



## The Technical Assistance Center for Lifespan Respite *Fact Sheet Number 61, April 2013*

### **Emergency Respite: Help for Family Caregivers in Critical Times of Need**

#### **Introduction**

Respite is defined as temporary relief for the family caregiver. It is most beneficial if used as early in the caregiving experience as possible and as frequently and regularly as resources will allow. However, there are circumstances when an emergency arises and respite is needed immediately. Emergency respite, also known as crisis care respite, is often needed when the caregiver experiences illness, job loss, death in the family, domestic violence, homelessness, or another emergency.

This fact sheet highlights a variety of situations where respite may be needed in the event of a family or personal emergency and is designed to help state agencies, community and faith-based respite providers, Lifespan Respite grantees and their collaborators understand the unique needs of this population of caregivers. Examples of state-funded or community-based emergency respite initiatives and possible funding sources are also provided. The fact sheet includes special considerations for family caregivers, respite providers and administrators, and Lifespan Respite grantees and their partners when using, planning for or implementing emergency respite services.

While there are a variety of services and supports that can assist family caregivers, they often don't know how to access them. Professional helpers also need to be familiar with the services that are available in their communities and how to direct

families to those services when an emergency arises. Awareness, insight and direction will help Lifespan Respite Programs and others develop strategies to create emergency respite options for families.

#### **What is Emergency Respite?**

Respite is temporary care for the relief of primary caregivers from their caregiving responsibilities. Respite is meant to prevent a crisis or any negative physical or emotional effects for the family caregiver and care recipient and is designed to ensure the well-being of not only the family caregiver, but also the family as a whole. However, sometimes respite is needed in an emergency situation to prevent the exacerbation of the crisis. When emergencies arise and a family caregiver becomes ill or cannot provide care for other reasons, emergency respite becomes an invaluable resource. Emergency respite, sometimes also known as crisis care or crisis respite, is short term care that may last from one hour to several weeks depending on the needs of the primary caregiver and may take place in-home or out-of-home (see Types of Services and Supports for Children and Adults on page 3). Emergency respite services not only provide the temporary care a family might need, but link families to more comprehensive support services if necessary. When dealing with the most vulnerable families, these services have also been shown to help prevent abuse or neglect.

## Circumstances Requiring Emergency Care for Vulnerable Children and Adults

*“I have been delaying some needed surgery because I have no one to care for my wife who suffers from MS” or “I want to be with my 5 year old daughter when she has surgery but I have no one to care for my 3 year old son with multiple disabilities.”* These are real challenges for family caregivers that call for emergency respite. Caregivers need to have a reliable provider to care for their loved one when they or another member of their family has a medical emergency. Sometimes families may assume that the care recipient with medical needs will be admitted to the hospital along with the family caregiver if no other option exists, only to find that this is not possible (Becker, 2005).

*“I have no use of my arms and use a Bi-PAP for sleep. Charlotte has been my caregiver since we married in 1967. She is almost supernaturally healthy and we have rarely faced the need to “outsource” my care—even as we aged, and even as I have increasing problems with balance and weakness in my legs due to post-polio...In early December of 2005, however, we suddenly found ourselves in the emergency room of a local hospital late at night. Charlotte had what turned out to be a ruptured appendix. She was very ill for several days and had to be quite careful with the recovery for six weeks afterwards. My doctor had assured me some years ago that in an emergency like this, he would admit me to the hospital for a couple of days while I worked out other arrangements. So we thought we had a workable emergency plan. We were wrong.”*

*~ Personal account of Lawrence Becker*

Families facing homelessness as a result of joblessness and housing foreclosures often face additional challenges when one or more family members are vulnerable due to their age or special needs. Homelessness presents an extreme crisis situation for families and caregivers who not only lack a roof over their heads, but may also need other essentials such as food and clothing.

*“My sister died and I would like to attend the funeral but I can’t take our brother who has physical disabilities with me because of his medical and assistive needs.”* Death is often sudden, with no time to make arrangements in advance. A death in the family can pose real dilemmas for family caregivers. Caregivers want to be able to share their grief and mourn a family member or close friend, but must also find a safe haven for the person in their care.

For a family caregiver who is entering a treatment program for drug or alcohol abuse, there are additional considerations. Because of the nature of the addiction, when an individual decides to seek treatment, the intervention must take place immediately or with almost no preparatory time. The need for care may also be extended beyond

just a few days or even weeks. While the caregiver recognizes his or her addiction and the need for treatment, they are likely to be concerned about losing their children to the child protection system or worried about what will become of the loved one who has been in their care.

Other groups of caregivers who may require emergency respite and face special considerations for possible respite placements include grandparents who are raising grandchildren, teen parents who are coping with parenting while still children themselves, those who are caring for someone with serious

medical conditions or severe dementia or mental illness, and gay, lesbian, bisexual or transsexual caregivers who are caring for their partners. A military couple, where one or both are deployed, may have no one nearby to care for their children until members of their immediate or extended families can come to their aid. In some cases minors are caring for ailing parents, grandparents, or their siblings. There are an estimated 1.3 to 1.4 million

child caregivers between the ages of 8 and 18 years old nationwide (National Alliance for Caregiving, 2005). These groups may have limited respite options or funding sources and/or are generally underserved because they face difficulty accessing community supports for a variety of reasons.

In the most extreme cases of impending crises, emergency care may be needed to prevent abuse or neglect of the care recipient. While the causes of abuse can be complex and stem from multiple familial, societal and cultural stressors, individuals with disabilities and the aging population can be at increased risk of maltreatment.

- **Elder Abuse:** According to the Office of Justice Programs in the US Department of Justice, elder abuse includes “intentional actions by a caregiver or other trusted individual that causes harm to an older adult. Elder abuse can also include the failure of a caregiver or other responsible party to provide for the basic needs of an elder. The comprehensive definition of elder abuse includes financial exploitation of older people, as well as physical abuse, neglect, emotional abuse, and sexual abuse.” State definitions of elder abuse may vary (Office of Justice Programs, US Dept of Justice, nd). Research indicates that more than one in ten elders may experience some type of abuse, but only one in five cases or fewer are reported (National Center on Elder Abuse [NCEA], 2010). It is estimated that in 90% of all reported elder abuse cases, the abuser is a family member, but may not necessarily be the caregiver. Researchers have estimated that anywhere from five to twenty-three percent of all caregivers are physically abusive (Institute on Aging, NCEA, nd).
- **Abuse of Children with Disabilities:** Children with disabilities are almost four times more likely to be victims of neglect, physical abuse, or emotional abuse, and almost 3 times more likely to be victims of sexual abuse than children without disabilities (Sullivan & Knutson, 2000). In 2011, 44 states reported that 11.2% (58,548) of children who were reported as victims of child maltreatment had a disability (U.S. Department

of Health and Human Services, 2012). A study in 2007 which examined the effects of crisis nurseries (crisis respite for children with and without disabilities who are at risk of abuse or neglect) found that families who used the nurseries had few, if any, other resources for keeping their children safe in times of crisis (ARCH, 2007).

## Types of Services and Supports for Children and Adults

A variety of respite options, if available in a community, would include in-home and out-of-home services. Each option requires consideration of the needs of the care recipient as well as the family caregiver. Some of these options are discussed here.

When the emergency necessitates that a caregiver has to leave their home for medical or legal reasons, it may be desirable for a respite provider to come to the family home allowing the care recipient to remain in familiar surroundings. This has the added advantage of not having to transport the care recipient or any assistive or medical equipment from one location to another. If the family has been accessing respite care in their home on a planned basis, it also means the provider is familiar with the care recipient as well as the home.

Respite can also take place in the home of a respite provider. If the provider is familiar with the family and has been providing care in the provider’s licensed home, the care recipient is likely to find the setting familiar and comforting. The same may be true of a respite center or facility where individuals come for short breaks. Familiar routines and personnel help to allay anxiety.

Community-based respite centers or programs or group homes may provide emergency out-of-home respite for all ages. Adult day care also may provide some short-term emergency respite services. In an emergency situation, the care recipient who is not familiar with such facilities or may have Alzheimer’s or other dementias might become anxious. In this case, it is up to the personnel or respite providers to

make the individual feel as comfortable as possible. Even if this care is only for a few hours, these facilities may require pre-screening and a doctor's certification before emergency respite is offered. In some instances, they may also exclude individuals with serious medical conditions or those who are ventilator-dependent.

Helping children feel comfortable when they are suddenly being cared for by someone other than their family caregiver, usually a parent, grandparent or other kin, requires some special skills. Programs known as crisis nurseries offer emergency care to children whose caregivers are unable to care for them for a short period of time, generally 3–30 days, although it might be just a few hours depending on the emergency or longer if the crisis is not resolved. Crisis nurseries are often licensed facilities that can provide care to a number of children, including siblings. In some states there are crisis care programs for children whose parents are seeking treatment for drug or alcohol addiction, keeping them out of the child protection system. Many crisis nurseries, such as **Providence House**

**in Cleveland, OH**, or the **Greater Minneapolis Crisis Nursery in Minneapolis, MN**, have expanded beyond emergency shelter services for children and may include a range of case management and supportive services, including home visitation, for both children and their families.

Sometimes the crisis nursery program offers services in licensed foster homes, known as respite homes. The homes are licensed for a specific small number of children which may include sibling groups. Crisis nurseries, facilities or respite homes, generally offer care to children from birth to age 12 years, but may serve adolescents as well.

Some licensed foster homes provide emergency care to children who may or may not already be in the foster care system because their foster parents are experiencing an emergency or a crisis with a child with difficult behaviors or emotional trauma. This type of emergency care provides a break for both the child and the foster parent.

When crisis nurseries or crisis respite for older children are available in communities, they can often provide shelter for children. However, finding overnight or extended stay emergency care for vulnerable adults may be more challenging. Increasingly, home health agencies, behavioral health providers, assisted living facilities, nursing homes and even some retirement communities are beginning to consider the importance of providing overnight emergency respite or shelter services and will do so if they have beds available. These options could be critical resources for emergency services, especially for adults and the aging population. However, as with short term emergency respite, they may exclude individuals who are ventilator-dependent, have serious medical conditions, or if the care recipient has Alzheimer's or other dementias. Some settings may not be age-appropriate or desirable for younger adults. Many also require pre-certification procedures of a care recipient before they would permit entry in the event of an emergency. This process may involve interviews with staff and completion of necessary paperwork in advance, and a current report from

### The Vanessa Behan Crisis Nursery Spokane, Washington

The nursery provides care for children from birth through age six in the event of a crisis or other emergency. The nursery also provides support for parents in the form of crisis counseling, referrals to community social service agencies, as well as parenting classes and family support groups. The Vanessa Behan Crisis Nursery is the only place for temporary respite care for children under the age of seven in the Inland Northwest, serving families from as far away as North Idaho and eastern Montana. For more information, contact the Vanessa Behan Crisis Nursery, 1004 E. 8th Ave., Spokane, WA 99202: Phone: (509) 535-3155 or visit their website at <http://www.vanessabehan.org>.

the care recipient's primary physician describing medical issues and verifying the absence of TB or other infectious diseases.

Consumer-directed respite options, where family caregivers may hire and train their own providers, and volunteer respite programs, can be used effectively to provide emergency respite services if there are sufficient numbers of qualified and well trained providers available in the community who are willing to work at a moment's notice or be called in the middle of the night.

## Barriers to Emergency Respite

As discussed, emergency respite services are difficult to find, especially if overnight or extended care is necessary, and payment sources for this type of care are extremely limited in most states. Sometimes families are isolated because of their caregiving responsibilities and they do not have a social network of family and friends to fall back on. Caregivers may depend on family and friends to help them out so much that the helpers eventually 'burn out' and are not there in time of need.

If no emergency respite services exist or no prior arrangements have been made in the event the family caregiver cannot provide such services, adult or child protective services may have to step in and temporarily remove the care recipient from the home. If protective services becomes involved it can open the door to extensive legal and punitive hurdles that add to the family's existing crisis situation.

A number of barriers may exist in some communities to emergency respite services. These include:

- **Regulatory Issues.** Licensing or other regulatory requirements for respite vary widely among states and often even within states. Respite programs may be subject to a variety of state licensing or regulations that are wildly divergent based on client eligibility, the type of respite being provided, the location of the respite, the funding source, and other criteria. In some

states and localities, regulation meant for child care settings, foster care, or general facility-based services are often imposed on respite because there are no specific respite provisions. Considerations for emergency respite can raise additional challenges on the regulatory front. Providers who want to offer respite on an emergency basis may face a complete absence of regulatory guidance or the other extreme of regulatory requirements that impose restrictions that are cost-prohibitive or overly burdensome.

- **Provider Reluctance.** There may be reluctance on the part of community providers or residential facilities to offer emergency respite. To ensure fiscal sustainability, many providers may want to know in advance that their available slots for respite are filled. They may be reluctant to reserve emergency spaces or beds in the event that they may not be filled.
- **Cost to Families.** If families aren't eligible for existing funding or emergency funds are not available through public sources, the costs of emergency care may be prohibitive.
- **Condition of the Care Recipient.** Some respite providers or programs that are generally available and able to provide emergency respite, will not provide respite to individuals who are ventilator dependent or have other serious medical needs, challenging behaviors, or who have Alzheimer's or other dementias.
- **Lack of Overnight Options.** Emergencies most often require overnight or extended stays to provide the family caregiver enough time to attend to the emergency or crisis situation, yet overnight and extended respite options for all ages and conditions are already in short supply, even for planned respite.
- **Limited Options for Consumer Direction.** Consumer or participant-directed respite allows family caregivers to hire and train their own respite providers, often choosing family or friends from their social support networks. However, when such networks are not available, family caregivers may turn to provider registries for assistance. These registries may not include

## Access of the Red River Valley – Center Crisis Respite

In Minnesota, a crisis respite program exists for adults with developmental disabilities who are eligible for the state's Medical Assistance Developmental Disabilities (DD) Waiver and live at home. Agencies licensed by the state Department of Human Services provide short-term care and crisis intervention in the home of a person with developmental disabilities receiving care or services. Out-of-home services may also be provided in an adult or child foster home. Crisis Respite services include: assessment of what led to the crisis; creation of a plan to help end the crisis and to keep the person safe; services for both medical and behavioral needs; and caregiver consultation and training as needed. The following are required for Crisis Respite Services:

- Crisis must involve a caregiver and/or service provider(s) who cannot support and protect the person (or others who live with them).
- Other resources for help must not be available – for example, general Respite Care must not be able to assist to end the crisis and prevent further crisis.
- Crisis respite will help the person to avoid institutional (out-of-home) placement.
- County must ensure that the services will not end in the person being unable to return home or to a foster home in the community.
- Costs may not be more than for long-term out-of-home care.

For more information, contact Access of the Red River Valley – Center, 403 Center Ave., Suite 512, Moorhead, MN, 56560; Phone: (218) 233-3991; Email: [access@accessrrv.org](mailto:access@accessrrv.org).

providers who are willing to work on an emergency basis or may not have any providers who designated that they are willing to work with limited notice.

- **Restrictive Intake Criteria.** In order to ensure that emergency respite slots are being used solely for emergencies, and to ensure that emergency respite staff are adequately prepared, respite programs may utilize criteria to assess the level of emergency. Some programs that offer emergency care may be inadvertently excluding individuals from their program because of intake criteria that are too restrictive or do not recognize the emergency situation that a particular family caregiver may be experiencing.
- **Advance Notice Requirements.** Some respite programs that offer emergency respite will only do so with prior notice of up to 48 hours in advance. Such advance notice would be acceptable in some circumstances, but if the crisis is immediately pending, this requirement becomes a barrier to care.
- **Overburdened Programs and Provider Shortages.** Increasingly, respite programs that attempt to offer emergency respite may be overwhelmed with requests that they cannot meet because of licensing or other regulatory requirements that restrict the number of individuals that can be served at any one time or the length of time that care is needed, a shortage of well-trained providers who are available 24/7, and limited resources. Maintaining a waiting list or turning family caregivers away during a crisis or emergency can defeat the purpose of supporting families with emergency respite options.
- **Lack of Training among First Responders.** Frequently, the first individuals to respond to a health care or other emergency are first responders such as law enforcement, fire and rescue teams or emergency medical technicians. They may not have the knowledge to recognize the needs of the care recipient when the family

caregiver is in crisis or the information about immediately available respite options for the individual.

## Considerations for Family Caregivers

Some caregivers have good support networks while others seem to have limited or no outside help or support. Some may be reluctant to ask for help while others may lack the trust to turn the care of their loved one over to someone else.

When a crisis occurs in a family and the caregiver must give up their caregiving role to another reliable individual, the caregiver is likely to be stressed and anxious about the incident that caused the crisis as well as the fate of their loved one. The care recipients will likely pick up on the anxiety and perhaps become agitated and anxious themselves. It is important to not only consider this, but to be prepared for it. It's important that all transitions are made as comfortable and anxiety-free as possible.

## Do Advance Planning

Searching for emergency respite in advance of an emergency situation will help alleviate fears about having to leave the care recipient suddenly. The search will involve as much advance planning as possible. Questions to consider when developing an emergency respite plan are:

- **Who are the respite providers in close enough proximity to provide assistance at any hour?** Well in advance of any emergency or crisis situation, family caregivers should make every attempt to identify in-home providers or out-of-home programs in the immediate area that will provide emergency respite. If possible, using these providers for planned respite experiences will help familiarize the care recipient to the program or provider and will also ensure that the provider is familiar with the care recipient's special needs. Make sure that the provider or program has all necessary medical and personal information about the care recipient in advance of the emergency.

- **Can the emergency respite accommodate individuals who are dependent on medications or other 'invasive' procedures for their survival?**

"My husband is an insulin-dependent diabetic. Can the program measure his blood sugar and administer the correct amount of insulin?" "My child can take no food or liquids by mouth and requires gastric tube feedings. Can the respite program legally and safely administer the feedings?" These are very real concerns for caregivers and may also be a liability issue for respite providers. All respite programs must have a risk management plan in place to protect the care recipients and those who are providing the care (ARCH National Respite Guidelines, 2011). Many programs are not equipped to provide care to someone who is ventilator dependent or has other serious medically related needs and it is important for caregivers and care recipients to have this information in advance.

- **Is the emergency respite program equipped to handle behavioral challenges imposed by the care recipient and do they have policies and procedures in place for doing so?** Consider an individual with serious mental health issues who may have a history of repeated suicide attempts, a child with autism, or an adult with dementia, who is adept at escaping his or her surroundings and running away. When the family is already in crisis due to the situation that warranted emergency respite, they need to feel confident that their loved one will be cared for in a safe, responsible and supportive manner. Not all respite programs can offer that degree of care. It is therefore up to the professionals who are assisting families in crisis, to assist them in finding appropriate accommodations for their loved one with extensive special needs. While these are concerns that everyone who seeks planned respite must consider, for those in a crisis situation there may not be time for the caregiver to research whether or not these concerns will be appropriately addressed.

## **Accessing Services**

If a family member is anticipating an emergency situation, like an impending trial date or a planned medical procedure, they have time to prepare for care that is out of the realm of their traditional planned respite. Even for a family who does not receive planned respite services, advanced warning provides them with an opportunity to find safe shelter for the family members in their care. There may be a family member who is in hospice care, whose death is imminent or a family member who is due to give birth. These situations allow caregivers to plan for short term 'emergency' respite care.

A mother caring for her adult son with Huntington's disease anticipated the birth of a grandchild. She arranged for family, friends and respite providers to care for her son while she traveled to help her daughter with her new grandson. "Not only did I have the opportunity to help my daughter with her new son but I also had some much needed respite from the care of my son." Sometimes emergency respite can offer 'two sides of the same coin.'

Not all families have additional family, friends and respite providers who they can call upon in an emergency. For those families who are isolated and lack family or a social network of potential helpers, there may be little recourse. Hopefully in an emergency situation they can contact their health care provider, hospital social worker, public health nurse, law enforcement or other professional helpers who can direct them to the services they may need.

There are always some emergencies that do not allow for a caregiver to thoughtfully turn over the care to someone else. Again planning in advance is critical. If a family caregiver becomes ill and dies suddenly without having a plan in place for the care of their loved one, what is likely to happen to that individual? Someone must step in to provide care until other arrangements can be made.

## **Educating Families about Preparing in Case of Emergency**

Many families don't necessarily plan for an imagined emergency that can place their loved one in an extreme vulnerable situation. Families who do not access planned respite services because they don't trust others with the care of their loved one or they don't want strangers coming into their homes are most at risk. These are difficult barriers to overcome. However if these families are not totally isolated and do regularly see a health care provider or attend religious services, education can begin. Health care providers who have been educated about the value of respite for family caregivers can provide the necessary information to educate the caregiver in the merits of respite care for both the caregiver and the care recipient. They can also stress the importance of having an emergency plan in place. More and more faith communities are becoming aware of the families in their midst who could benefit from a break from their caregiving responsibilities. Often those who attend the same parish or synagogue can help the caregiver to confront their trust issues and realize the importance of preparing for a possible emergency.

Planning for a possible emergency is somewhat easier for families who regularly use planned respite or are involved in other family caregiver support services. They already have a relationship with a provider and can more easily broach the subject of planning in the event of an emergency. Families who use planned in-home respite don't usually have trust issues around the care of their loved one nor of having someone in their home when they aren't there.

## **Considerations for Respite Providers/Administrators**

Respite providers or programs may be reluctant to engage in emergency respite services for a variety of reasons, including limited resources and staff, regulatory barriers, liability concerns, and cost. However, with adequate planning and partnerships with family caregivers, lifespan respite

programs, and others, it is possible to overcome these obstacles and plan accordingly to provide emergency respite services. To provide such services, special attention should be paid to the following topics:

### ***Training and Education for Emergency Respite Providers***

Training for emergency respite providers is not dissimilar to training for planned respite providers. However, in addition to basics such as first aid, CPR, universal precautions, confidentiality and other program requirements, individuals who provide emergency respite must receive additional training in meeting the physical and emotional needs of the care recipient. Depending on the nature of the emergency, a provider may have limited information about the needs of the care recipient. It is critical that they first gather the most essential information, such as primary care physician, medications, allergies, etc. and then gather more information as time or circumstances permit. Intakes need to be brief and to the point, gathering the most essential information first. Equally important is the ability to provide a calm, low stress environment for the care recipient and to have tools available to help the care recipient deal with any anxiety they may be having.

Provider training should include responding to the emotional needs of the care recipient and the family caregiver. An emergency situation can cause extreme emotional crises and providers will need to have tools to diffuse any anxiety of the caregiver, instilling confidence that their loved one will be safe. While the provider will want to be emotionally supportive it is important for them to be taught not to impose their personal values on the caregiver.

### ***Screening Families for Emergency Respite***

When an emergency respite program is contacted by a helping professional or by the family caregiver directly, a series of questions (age, special need, circumstances warranting emergency placement, etc.) can assist the provider in determining if an

individual is appropriate for care in their program. Most programs have screening criteria. For example, is the program equipped to handle an individual who requires adaptive equipment? Is there another trusted family member or friend who is willing and able to provide care? Is a bed available or will one become available soon? Is a trained provider available to provide in-home care? Providers must consider safety and capacity concerns when developing emergency respite screening procedures to avoid developing criteria that are so restrictive that they unintentionally exclude families or fail to recognize the emergency.

### ***Sufficient Staffing***

Often, free-standing emergency care facilities require in-depth administrative planning in order to provide staffing. Because emergencies aren't planned, it is difficult to know how many staff to have available on a given shift. Sometimes there are no individuals in care, while other times a facility may be at capacity. Well thought-out plans for either extreme are a necessity. A readily available pool of trained volunteer providers can be extremely beneficial. Detailed guidance on how to recruit and train respite volunteers can be found in the ARCH Volunteer Respite Manual ([http://archrespite.org/images/Books/VolunteerRespite\\_Manual\\_Revised\\_11.12\\_web.pdf](http://archrespite.org/images/Books/VolunteerRespite_Manual_Revised_11.12_web.pdf)).

### ***Cultural Considerations***

Providers also need tools to feel comfortable interacting with families of different cultures. Simply put, every family has its own unique culture and means of communicating with one another. The emergency respite provider must be open to working with families of varying cultures and be able to deal with language or other communication barriers. Sometimes individuals with disabilities have special means of communicating. The provider must be familiar with or able to learn those special means. If interpreters are necessary, are they available? Larger communities often have a pool of volunteers available to interpret in medical or

emergency situations. Interpreters may be available through faith communities. The respite program will want to know how to contact an interpreter in the event one is needed.

### **Considerations for Lifespan Respite Programs and Providers**

Lifespan Respite programs can play a tremendous role in identifying the need for emergency respite in communities, the populations in greatest need, and the services and funding sources currently available to fill the gap. In the event that there is insufficient available and accessible emergency respite, the Lifespan Respite program can work to raise awareness, develop partnerships to help fill the gap, help recruit and train emergency respite workers and volunteers and first responders, and even provide emergency respite funds to help families pay for care.

### **Developing Important Partnerships**

In order to advance the availability of emergency respite services, Lifespan Respite grantees need to inventory the stakeholders who are likely to build upon existing resources and include emergency respite services. It may take some brain storming to find or recruit appropriate programs and/or individuals to become part of the Lifespan Respite program. Representatives from the medical and social work community, law enforcement and other first responders, business and corporations, abuse/neglect prevention groups, and diverse faith communities, to mention a few, can bring new thinking and creativity to the table. Family caregivers can serve as expert resources in designing programs and in developing program guidelines and training.

Child or adult protective services can form important alliances with Area Agencies on Aging (AAAs), the State Respite

Coalition or Lifespan Respite program to develop comprehensive approaches to abuse prevention that include respite. For example, in Maricopa County, Arizona, Adult Protective Services (APS) and the Maricopa County Area Agency on Aging have joined forces to take a holistic approach to abuse prevention by offering a wide range of supportive services. In the event of an emergency situation when a family becomes known to APS, APS can turn to the AAA for supportive services and will link clients to respite using Family Caregiver Support Program funds if the care recipient is eligible. Similarly in Nebraska, Adult Protective Services, during the course of an investigation of an abuse or neglect report, works with the Nebraska Respite Network, the state's Lifespan Respite program, to assist with arranging for respite services for caregivers and family members. In some states, the Children's Trust Fund, which may be responsible for community-wide child abuse prevention strategies, contracts with the state respite coalition or other local providers for respite or crisis nursery services for at-risk families with the goal of preventing abuse before it occurs.

### **Community Marketing and Training**

Lifespan Respite Programs can market emergency respite as part of their regular public education strategy for hard-to-reach family caregivers. In collaboration with their respite coalitions and ADRC partners, Lifespan Respite Programs can

**According to the *Council on Scientific Affairs*, "Primary care physicians can provide a strong model to guide relationships with family caregivers. An effective relationship model acknowledges the key linkage role of the primary care physician and recognizes that caregivers and patients form interdependent units. It also considers the caregiver as a partner with the physician in the care of the patient. The physician demonstrates concern for and carries out periodic assessment of the caregiver as well as the patient and validates the role of the caregiver."**

**~ *Council on Scientific Affairs*  
American Medical Association, 1993**

## Examples of Training Members of the Health Community in the Needs of Family Caregivers and Available Supports

- **Family Caregiver Alliance (FCA):** The Family Caregiver Alliance offers trainings for caregivers about communicating with health care professionals. The intervention trains the caregiver to communicate their needs and to be proactive in preparing for possible emergent situations which place the care recipient in a vulnerable situation (oral communication with Michelle Venegas, 2/21/13). For more information, contact Michelle Venegas, FCA, at [mvenegas@caregiver.org](mailto:mvenegas@caregiver.org).
- **North Carolina Lifespan Respite Project:** The NC Lifespan Respite Project worked with Community Care of Western North Carolina, a public-private partnership which provides case management services for people with chronic health conditions in North Carolina, (including recipients of Medicaid, Medicare and some other insurers) and MAHEC (Mountain Area Health Education Center) Family Health Center to develop training about the importance of the caregiver to the patient's well being. Although training development takes weeks of working with the health care professionals and physicians, the value is that those providers take ownership of the training and therefore are amenable to making changes within their system. For more information, contact Alicia Blater, M.S., APR, Family Caregiver Support Program Consultant, Lifespan Respite Project Director, NC Division of Aging and Adult Services at [alicia.blater@dhhs.nc.gov](mailto:alicia.blater@dhhs.nc.gov).
- **Nebraska Respite Network:** The Nebraska Lifespan Respite Network has instituted a crisis respite program to help families pay for respite in emergency situations (see Lifespan Respite in the Federal Funding Section on page 14). The resultant increased awareness about the availability of crisis respite funding has necessitated an increase the number of providers willing and able to help in emergency situations. The Department of Health and Human Services is exploring tele-health options for first responder training and professional outreach.

reach out to the larger community to market both planned and emergency respite to those who may not otherwise know of the services and to educate about its availability in the community. Medical facilities, emergency services personnel, social workers, law enforcement, Child Protective Services (CPS), Adult Protective Services (APS), and the volunteer and faith community can be key partners in this effort. These groups and individuals interact with families on a variety of levels and can encourage families to not only seek out, but to use, respite services. Once families are linked to planned respite services, it makes finding emergency respite so much easier.

It's important for Lifespan Respite programs and state respite coalitions to develop strategies for

educating and training professionals, especially emergency first responders and those in the medical and mental health communities who may be the first to come in contact with family caregivers during emergency situations, about respite services that are be available to those who need them. These helping professionals can be invited to join a respite coalition and become knowledgeable about lifespan respite and respite resources that can be available in the event of an emergency. Community stakeholders can play an important role by providing crisis respite services as well as community outreach to underserved and hard to reach communities, or participate in education or training programs sponsored or arranged by the Lifespan Respite Program. If emergency respite

resources are available, partners can then be called upon to help develop, recruit and train others in the provision of emergency or crisis respite.

### ***Emergency Respite Criteria and Capacity Building***

Lifespan Respite programs may want to think carefully about establishing criteria or guidance for emergency respite, especially in the face of provider and funding shortages. Program administrators who are making decisions about what might constitute an emergency situation and who might be eligible should carefully weigh cost issues and service availability with the very real needs of family caregivers whose very survival could depend on the availability of emergency respite help. Inadvertently excluding individuals from emergency respite services because of overly restrictive intake criteria or definitions should be avoided. Such decisions should also be made hand in hand with plans to increase emergency respite service capacity through provider recruitment and training initiatives and establishment of emergency funding sources.

### **Funding to Support Emergency Respite**

Funding for emergency respite might be available through federal, state, or private funding sources administered by state agencies, volunteer, and community or faith-based organizations or facilities.

#### ***Federal Funding***

**Section 1915(c) Medicaid Home and Community-Based Services Waivers (HCBS).** States can provide home and community-based services through Medicaid waiver programs, as long as these services are required to keep a person from being institutionalized. Generally, every state offers some respite assistance through various Medicaid Waivers. The largest source of federal funding for respite is available through 1915(c) Medicaid waivers.

**Many, if not most, of these waivers provide funding for emergency respite services.** Each state's eligibility criteria and funding for waivers is different; check with your state's Medicaid office or find information on the state-specific search

results pages of the National Respite Locator Service ([www.respitelocator.org](http://www.respitelocator.org)). You can also search for "emergency respite" in ARCH's Home and Community-Based 1915(c) Medicaid Waivers for Respite Support: State-by-State Tables of Medicaid Waiver information related to respite (Perrin, C., 2011).

### **Defining Emergency Respite in Georgia**

The Georgia Department of Human Resources, Division of Aging Services, has developed requirements for non-Medicaid home and community-based services that are funded through the Family Caregiver Support Program and other state and federal programs to be followed when Area Agencies on Aging provide or contract for the provision of out-of-home respite services to caregivers of frail elderly people, or caregivers of persons of any age with Alzheimer's disease or related dementias. These guidelines define emergency respite as the immediate placement of a dependent elderly adult or adult with dementia in an appropriate facility or residence of a trained respite care worker in response to and during an emergency or unplanned event to substitute for the primary caregiver. An emergency is:

- an unplanned event that results in the immediate and unavoidable absence of the caregiver at a time when no other qualified or appropriate substitute caregiver is available; or
- an unplanned situation that prevents the caregiver from providing the care needed by the frail older person; or
- an unplanned event that threatens the health and safety of the frail older person, including changes in health status of the caregiver.

**National Family Caregiver Support Program (NFCSP).** Authorized under the Older Americans Act, the program calls for State Units on Aging to work with regional Area Agencies on Aging, local community-service providers, and Tribal Organizations to offer five basic services for family caregivers: 1) information; 2) assistance accessing support services; 3) individual counseling, support groups, and caregiver training; 4) respite; and 5) limited supplemental services. Emergency respite services may be provided by the local AAA. Funding may be available for caregivers providing care for someone over the age of 60 or someone of any age with Alzheimer’s disease or other neurological conditions. Also eligible are: grandparents and other relative caregivers (not parents) 55 years of age or older providing care to children under age 18, and grandparents and other relative caregivers (not parents) 55 years of age or older providing care to adults age 18-59 with disabilities, to whom they are related by blood, marriage, or adoption. Tribal Organizations can set an age lower than 60 at which members can be considered as elders eligible for services. In most states, the National Family Caregiver Support Program is administered through local Area Agencies on Aging (AAA). The Elder Care locator service at <http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx> provides links to local AAAs.

**Social Services Block Grant (SSBG).** The program provides funds for social services to families with special needs, adults with disabilities, and the aging population. Among its goals are to prevent neglect, abuse or exploitation of children and adults, and prevent or reduce inappropriate institutional care. Adult daycare, respite and crisis care are accepted SSBG funded services. While available funds may be limited, states receive the funds with few strings attached. The annual allotments are noncompetitive, there is no required match, and the funds may be used to support public agencies or to contract with private service providers. Client eligibility is not restricted and service provider qualifications are flexible.

**Community-Based Child Abuse and Neglect Prevention Program (CBCAP).** CBCAP is focused on supporting community-based efforts to prevent child abuse and neglect. Respite and crisis care are considered core prevention services, but states retain the authority to set their own funding priorities as long as certain basic needs are met. A lead agency identified by the state administers the funds, assesses needs, and plans a statewide prevention approach. Funds have been used by states to make grants to local agencies to provide services, including respite and crisis care. Within certain limits states may establish their own eligibility requirements. The eligibility of local providers is not restricted. States with programs that leverage local funds can receive significant federal bonuses. Examples of state uses of CBCAP funds for crisis respite are:

- **Wisconsin.** The Wisconsin Respite Care Association in partnership with the state Children’s Trust Fund works to prevent initial occurrences of child abuse and neglect by targeting planned and/or emergency respite care to families exhibiting risk factors. The organization has established regional partnerships to coordinate resources and deliver direct respite care services, establish guidelines and standards for programs and providers, establish evaluation protocol, and provide training and technical assistance. For more information, see the Respite Care Association of Wisconsin at <http://respitewarewi.org/content/child-abuse-prevention>.
- **Utah.** The Utah Division of Child and Family Services uses CBCAP funds to increase access to crisis respite, supporting 13 Family Support Centers that together offer 15 shelter programs across the state. These centers— part of the Utah Association of Family Support Centers—have all received special training to increase their capacity to evaluate and report outcomes. One audience for these results is the state’s Lifespan Respite Advisory Council, of which the CBCAP Program Administrator is a member. This multi-stakeholder council works to improve access to

and coordination of respite services statewide (FRIENDS National Resource Center, 2011).

**Lifespan Respite.** Lifespan respite programs are built on existing federal and state funding sources and Lifespan Respite grants are designed to help states build or enhance coordinated systems of planned and emergency respite care. Lifespan Respite Systems are in place to help states identify respite funding and to coordinate and maximize the use of state funding streams, and may provide limited emergency respite funding. Two states that have developed strategies to support emergency respite are:

- **Illinois.** The Illinois Lifespan Respite program established an emergency respite program during the grant period which ended in August 2012. The program offered funding of up to \$500 per year (\$1000 with special approval) and resources to support caregivers of children or adults with special needs who have an urgent need for respite care in the absence of any other funding source. The program supported the caregiver's decision to request emergency respite care and determine where the care will be delivered and by whom. Due to federal funding limitations and budget constraints, this program has been temporarily suspended. However, program guidance and emergency criteria can still be accessed on the Illinois Respite Coalition webpage at [http://www.illinoisrespite.org/index.php/emergency\\_respite\\_care\\_services](http://www.illinoisrespite.org/index.php/emergency_respite_care_services).

- **Nebraska.** Those eligible for financial assistance for the crisis/emergency respite program of the Nebraska Respite Network, the state's Lifespan Respite program, include families who do not qualify for any existing respite programs or services. A maximum of \$1,000 per family per calendar year is allowed. Exceptions must be approved by State Respite Program staff (unless payment for crisis respite is provided by funds not included in current subgrant).

Crisis Respite Funds may be used for crisis situations defined as an unforeseen circumstance or unplanned event that calls for immediate

action or an urgent need for short-term assistance or relief to substitute for the Caregiver in the absence of any other funding source.

- An unplanned event that jeopardizes the health and safety of the frail or disabled child or adult (Care Recipient).
- An unplanned event that jeopardizes the health and safety of the Caregiver by placing the frail or disabled child or adult in danger (Care Recipient).
- An unplanned situation that prevents the caregiver from providing the care required by a frail or disabled child or adult living at home.
- Results in the immediate and unavoidable absence of the caregiver from the home in an excess of 4 hours at a time when a qualified caregiver is not available.

For more information, contact Sharon Johnson, Medicaid and Long-Term Care, (402) 471-1764; [sharon.j.johnson@nebraska.gov](mailto:sharon.j.johnson@nebraska.gov).

### **State Funding**

A number of states fund their own statewide respite programs for adults or the aging population or utilize other state funding streams to help families pay for respite. Several have made sure to include emergency respite among options available for family caregivers. Examples include:

- **North Carolina Health Choice.** North Carolina CHIP, known as Health Choice, has a separate component for children with special health care needs, defined as those who have a condition lasting 12 months or more that interferes with the child's daily routine and requires more medical care and family management than needed by most children. Eligibility is certified annually by a physician. Services under this additional coverage include emergency respite for "unplanned situations in which family members temporarily do not have the capacity to safely care for their child or when changes in their child's health, behavior, or development require

in-home or out-of-home temporary support.” All services under this coverage require prior approval and documentation from a medical provider that the service is medically necessary.

- **New Jersey Statewide Respite Care Program, NJ Department of Health and Senior Services, Emergency Respite Provisions.** The Statewide Respite Care Program is designed to provide assistance to families by giving unpaid caregivers a break from the daily responsibility of caring for relatives or friends who are aging or have disabilities. Funding for the program comes from casino revenues. Respite may be used occasionally or at regularly scheduled times or to cope with an emergency. The program serves New Jersey residents age 18 or over with chronic physical or mental disability requiring supervision or assistance with basic daily needs from a caregiver. Income criteria include liquid resources of less than \$40,000 (\$60,000 for couples). There are a number of services such as campership, companion services, social adult day services, homemaker, home health aide, medical adult day services, adult family care, nursing facility and assisted living. The rates vary and are established in regulation, N.J.A.C. 8:82.

In an emergency, sponsor agencies in each county may authorize respite services and defer the usual financial (income and asset information), and clinical (health care provider’s certification of the care receiver’s need for assistance) application process. Caregivers respond to a brief questionnaire which “presumptively” confirms their eligibility. The caregiver also agrees to the terms of the program including their responsibility for the payment of any applicable cost-share. As the caregiver’s situation becomes stable, they are asked to complete the application forms and supply the required documents. Rates for emergency respite are the same as for planned or scheduled respite. Emergency respite may be available the same day or in several days depending on the nature of the emergency, the availability of providers and the availability of funds in the county in which

services are requested. For more information, visit <http://www.state.nj.us/humanservices/doas/services/srcp>. To reach the Statewide Respite Care Program in a county, call the Aging & Disability Resource Connection (ADRC) toll-free at 1-877-222-3737.

### **Private Funding**

Increasingly, the private sector has recognized the need to make emergency respite services and providers available to those they serve. Services and funding assistance may be provided by organizations such as the Alzheimer’s Association, Easter Seals, United Cerebral Palsy or other community-based agencies.

### **Quality Services for the Autism Community (QSAC) Emergency Respite Fund**

QSAC is a nonprofit organization founded in 1978 by a group of parents of children with autism. Educational, residential, therapeutic and family support services are provided at 21 facilities in Manhattan, The Bronx, Queens, and Nassau County to over 2,700 people each year, including 1,100 individuals who receive direct services. QSAC has funds available to assist families living in Queens to pay for emergency respite in times of crisis. The Emergency Respite Fund is designed to assist families in coping with unexpected family illnesses, pregnancies, deaths, and/or extreme emotional stresses. Contact Information: For more information about the Fund please call Farzana Karim at (718) 7-AUTISM, ext. 1233.

## Recommendations

### *For Family Caregivers*

1. Research options and funding sources for emergency respite before an emergency occurs. Contact your state Lifespan Respite Program, state respite coalition, Medicaid agency, or Aging and Disability Resource Center for a list of possible services, funding possibilities and other resources for emergency care or search your state's resources in the ARCH National Respite Locator Service ([www.respitelocator.org](http://www.respitelocator.org)).
2. Reach out to potential providers to find out about their criteria and process for accessing care in an emergency and do as much advance planning as possible. If necessary, pre-certify the care recipient in more than one program or with more than one home care agency. Before an emergency occurs, utilize these providers for planned respite so that the provider and the care recipient will be prepared and comfortable with the respite arrangement in an emergency situation.
3. Prepare a list of questions to ask potential providers. Questions to consider include whether the program can legally and safely administer medication or gastric tube feedings and if the program has a risk management plan to protect care recipients.
4. Inquire about the credentials and work experience of the staff/volunteers who will be providing care.

### *For Respite Providers/Administrators*

1. Provide training for emergency respite providers on providing appropriate intake and on how to meet the physical and emotional needs of care recipients who need emergency care.
2. Develop and use appropriate emergency respite screening criteria that are not overly restrictive, but take into account program capacity and safety.

3. Provide tools for staff on how to interact with families of different cultures. If appropriate employ dual language staff or have an interpreter available to translate for families.
4. Prepare staff to make the transition into care as comfortable and anxiety-free as possible for both the care recipient and care provider.
5. Recruit a sufficient number of respite providers or volunteers who are willing to be available on short notice with a plan for continued care if necessary.

### *For Lifespan Respite Programs*

1. Collaborate with the faith community, medical facilities, first responders and other emergency services and others who will interact with families to share information about emergency respite and encourage families to utilize services. Provide or arrange for training of these individuals if necessary.
2. Coordinate with community partners and respite coalitions to provide emergency respite services, recruit and train new providers and volunteers, and to educate the community about accessing available services.
3. Include families in the process of designing emergency respite programs to ensure that families have appropriate service options that address their needs. Consider consumer-directed options that give families additional choice and control.
4. Compile a list of emergency respite funding sources to help families pay for emergency respite and/or develop an emergency respite fund for this purpose.
5. Develop plans to build sustainable respite capacity to ensure that there are sufficient providers and services available to respond to the need for emergency respite services.
6. When conducting environmental scans or developing respite registries, collect information on the availability and willingness of providers

and programs to provide emergency, overnight and extended care respite.

7. Develop guidance for emergency respite screening criteria that are not overly restrictive, but take into account program capacity and safety.

## Conclusion

While respite is defined as temporary relief for the family caregiver and ideally should be available as early and as frequently in the caregiving experience as possible, emergencies do arise warranting immediate care for a vulnerable care recipient. Emergencies vary as do types of emergency respite programs. Professional helpers need to be aware of what emergency respite care options and funding sources are available in their community and develop ways to fill gaps and create new options. Training and education for emergency respite providers, first responders, family caregivers and the general public are essential. Funding for services needs to be affordable or available at no cost to families. Lifespan Respite grantees need to inventory their stakeholders, including family caregivers, to learn of existing emergency resources and determine what gaps exist in their respite systems. Plans should be developed to build and sustain emergency respite options and funding sources for families.

## Resources

### ARCH National Respite Network and Resource Center

[www.archrespite.org](http://www.archrespite.org)

The ARCH National Respite Network includes the National Respite Locator, a service to help caregivers and professionals locate respite services in their community, the National Respite Coalition, a service that advocates for preserving and promoting respite in policy and programs at the national, state, and local levels, and the Center for Lifespan Respite T/TA which is funded by the Administration for Community Living (ACL)/Administration on Aging (AoA) in the US

Department of Health and Human Services. The ARCH National Respite Locator Service ([www.respitelocator.org](http://www.respitelocator.org)), a searchable national data base of respite providers, programs and funding sources, provides information on each provider in the data base on their capacity and willingness to provide emergency or crisis respite services and overnight or extended care. Individual providers should be contacted to ensure that the information is current.

### Child Welfare Information Gateway

[www.childwelfare.gov](http://www.childwelfare.gov)

Child Welfare Information Gateway connects child welfare and related professionals to comprehensive information and resources to help protect children and strengthen families. Featured topics include child abuse and neglect, foster care and adoption.

### Family Caregiver Alliance

[www.caregiver.org](http://www.caregiver.org)

Family Caregiver Alliance (FCA) is a public voice for caregivers. Programs support and sustain the important work of families who are caring for loved ones with chronic, disabling health conditions. FCA's programs focus on information, education, services, research and advocacy.

### FRIENDS National Resource Center

[www.friendsnrc.org](http://www.friendsnrc.org)

FRIENDS is the National Resource Center for Community-Based Child Abuse Prevention (CBCAP) and provides training and technical assistance to federally funded CBCAP Programs. FRIENDS is an acronym for Family Resource Information, Education and Network Development Services. Their website includes summaries of CBCAP state annual reports that describe respite or crisis nursery services funded by the state with CBCAP funds.

### National Center on Elder Abuse

[www.ncea.aoa.gov](http://www.ncea.aoa.gov)

The National Center on Elder Abuse (NCEA) serves as a national resource center dedicated to the prevention of elder mistreatment. First established by the U.S. Administration on Aging (AoA) as a national elder abuse resource center, NCEA

serves as a multi-disciplinary consortium of equal partners with expertise in elder abuse, neglect and exploitation.

### **Year of Elder Abuse Prevention (YEAP) Toolkit Administration on Aging (AoA)**

[http://www.aoa.gov/AoARoot/AoA\\_Programs/Elder\\_Rights/YEAP/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/Elder_Rights/YEAP/index.aspx)

AoA collected information, tools, and resources to support federal, state and local partners in their efforts to raise public awareness about elder abuse and shed light on the importance of preventing, identifying, and responding to this serious, often hidden problem. The YEAP toolkit includes an outreach guide, event planning materials, fact sheets, a Frequently Asked Questions booklet, web banner designs, YEAP poster, as well as customizable YEAP templates for newsletters, Power Points, and event flyers.

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