needs of their consumers.

Below are some funding sources that are frequently used to provide respite services to families.

The Community Based Family Resource and Support (CBFRS) Program

This program, established by Title II of the Child Abuse Prevention and Treatment Act (CAPTA) Amendments of 1996, was designed to support state efforts to create and operate statewide networks of community-based, family-centered, prevention-oriented family resource and support programs with the goal of strengthening families and reducing the incidence of child abuse and neglect. One lead agency in each state applies for and administers these funds. Information about each state, including respite programs funded under CBFRS, can be found in the one-page summaries of the states' fiscal year 1999 performance reports prepared by the FRIENDS National Resource Center for Community-Based Family Resource and Support Programs (2001). The summaries can be accessed on the Internet at www.chtop.com/friends/Summaries.htm.

Promoting Safe and Stable Families

This block grant program seeks to preserve families by strengthening families and preventing and reducing child abuse and neglect. Funds are based on the number of children in the state receiving food stamps and require a 25% state match; they can be used to pay respite and crisis care providers and to develop and maintain provider networks. States set their own requirements for both consumers and providers. On January 17, 2002, President Bush signed into law the reauthorization of the Promoting Safe and Stable Families (PSSF) program (107-133, H.R. 2873). This legislation reauthorizes PSSF for five years with mandatory funding set at \$305 million, a continuation of the same level of funding. The reauthorization allows Congress to supplement this funding with discretionary funds on an annual basis. For this year Congress appropriated an additional \$70 million in discretionary dollars bringing PSSF to a level of \$375 million in fiscal year 2002

Adoption Assistance

States receive federal funds under the Title IV-E Adoption Assistance program to provide subsidies as an incentive to families adopting children with special needs to facilitate the adoption. Subsidies may be paid by federal or state funds, or in combination, depending on the eligibility of the child, and each state administers its program separately. Subsidy agreements are negotiated before the adoption is finalized, but may be renegotiated. Agreements may include monthly maintenance payments, medical coverage, and other services including respite care, if permitted by state and county policies. Twenty states do not include respite in their subsidy agreements, although respite may be available through state offices providing services in specific areas such as mental health or developmental disabilities; 18 states may include respite funds or services, but eligibility is limited by factors such as health or mental health status or total subsidy being paid to the family; 12 states and the District of Columbia fund respite or provide it as a service, usually for a specific number of days per month or year. For a description of each state's position on respite, as well as other provisions of their adoption subsidies, see the North American Council on Adoptable Children's *State Adoption Subsidy Profiles* (2001) at www.nacac.org/subsidy_stateprofiles.html.

Foster Care Programs

According to Darer (2001), at least 22 states build respite for foster families directly into their programs, either offering or allowing a set number of days per year. This varies from 4 to 36 days per year, and depends in some states on the level of foster care being provided. Another 10 states will authorize respite on a case by case basis, often with a requirement of demonstrated need; 12 states and the District of Columbia have no statewide policy, often because foster care services are administered on a county or regional level. The remaining 5 states did not participate in the survey. Of those states with respite policies, the majority required respite providers to be licensed, either as foster parents or as respite providers. Several allow other individuals who know the child well, such as relatives or neighbors, to provide respite, generally after attending some training or undergoing a background check. The most common difficulty cited in providing respite is a shortage of providers, a particular problem when providers must be licensed foster homes and states are facing shortages in the number of homes available for foster care. In states without policies, foster parents often provide respite for one another on an informal basis.

National Family Caregiver Support Program (NFCSP)

This portion of the Older Americans Act provides \$125 million for support services to family caregivers of individuals 60 and older and grandparents and other relatives 60 and older who raise children. Ten percent of funds can be used for support services (including respite care) for older grandparents and other relatives raising children, although states are not required to do so. Initial funding under this act was released in early 2001. For information on implementation of the NFCSP in a particular state, contact the State Unit on Aging. Contact information for each state is available on the website of the Administration on Aging at www.aoa.gov/aoa/pages/state.html.

There are various funding sources for families seeking respite because of a child's medical, developmental, behavioral, emotional, or mental health status, all of which can apply to resource families as well as to birth families. Lists of federal funding sources are provided by ARCH (1999) and Day (1999). (See Section VII for complete references.)

Summary

A review of the literature and results from the surveys, focus groups, and site studies revealed numerous program and practice issues that may create challenges for families in need of planned and crisis respite services. Families may fail to take advantage of respite because they do not trust respite agencies or providers. In other cases, families may want to use respite but there is a shortage of respite providers or the type of respite service offered does not match their needs.

Resource families, which include foster families, adoptive families, and kinship caregivers, face some of the same barriers. Because of their involvement with the child welfare system, they may be even more restricted in their ability to access needed respite services. Regulations may limit the number of children in a respite provider's home. The pool of respite providers may be depleted as providers become licensed foster parents. Cost plays a role as foster care

maintenance rates are not adequate to pay for respite. Resource families may also distrust agencies and providers or fear being judged by them.

Funding for respite can come from various sources, depending on the particular need or population of the consumers. Funding sources that provide respite services to families include the Community Based Family Resource and Support Program, the Promoting Safe and Stable Families (Title IV-B, Subpart 2), Adoption Assistance, foster care programs, and the National Family Caregiver Support Program. Funding is aimed at strengthening families; reducing child abuse and neglect; facilitating the adoption of children with special needs; and providing respite for foster families, relatives raising children, and family caregivers of older individuals. Each funding source has its own requirements and the availability of funds differs within states and between states.

Recommendations

Organizations and communities are growing more interested in the development of respite care programs to support families of children with special needs, resource families, and for child abuse and neglect prevention. This effort to explore the current status of respite programs for families with children was a first attempt to describe the overall nature of existing services and some of the major issues involved in providing them. Our inquiry into the current state of such programs reveals that, while the overall goal of family support is being addressed to a greater degree than in the past, the services available are insufficient to meet the needs of families. We offer the following recommendations as next steps in defining and creating a responsive and workable system of respite care.

Address the concerns that families have regarding agencies and providers.

Information obtained from site studies, focus groups, telephone surveys, and the literature all point to lack of trust as a major barrier to families accessing respite services. It is essential that agencies and organizations seeking to provide respite care build a higher level of trust with their families, beginning with reaching out to gain an understanding of the particular issues that concern their client population(s). This outreach should include children and youth's opinions about respite care. Once specific issues of trust are identified, efforts can be made to promote better relationships and to address and resolve systemic problems that present barriers. Initiatives undertaken in a particular jurisdiction would depend on locally identified needs, but might include such diverse efforts as exploring the attitudes of agency staff, including families on planning or review boards, offering specialized training to respite providers and agency staff about respite care as a valuable and needed service, media outreach campaigns, and presenting clear messages to families and staff about the value of respite care. Similar efforts should be made to assist families with issues of guilt, sense of duty, fear of being judged, and other emotional barriers to accessing respite services.

Develop and promulgate best practice standards for planned and crisis respite services.

There are no national standards for the provision of respite and crisis care services. Communities and states vary widely in the expectations, regulations, licensing, and legislation that apply to respite care providers. The development and dissemination of national standards would provide important guidance to the field about how to best develop and deliver these services. Issues to be considered in developing standards include

- clear definition of what respite is and is not;
- quality of care;
- safety of care;
- flexibility of services;
- family involvement (including children and youth) in the service plan;
- basic safety training;
- training for providers;
- support for providers;
- provider to client ratios;
- supervisory caseload ratios;

- provider rates and reimbursement;
- in-home vs. out-of-home care requirements;
- expectations of services to be received;
- value of services to the child, as well as for the caregiver receiving respite;
- involvement of the managed care industry;
- individual providers vs. programs and agencies;
- confidentiality;
- risk management;
- liability;
- services for underserved infants and teens;
- developmentally appropriate levels of care; and
- sibling care.

Conduct research on existing respite programs that can inform cost-benefit analyses for the use of respite in the prevention of child abuse and neglect, in the retention of foster and kinship care homes, in supporting the adoption of children with special needs, and in preventing adoption dissolution.

Although most child welfare professionals believe that respite is an inexpensive and effective tool in supporting families, the evidence to support this belief is primarily anecdotal. There is a need for formal studies using cost-benefit analysis techniques to quantify the value of respite services. With these figures in hand, agencies will be better armed to face funders, legislators, and the general public with data that prove the value of planned and crisis respite care.

Educate families, child welfare workers, public and private agencies, the general public, and legislators about the benefits of respite for resource families and as a component in the prevention of child abuse and neglect.

Research data are not, in themselves, sufficient to cause a change in understanding about the value of respite services. Training and education, in both formal (such as schools of social work, foster parent preservice and inservice curricula, presentations to legislators and funders) and informal settings (such as opinion and editorial pieces and information booths at community events) are needed to bring about a clearer grasp of the ways respite care can contribute to family preservation and child abuse prevention efforts. In addition, advocates must learn to use the tools of marketing and public relations to reach out to multiple audiences to present both facts and personal stories that speak to people's hearts as well as minds.

Support state and national efforts to legislate the creation and maintenance of lifespan respite networks.

The Lifespan Respite Task Force is a group of national organizations and state coalitions convened by the National Respite Coalition. The focus of their work is to promote lifespan respite legislation at the state and national levels. They have drafted a lifespan discussion draft bill that contains three main points.

- Establish statewide lifespan respite entities to identify, assess, and coordinate respite and crisis care funding and services in each state, and to plan the development, identification, or enhancement of new or existing local respite infrastructures;
- Identify statewide respite infrastructures composed of local entities that can directly serve families; and
- Authorize funds for implementing respite and crisis care programs.

Information about the Task Force, its work, and the proposed legislation can be found at the website of the National Respite Coalition at www.chnp.com/TForce.htm.

Similar legislation can be enacted at the state level. As of April 2001, Lifespan Respite Acts have been passed in Nebraska, Oregon, and Wisconsin, and several other states are actively working on statewide programs or legislation (Kagan, 2001).

In addition to these five major recommendations, a number of additional issues, some more applicable to state or local attention, are ripe for further inquiry:

- assessing the need and availability of services, including the amount of time allowable per family, per episode, and per year;
- parental choice in selecting providers;
- parental involvement in training providers;
- funding and eligibility requirements;
- the emergence of respite coalitions to share resources, avoid duplication of services, and address common issues;
- location of services;
- providing materials and services in languages other than English;
- licensing requirements;
- availability of 24-hour care;
- how families are informed about the availability of services;
- the effect of wait lists and having to turn families away if other resources are not available;
- resource and referral capabilities;
- provider recruitment; and
- differences in geography and population density, urban vs. rural settings, etc.

Finally, this inquiry has confirmed the need for a comprehensive approach to planned and crisis respite care, including a national and state legislative strategy, additional research, a broad effort to educate child welfare professionals and the public about the value of respite for families, program and funding models, clear guidelines for practice, and practice tools. Such an effort will benefit families tangibly by providing relief, support, and resources needed to successfully care for children.

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