

NATIONAL RESPITE GUIDELINES

Guiding Principles for Respite Models and Services





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The mission of the ARCH National Respite Network and Resource Center is to assist and promote the development of quality respite and crisis care programs; to help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums.

The ARCH National Respite Network and Resource Center consists of the ARCH National Respite Resource Center (www.archrespite.org), the training and technical assistance division, which provides support to service providers and families through consultation, training, evaluation, and research. The ARCH National Respite Network also includes the National Respite Locator (www.archrespite.org/respitelocator), a service to help family caregivers and professionals locate respite services and funding sources in their community, the National Respite Coalition (www.archrespite.org/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 Technical Assistance Centers for Caregiver Programs and Lifespan Respite (www.archrespite.org/ta-center-for-respite), a joint venture with the Family Caregiver Alliance (www.caregiver.org) of San Francisco, which is funded by the Administration on Aging (www.aoa.gov) in the U.S. Department of Health and Human Services. The TA Center for Lifespan Respite provides training and technical assistance to State Lifespan Respite grantees and their stakeholders, including State Respite coalitions, ADRC representatives, and others interested in building such systems at the state and local levels.

Caregiver Programs
& Lifespan Respite:
Technical Assistance Centers





INTRODUCTION

What is Respite?

The Lifespan Respite Care Act of 2006 defines respite care as “planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult.” Respite services may be provided in a variety of settings, on a temporary basis, including the family home, adult day centers, respite centers, or residential care facilities. Respite is a key component of family support and home and community-based long-term services and supports. Respite services strengthen family systems while protecting the health and well-being of both caregivers and care recipients.

Respite

- ☞ is a vital part of the continuum of services for families;
- ☞ reduces family stress and thereby helps preserve the family unit;
- ☞ supports family stability;
- ☞ prevents or delays lengthy and costly out-of-home placements;
- ☞ prevents possible abuse and neglect situations; and
- ☞ preserves caregiver – care recipient relationships.

For more information about accessing and using respite services, consult *The ABCs of Respite: A Consumer’s Guide for Family Caregivers*. <http://www.archrespite.org/consumer-information>

Federal Lifespan Respite Care Act

Congress authorized the Federal Lifespan Respite Care Act in 2006. In 2009, the U.S. Administration on Aging (AoA) was given responsibility for program implementation and administration. AoA is working closely with representatives from across the age and disability spectrum to ensure that Lifespan Respite Care Programs meet the respite needs of caregivers of children and adults of all ages with special needs. Lifespan Respite is defined as “coordinated systems of community-based respite for family caregivers of children or adults regardless of special need (PL 109-442).” Lifespan Respite Care Programs advance the following objectives:

- ☞ expand and enhance respite services in the states;
- ☞ improve coordination and dissemination of respite services;
- ☞ streamline access to respite programs;
- ☞ fill gaps in service where necessary; and
- ☞ improve the overall quality of the respite services currently available.

History of the National Respite Guidelines

The *National Respite Guidelines* were originally produced in 1994 to assist providers of respite care for children and youth in their desire to strive for quality respite programs. At that time, respite systems included a broad array of informal and formal programs and settings. The guidelines were intended to assist providers of respite care to assess, enhance, and expand respite services for children.

In recent years, the focus on lifespan respite has expanded the continuum of respite models and settings, and there is a continued need for national guidelines to guide professionals as they strive to enhance and expand respite systems and services. Today respite has many faces and can include informal care provided by family members, friends, and neighbors, as well as in-home care, center-based care (e.g., adult day programs), volunteer programs, recreational programs (e.g., therapeutic recreation, camps), residential programs (e.g., group homes, assisted living facilities), and hospital based services.

Using the Guidelines

The guidelines provide a summary of guiding principles addressing quality indicators for all respite models and services. They can act as a checklist for providers of respite to review as they address respite service delivery issues. The guidelines are intended to be used by respite provider programs, individual providers, health care providers, human services agencies (i.e., disability, health, aging, and children), state agencies, planning groups, stakeholders, and others who are interested in advancing quality respite. State organizations can use the guidelines for planning future respite systems and to provide consultation and technical assistance for local and regional agencies and programs. Local organizations and agencies can use the guidelines as they assess, plan, develop, and enhance or expand specific respite programs and services in their community. Some sections of the guidelines may be helpful when family caregivers directly recruit and hire their own respite providers. For more information on how to assess and use respite, consumers, family caregivers and care recipients may want to refer to the checklists and additional information included in the *ABCs of Respite: A Consumer Guide for Family Caregivers* mentioned earlier.

The guidelines are not intended to be standards or licensing requirements. As the title suggests, they are guidelines or guiding principles for respite programs to follow or consider. The current revisions to the guidelines have incorporated language and best practices to effectively include individuals with special needs across the lifespan.

Note: Keep in mind that the guidelines are for the most part generic although there may be an occasional reference to specific age populations. For example, “infants are held during bottle feedings,” or “trips to the mall are available for teens” or “respite is available evenings and nights for individuals with Alzheimer’s.”



FAMILY CAREGIVERS

Overview

The respite guidelines address the respite needs of family caregivers providing ongoing care for infants and toddlers, school age children, youth, adults, and the aging. Most guidelines are generic with occasional references to specific age or disability populations where appropriate. Caregiving needs are related to many health care and disability needs. These could include children and adults with developmental disabilities, adults with acquired disabilities (e.g., spinal cord injury, traumatic brain injury), and the aging population experiencing health and disability issues (e.g., Alzheimer's, heart disease, stroke, arthritis).

Since family members are the ongoing caregivers and the cornerstone of quality of life for the individual needing care, it is important to identify and respect their needs and preferences. Further, it is essential to involve them in the provision of respite services and options, ensure that they have access to frequent and sufficient amounts of respite as early in their caregiving experience as possible, and to help them to better use their respite time in order for it to be more meaningful (Utz, Lund, Caserta & Wright, 2011). At the same time, the respite experience should be meaningful for the care recipient, as well as safe.

Who are Family Caregivers?

Family caregivers encompass a broad array of family members and others who might be providing care for these populations, including parents, grandparents, adult children, spouses, siblings, other family members, neighbors, friends, and foster and adoptive parents. Family caregivers include individuals providing care for children or adults with disabilities, and those caring for the aging. Some caregivers might be providing care for children with disabilities, as well as aging parents. In 2009, an estimated 65.7 million people in the U.S. served as unpaid family caregivers to an adult or child. More than half of care recipients (56%) are under age 75, and almost one-third (28%) are under age 50 (National Alliance for Caregiving, *Caregiving in the U.S.*, November 2009, <http://www.caregiving.org/data/CaregivingUSAllAgesExecSum.pdf>).

Care recipients encompass a broad array of individuals across the lifespan who need temporary care so that family caregivers can receive a respite break. Care recipients can include infants, toddlers, school age children, youth, young adults, adults and the aging. They include individuals with developmental disabilities; those with acquired disabilities through illness or disease, injury or combat duty; those at risk of abuse and neglect; and those who are aging with health and/or disability issues. Care recipients may require continuous care which can be taxing on family caregivers and indicate a need for a break from caregiving responsibilities. Also, care recipients benefit from meaningful respite experiences that provide enjoyable, stimulating, enriching, or therapeutic activities. Care recipients who are constantly in the care of their parent, sibling, spouse or child may also need a break from their caregiver and an opportunity to experience the company of someone other than their caregiver. Both the caregiver and the care recipient need and can have a positive respite or short break from one another.

Family Caregiver Involvement

Family caregiver involvement encompasses the inclusion of family caregivers in all aspects of quality, accessible respite service delivery. It is important to clearly define family roles so that they can be effectively involved in activities such as surveying caregiver needs, planning respite services, and program evaluation.

- ☞ Respite programs provide information about respite services and options to physicians, health care, social work, disability, and aging service providers to facilitate family caregivers having access to respite early in the caregiving experience.
- ☞ Respite programs assist family caregivers in identifying their particular need(s) for services through timely, volunteer caregiver assessments or through informal discussion to ensure that they gain the greatest benefits from respite.
- ☞ Family caregivers are involved in service design and implementation.
- ☞ Respite programs solicit family caregiver input regarding service delivery on an ongoing basis (e.g., needs assessments, service satisfaction surveys, advisory boards).
- ☞ Respite programs and family caregivers work together to clearly define family roles and responsibilities within the services being provided.
- ☞ Respite services are developed so that they are family-centered (take into consideration the needs of all family members).
- ☞ Respite programs build on the strengths and resources of families.
- ☞ Respite is planned so that it can be available early in the caregiving experience and in a frequently and therapeutically sufficient dosage to positively affect the family caregiver's health and well-being.
- ☞ Family caregivers receive appropriate emotional support and reassurance about having their loved one in care.
- ☞ Family caregiver preferences for service entry, location, hours, activities and delivery, are respected and accommodated, as appropriate.
- ☞ Families have access to their loved ones while they are in care.
- ☞ Family caregivers are encouraged to value their respite time and engage in respite activities that will maximize their benefits and outcomes.

Family Diversity

Family diversity is reflected in each family's unique characteristics such as race, ethnicity, language, family composition, socio-economic status, and religious beliefs. It is important that respite programs and providers respect these characteristics in the provision of respite services.

- ☞ Each family's cultural, racial, and linguistic identities are acknowledged, respected, and supported.
- ☞ Each family's spiritual beliefs are acknowledged and respected.

- ☞ Diversity in family composition is acknowledged and supported in the provision of respite services (e.g., grandfamilies; foster and adoptive families; single parent families; lesbian, gay, bisexual and transgender families (LGBT)).
- ☞ Every effort is made to incorporate the family’s cultural and linguistic needs into respite services.



RESPITE SYSTEMS

Overview

Respite systems encompass a wide array of services and options to meet the diverse and changing needs of family caregivers. Some respite services are informal or self-directed, while others are formal or agency sponsored. Care can be provided on a planned or emergency basis and may include day, overnight, weekend care, or extended care. Respite systems offer a range of temporary service options to meet the current and future needs of family caregivers, keeping in mind that respite is meant to be temporary and is not intended as a substitute for full-time child or adult day care that is used solely to allow a family member to work or attend school on a regular basis. While full-time child or adult day care may result in a respite “outcome” for some family caregivers, other funding sources exist to support this level of care. This section addresses key considerations for respite care systems including models of care and ensuring quality respite service delivery.

Respite Care Models

In order to offer family caregivers a range of respite service options that will meet their current and future needs, communities and programs provide respite service options that address the changing needs of families. Settings such as child care centers, foster care homes, group homes, assisted living or nursing homes provide primarily full-time care. However, they can also be made available on a temporary basis to provide respite, especially when overnight respite is desired or required.

- ☞ Respite services can include the following settings and options:
 - ☛ An in-home respite program, where services are provided in the family’s home or a care provider’s home
 - ☛ A center-based respite program, where family caregivers bring the care recipient (e.g., child, adult, aging individual) to a facility in the community to receive respite care
 - ☛ A child or adult care setting, such as a child or adult care center or a family day care home or adult family home, which is designed to provide temporary respite care in addition to their regular child or adult care services
 - ☛ Recreational programs provided through parks and recreation departments and YMCA programs, which provide recreational programs that offer respite breaks
 - ☛ Generic community programs where children or adults receiving respite services are integrated into programs

- Summer or weekend camps that provide day or overnight options
- Residential and group home programs with designated respite beds
- Licensed foster homes for children and adults
- Emergency shelters and shelters for the homeless
- Hospital-based programs
- Assisted living or nursing home respite programs
- Cash assistance, voucher, or parent subsidy programs so family caregivers can pay for and access respite care options of their choice
- Registries that list providers so family caregivers can make their own decisions on choice of providers
- Informal supports (social capital) such as neighbors, friends, other family members, faith-based groups, cooperatives, or volunteer efforts

Respite Care Providers

Respite programs provide the administrative home for many respite providers and engage in provider recruitment, hiring, training, and supervision. Respite provider qualifications and training are among the greatest predictors of respite quality and safety. The information presented in this section and the sections that follow is pertinent for respite providers working within a formal respite program which is administered by an agency. Some of the information included may also be appropriate for providers who provide respite services as independent contractors or as part of a generic community service (e.g., parks and recreation program), or who provide respite more informally (e.g., volunteer program, respite co-op). In situations where cash assistance is provided through Medicaid waivers, family support programs, or other funding sources for family caregivers to locate, train, and hire their own respite provider (i.e., participant-directed respite), then the family caregiver may want to directly address some of the guidelines in this section to help them assess a potential respite service.

Qualifications

Well-trained, knowledgeable, and experienced respite providers are the key to a successful, safe, and enriching respite experience, ensuring that family caregivers are confident that their family member is receiving quality care. It is essential that respite programs thoroughly assess provider competencies, qualifications, work experience, and background.

- Respite programs conduct provider interviews, contact references, and require criminal background checks.
- Respite programs assess provider knowledge about human development and developmentally appropriate activities.
- Respite programs ensure that providers have work or volunteer experience working with the population they are serving (i.e., family caregivers, children with disabilities, adults with dementia, families in crisis).

- ☞ Respite programs ensure that providers are physically and emotionally able to provide the care (e.g., by assessing work/volunteer experience, asking specific open-ended interview questions, and checking work and character references).

Recruitment

Targeted respite provider recruitment activities help respite programs strengthen and sustain provider capacity so that the respite program can effectively and consistently meet the needs of family caregivers and care recipients without interruption. Recruitment strategies can vary depending on the respite program and family caregiver requirements, but can include community outreach, advertisements, and informal networking.

- ☞ Recruitment campaigns for providers are carefully planned to encourage potential providers to respond to the need for respite.
- ☞ Family caregivers are encouraged to identify their own respite providers whenever appropriate from formal or informal supports.
- ☞ Efforts are made to recruit respite providers from various ethnic, racial, linguistic, and cultural groups, as well as from socially diverse families (e.g., grandfamilies; foster and adoptive families; single parent families; lesbian, gay, bisexual and transgender families (LGBT)) in order to provide a diverse workforce.
- ☞ Respite programs recruit providers who can effectively address specific family and care recipient needs (e.g., fluent in family's first language, trained to work with individuals with dementia).
- ☞ Respite programs recruit respite providers representing both male and female role models for children and youth.
- ☞ Respite programs recruit respite providers who live in areas easily accessible to families needing services, or plan to address resulting transportation issues if this is not possible.

Hiring and Retention

Respite programs have policies and procedures in place for hiring providers and volunteers.

- ☞ A job description is developed for all paid and volunteer respite positions, including the knowledge and skills needed to perform the designated job.
- ☞ Respite providers and volunteers are required to submit a job application, provide references, and participate in an interview.
- ☞ Respite programs conduct criminal background checks.
- ☞ Respite providers are given a contract outlining provider and/or volunteer roles and responsibilities.
- ☞ Once hired, respite providers and volunteers are given a general program orientation and participate in pertinent training activities.
- ☞ Respite programs provide ongoing support and supervision, including evaluating and providing feedback on the performance of each provider and volunteer.

- ☞ Respite programs make every effort to pay providers wages appropriate to their level of experience and the type of care they give (e.g., community care versus medical respite care).
- ☞ Whenever appropriate and possible, respite providers receive benefits such as health insurance, paid sick and vacation days, and a retirement package.

Volunteers

Volunteers are a valuable and cost effective resource for respite programs. So that volunteers can be effectively used to support the respite experience, programs must develop a clear vision of the role(s) volunteer recruits play in their program. Depending on their skills, education, and background, volunteers can serve in a broad array of roles.

- ☞ Respite programs consider using volunteers to provide a number of roles including clerical, fund raising, grounds' improvements, as well as direct services.
- ☞ Respite programs dedicate administrative staff time to careful recruitment, training, retention and supervision of volunteers.
- ☞ Volunteers are recruited from the general community targeting potential volunteers through entities such as senior organizations, colleges and universities, corporate volunteer programs, service organizations, and faith communities.
- ☞ If volunteers are providing direct services, respite programs plan for a comprehensive orientation, training, ongoing support and supervision, as well as specific volunteer job roles.
- ☞ Volunteers are carefully matched with respite program needs. For example, more complex medical needs among children or adults with disabilities, or older care recipients with later stages dementia, may require more highly trained or more closely supervised volunteers to provide respite.
- ☞ Respite programs plan for ways they can recognize volunteers for the services they perform (e.g., recognition events, participation in staff training).

Training

Once respite programs and volunteers have been recruited and hired, it is essential that they receive pre-service training as well as regular in-service training on topics relevant to their work. Training activities can be designed to include an initial orientation, group training, individualized training on specific care recipients' needs, and periodic in-service training to enhance provider skills. Ideally, more than one method of training is offered to address various provider learning styles and needs.

- ☞ Family caregivers and adult care recipients are involved in determining training content and in supervising or assisting in the training of providers, as appropriate. Training can involve formal group presentations, as well as direct training of respite providers by family caregivers and/or adult care recipients in the home.

- 🌀 Respite providers and volunteers receive training which not only enhances their skills, but also lets them know they are a valued member of a respite team, worthy of receiving information to improve the quality of their work.
- 🌀 Respite providers and volunteers receive training prior to providing care. Training is individualized to meet the needs of providers. In some situations, providers may already possess the requisite skills and background. In general, the following topics are included in training for providers. Additional topics may need to be added in specific circumstances.
 - 🌀 Overview of respite services and importance of respite as a valued service
 - 🌀 Overview of family caregiving issues, including but not limited to the positive and negative physical, emotional and familial consequences of caregiving
 - 🌀 Caregiver stress and resultant outcomes
 - 🌀 Confidentiality
 - 🌀 Communication skills
 - 🌀 Disability awareness
 - 🌀 Respect for the independence and abilities of the care recipient
 - 🌀 Child, adolescent, and adult development and aging issues, as appropriate for the respite setting
 - 🌀 Conditions of individuals which respite providers are likely to encounter, such as disabilities, chronic or terminal illnesses, dementia and those at risk of abuse and neglect
 - 🌀 Family diversity (cultural, ethnic, racial, linguistic, family composition)
 - 🌀 Effective ways to work with families of individuals with disabilities and chronic or terminal illnesses and/or families in crisis
 - 🌀 Planning and preparing developmentally appropriate activities; maintaining appropriate routines and schedules for those in care
 - 🌀 Policies and procedures for the respite program, including expectations for reporting and documentation
 - 🌀 Emergency procedures (First Aid, CPR, program emergency protocols)
 - 🌀 General information about the spread of infectious disease, and universal precautions to be used in the care of individuals to avoid the spread of disease
 - 🌀 Program procedures for the administration of medication and other health related tasks; special hair and skin care
 - 🌀 Abuse and neglect detection and reporting protocol for mandated reporters
 - 🌀 Crisis intervention; issues in domestic violence and substance abuse
 - 🌀 Behavior management; what behaviors to expect from individuals with specific disabilities such as autism, and managing individuals with difficult behaviors, including dementia, and of those whose family is experiencing a crisis

Supervision

Supervision is a means of overseeing one's work, offering guidance and verbal and emotional support to those who are providing care either on a paid or volunteer basis. Such teaching and debriefing opportunities enhance the quality of the care being provided.

- ☞ All respite providers, whether paid or volunteer, receive ongoing supervision and support.
- ☞ An administrative staff person is assigned the duty of maintaining consistent and ongoing contact with respite providers to answer questions, listen to their concerns, and share in the joys of providing respite services.
- ☞ Regular staff meetings and in-service training are available to all respite providers.
- ☞ In case of emergencies while an individual is in care, respite providers have access to an administrative staff person at all times.
- ☞ Whether performing their work in the company of co-workers or in the isolation of their home or the family's home, respite providers have access to peer support to share concerns and receive support.
- ☞ Respite providers and respite programs exceed state licensing requirements, as needed, in determining the ratio of caregivers to providers. Some individuals in care, especially young children or the elderly with dementia, frequently have additional needs for assistance and supervision. Respite providers can more readily respond to those needs if they have only a few individuals in their care.
- ☞ Respite programs determine the provider/care recipient ratio by assessing the individualized needs of each care recipient. In practice this will mean that some care will be appropriately provided in small groups, and, in some instances, care will be provided on an individual basis.
- ☞ Documentation and reporting procedures are in place to reflect the respite provider service location if it is different from the immediate supervisor's location.

Quality Care

Respite programs and providers strive to deliver excellent, high quality respite in every aspect of caregiving from easy access to services, including information and referrals to other services, to a safe environment with an emphasis on health, hygiene and good nutrition. Programs are prepared to address individual medical needs and have established systems to handle emergencies.

Access to Services

Respite services are "family friendly" and easy to access.

- ☞ Family caregivers are clear about what they need to do to receive services (i.e., who to call, intake paperwork, eligibility, providing medical information and releases).
- ☞ Respite programs have one point of entry or "no wrong door" for family caregivers to access services (e.g. help line, referral agency, service coordinator, case manager).

- ☞ Respite programs make the service entry process clear to family caregivers and easy to follow.
- ☞ Respite programs have guidelines for eligibility, selection, and priority for services.
- ☞ If necessary and appropriate, respite programs maintain a waiting list and provide respite services to those family caregivers as soon as possible based on criteria developed by the respite program.

Information and Referral

Respite may be one in a range of possible services necessary to support the family caregiver. If specific ancillary services are not available to family caregivers within the respite program, they are referred to other community agencies that may be able to meet their related service needs. Respite programs encourage and help family caregivers identify formal or informal supports or available social capital through caregiver assessment or informal discussion.

- ☞ Respite programs identify and maintain current information on other community services that family caregivers may find helpful.
- ☞ Respite programs actively work to be included in information and referral (I & R) and other “no wrong door” community systems.
- ☞ Respite programs share information with family caregivers to increase their awareness of, and access to, additional needed services.
- ☞ Respite programs facilitate referral to other services, when requested.
- ☞ Respite programs coordinate with other service providers as active partners in individual and family systems of care.
- ☞ Respite programs provide or assist in accessing additional related services to enhance the respite experience and to meet other family caregiver needs. Examples of related services may include, but are not limited to:
 - ✦ Transportation
 - ✦ Health care information or services (e.g., insurance, medical, mental health, chronic health conditions, disability)
 - ✦ Case management or service coordination
 - ✦ Counseling and therapy services
 - ✦ Early intervention services for infants and toddlers
 - ✦ Occupational and physical therapy services
 - ✦ Parent/Family caregiver education
 - ✦ Support groups for care recipient or family members
 - ✦ Financial assistance
 - ✦ Home health care services

Privacy/Confidentiality

Family and care recipient privacy and confidentiality are respected at all times by respite program staff and volunteers.

- ☞ Respite programs only request information that is necessary for the provision and evaluation of services.
- ☞ All written records, email correspondence, and interactions (e.g., phone conversations, meetings) are kept confidential.
- ☞ Respite programs adhere to the Health Information Privacy Accountability Act (HIPAA) rules related to sharing health care information.
- ☞ Respite services are designed to respect each care recipient's privacy, personal space, and possessions.
- ☞ Each care recipient's need for privacy is respected without compromising safety and quality of care.

Safety

The respite care setting is clean, safe, and free of hazards.

- ☞ Children and adults are able to easily explore the respite setting, and the environment is free of safety hazards. (e.g., a toddler is not exposed to a play area that includes tiny toy pieces that could end up being choked on or swallowed; adults with mobility issues are not restricted due to scatter rugs that pose a hazard).
- ☞ Exits are secured to prevent care recipients from wandering away from the respite setting.
- ☞ Care recipients are supervised by an adult at all times while in care.
- ☞ Care recipients are protected from physical, sexual, and emotional abuse by others in the program and care providers.
- ☞ Respite programs adhere to state child and adult protective services requirements as mandated by law.

Nutrition

Each individual receiving respite care receives good nutrition.

- ☞ Food preferences are respected in planning and providing for each individual's nutritional needs. Specialized needs due to religious requirements or health needs of individuals are provided as appropriate.
- ☞ Federal United States Dietary Guidelines for Americans, released by the Secretaries of Health and Human Services and Agriculture, are followed for all age groups.
<http://www.health.gov/dietaryguidelines/>
- ☞ Meals are attractively presented, occur regularly and frequently, and are not limited in quantity (unless under physician's orders), withheld, or forced.
- ☞ Meals are provided in a socially pleasant environment and care providers are encouraged to eat with the care recipient(s).

- ☞ Care recipients are encouraged to feed themselves as independently as possible. Feeding assistance and support is provided when necessary.
- ☞ Age appropriate adaptations are used, such as infants are always held for bottle feedings and spoken to while being fed.

Hygiene

Individuals receiving respite care are provided good hygiene and access to needed toileting and bathing facilities.

- ☞ Care recipients receive hygiene assistance, support, and adaptations as needed.
- ☞ Care recipients who need assistance are bathed and dressed in clean, appropriate clothing and are shown respect in the process.
- ☞ Care recipients have daily oral hygiene.
- ☞ Care recipient's hair is clean and free of lice, and is brushed and combed as well. Hair is never cut or styled without permission. Special hair and skin care are available for individuals who need it.
- ☞ Respite programs adhere to specific state and local health department requirements as appropriate.

Universal Precautions

Respite providers are trained in universal precaution techniques. Universal precautions were developed by the Centers for Disease Control and Prevention in the 1980s to reduce the spread of infection among health care providers and patients in health care settings. Such precautions are necessary in order to prevent the spread of disease, whether caring for one individual or several at the same time.

- ☞ Respite providers wash hands properly and frequently.
- ☞ Respite providers wear disposable gloves when in contact with bodily fluids (i.e., urine, feces, blood, saliva, open wounds).
- ☞ Articles soiled with bodily fluids are properly disposed of in a covered container.
- ☞ Hands are washed prior to and after changing diapers or assisting with toileting.
- ☞ Personal grooming articles, such as combs and toothbrushes, and clothing are never shared and are labeled and stored separately.
- ☞ Equipment and toys are cleaned and sanitized frequently, particularly in respite programs that care for infants and toddlers who tend to put everything in their mouths.

Medical

Community respite providers need medical information and knowledge in order to address the needs of care recipients who have medical and technology needs in respite settings. Medical needs can vary from tube feedings to administering medications to suctioning tracheotomies and

using adaptive equipment. Respite providers are trained in how to deal with the unique medical requirements of care recipient(s).

- ☞ Community respite program and providers secure appropriate and necessary medical equipment and technology for care recipients.
- ☞ Respite providers are familiar and well-versed in the use of needed adaptive equipment and assistive technology.
- ☞ Respite programs and/or respite providers solicit and maintain pertinent medical information.
- ☞ Respite programs ensure that there is signed consent (or medical release) for the administration of prescription and over-the-counter medications to care recipients. Consent must be given by the family caregiver, parent, or guardian and under applicable state laws.
- ☞ Medication administration documentation includes date, time, dose, and name of the person who administered the medication. A copy of the medication documentation is given to the primary family caregiver when the individual leaves care.
- ☞ If necessary, family caregivers are assisted in accessing any needed health care for their loved one, or are referred to appropriate services.
- ☞ Respite programs follow pertinent state health department or any state requirements related to medication administration.

Emergencies

Respite programs have emergency plans and resources in place to address emergencies.

- ☞ Respite programs ensure that respite providers have the necessary information, resources and contacts available to address care recipient emergencies.
- ☞ The service agency and respite provider have information on contacting the family caregiver in the event of an emergency. When an emergency occurs, the family caregiver is contacted immediately or as soon as possible.
- ☞ Respite programs require a signed consent (or medical release) by the family (primary caregiver; parent or legal guardian), to allow for immediate medical emergency treatment in the event of an accident or illness while the individual is in care.
- ☞ If the care recipient receives medical attention while in care that includes receiving new medications, written permission to administer medications in accordance with the prescription is obtained from the physician prescribing medications. Documentation includes date, time, dose, and name of the person who administered the medication. A copy of the medication documentation is given to the family caregiver when the individual leaves care.
- ☞ As appropriate, respite programs maintain copies of health legal documents including durable power of attorney, health proxy, and do not resuscitate (DNR) orders.

Providing Respite

Respite care provision is family directed and individualized to meet the varied needs of the care recipient and the family caregiver and to provide a meaningful experience for the care recipient. Care is provided in the family's home, in the provider's home or in a community facility or setting. Services are flexible and respond to the changing needs of the family, including both times and places where care is available. Caregivers may hire their own providers or may use a respite care program.

Individualized Across the Lifespan

Each person receiving respite services is treated as an individual, and not treated in a prescribed manner based on his/her special needs. Each individual's unique strengths and needs are acknowledged and planned for accordingly, with respect to their social development and family context.

- ☞ Care recipients are not grouped or labeled based on their disability and/or presenting diagnosis. In some instances it may be appropriate to group individuals who need intensive supervision due to medical needs or diagnoses (e.g., individuals with dementia).
- ☞ Respite programs ensure that the care provider has appropriate skills and sufficient information about the care recipient to effectively meet his or her needs.
- ☞ Family routines and preferences are respected and maintained whenever possible (e.g., the care recipient may adjust better to the care setting if specific mealtimes are maintained).
- ☞ Respite services support the care recipient's social development with respect to their cultural, family and social history.
- ☞ Each care recipient's spiritual beliefs and practices are acknowledged and respected. Individual religious practices are encouraged at the request of the individual and/or family.

Appropriate Activities

Care recipients are supported in ways that enhance their physical, cognitive, emotional, cultural, spiritual, and social well-being. Activities are planned to be safe, creative, engaging and developmentally appropriate.

- ☞ Care recipients are encouraged to express their pleasure, joy, fears, anxieties, frustrations, anger, and/or sadness, and without compromising the safety of the individual, others in care, or the care provider(s).
- ☞ Care recipients are encouraged to perform physical activities which they have an interest in, which they are capable of, or which they are learning, and which do not compromise their safety.
- ☞ Opportunities to engage in safe and developmentally appropriate social activities with others are provided and encouraged.
- ☞ Care recipients are provided with interesting, creative and developmentally appropriate activities.

- ☞ Television viewing is minimized for all age groups. If television is viewed, programming is developmentally appropriate, and the care provider interacts with the care recipient and provides companion activities to enhance the experience.
- ☞ While in respite care, care recipients have a structured schedule if necessary to help them feel secure. (e.g., periodic free play sessions with options and choices for children are part of the daily schedule; predictable schedule for individuals with dementia).
- ☞ Respite programs ensure that individuals cared for in mixed age groupings do not become bored with activities above or below their developmental level. Everyone needs to experience competencies and challenges that enhance self-esteem.

Flexibility of Care

Respite services are planned and developed so that a variety of family and care recipient needs can be met. A flexible continuum of care is available to meet the changing needs of families. There are times when families want care provided in their home and other times when they prefer out-of-home care. Sometimes they want care scheduled on a weekly basis and other times need care for a weekend or a more extended period.

- ☞ Respite service options are flexible and responsive to the changing needs of families.
- ☞ Respite service options include care that is available during the day, in the evening, for overnight care, and for longer periods, if necessary.
- ☞ Respite services are available in generic community settings where family caregivers receive other services, whenever possible.
- ☞ Respite service options include the availability of care on a planned or immediate basis, to be responsive to family caregiver needs.
- ☞ Respite programs ensure that family caregivers and care recipients have a choice of provider and if needed can request a change in provider.
- ☞ If requested and appropriate, family caregivers seeking respite for a child with special needs are able to receive respite services for all of their children. If respite is offered outside the family's home, siblings remain together or have access to one another.
- ☞ When receiving respite care in out-of-home settings, care recipients are provided the opportunity to bring specific personal possessions in addition to clothes and hygiene items (e.g., stuffed animal, pillow, music, photographs).
- ☞ When respite is provided in response to a crisis, the respite provider is connected to pertinent services in order to support the family and the care recipient through the crisis and follow-up resolution.

Family Caregiver Directed Respite (Participant-directed Respite)

Family caregivers can independently recruit, hire and train respite care providers using personal funds, vouchers, or stipends. Providers may include informal caregivers such as family or friends as well as paid providers. Family caregivers can do this with or without the assistance of a respite program.

- ☞ Family caregiver directed respite can include informal options where other family members, friends, or neighbors provide care, or more formal arrangements where the family caregiver directly hires an individual to provide respite in their home or an agreed upon community setting.
- ☞ When hiring respite providers, family caregivers may need support and information related to interviewing and selecting a provider for their family member.
- ☞ When appropriate, respite programs can provide family caregivers with pertinent resources for interviewing and selecting a provider (e.g., Dellinger-Wray & Uhl, 1996 and ARCH's *The ABCs of Respite: A Consumer's Guide for Family Caregivers*, both provide useful checklists).
- ☞ When family caregivers independently hire respite providers, they need to carefully plan for training focused on the individualized needs of the care recipient.
- ☞ When family caregivers directly hire their own care provider, they act as an employer and provide payment for services. Agencies involved in providing funds and/or training respite providers should make families aware of pertinent Internal Revenue Requirements (IRS) and other relevant federal or state labor laws or standards (see subsequent section on Legal Considerations).



ADMINISTRATION

Overview

Program administration encompasses ways in which programs are governed and implemented. It takes into account advisory boards, program policies and procedures, risk management, legal considerations, and licensing requirements. Also, the program's involvement with the local community has implications for how the program is connected to the greater community for referrals, resource sharing, partners and potential donors. Respite programs have a responsibility to evaluate their services, effectiveness, and performance.

Program Administration

Respite programs are equipped with advisory or governing boards to assist in the preparation of policies and procedures and to create a plan for risk management.

Advisory Committee/Board

Nonprofit agencies develop pertinent advisory committees or governing boards.

- ☞ An advisory committee or board is established to provide oversight for respite programs. Representation includes family caregivers, community members, and professionals involved in human services.

- ☞ Depending on program needs, it may be helpful to include an attorney, accountant, health care professional, care provider, psychologist, marketing professional, or other relevant community members.
- ☞ If an advisory committee or board is already in place, a representative or subcommittee is assigned to address relevant respite program issues.

Policies and Procedures

Each respite program develops policies and procedures which address the specific needs of their program.

- ☞ Respite programs have a mission statement which is reviewed and updated as needed.
- ☞ Specific respite program goals, objectives and action plans are established.
- ☞ Policies and procedures are developed on the following topics, when appropriate for the respite program model:
 - ✦ Program mission statement
 - ✦ Types of services available
 - ✦ Standards of care for those receiving services
 - ✦ General emergency procedures (e.g., medical, home or facility)
 - ✦ Family caregiver and care recipient rights and responsibilities
 - ✦ Family caregiver and care recipient confidentiality policy
 - ✦ Program entry and departure procedures
 - ✦ Record keeping requirements
 - ✦ Medication administration and other health related tasks
 - ✦ Procedures for transporting individuals in care
 - ✦ Staff behavior and professionalism
 - ✦ Staff communication
 - ✦ Staffing ratios
 - ✦ Staff job descriptions
 - ✦ Other program specific topics

Risk Management

Risk management is a planned process for reducing an organization's potential liability and loss of assets (Horowitz and Sprague, 1994). Respite programs have a risk management plan in order to identify, control or reduce risks, and to address quality of care and liability issues.

- ☞ Respite programs have policies and procedures which describe all program services, staff responsibilities, and operating procedures as outlined in the previous section.
- ☞ Respite programs have a risk management plan that addresses the following steps:
 - ✦ Identifying risks for providing services through the program

- ✦ Analyzing and evaluating risks
 - ✦ Controlling or reducing risks.
 - ✦ Protecting the agency, employees, and the consumers of services
 - ✦ Addressing any risk management failures to avoid future problems
- ☞ Respite programs consult with an attorney to review all policies and procedures, as well as the risk management plan.

Legal Considerations

Because there are so many models of respite programs, it is the program's responsibility to determine where it fits under state licensing regulations. Respite programs serve individuals across the lifespan in a variety of settings from child care facilities to nursing homes. Therefore, programs must ascertain and work with state licensing and/or certification agencies, to locate the entity that most fits their program and to maintain contact and follow those regulations. Programs also comply with IRS regulations.

State Licensing Requirements

Respite includes a broad array of service options, some of which are licensed and/or regulated. Many respite programs are currently licensed and/or regulated through other program categories, such as child care, child or adult family homes, nursing homes, residential care, emergency shelter care, home health care or foster care.

- ☞ Respite programs have a responsibility to be aware of and to comply with the specific state licensing requirements that may govern their activities.
- ☞ In order to determine if any program services require licensing, respite programs are in contact with their pertinent state and local licensing agencies.
- ☞ Home and center-based respite programs determine whether local or state law requires the health department and fire department to inspect the premises on a regular basis.
- ☞ The care recipient's family is made aware of whether or not the service provided falls under state licensing requirements.

IRS Requirements

Respite agencies providing services through interagency, voucher or stipend (e.g., cash assistance) models address Internal Revenue Service (IRS) requirements as appropriate. Many respite services are provided through interagency efforts. In some instances a particular agency employs the care provider. Other times the care provider may be an independent contractor (i.e. self employed) or the family may choose and employ the provider.

- ☞ Respite programs that contract with providers to care for individuals in their homes or the family's home, must inform them that as independent contractors they must comply with IRS code requirements for the self employed. All federal, state, and local taxes must be paid by the independent contractor.

- ☞ When the family chooses and employs the respite provider, collaborating agencies or programs share the requirements of IRS Publication 926 – Employment Taxes for Household Employers.
- ☞ Families and respite providers comply with state and federal labor laws and standards.

Community Involvement

Family caregivers provide care for family members across the lifespan. Family caregiver needs are dynamic and change over time, and are variable depending on the specific needs of their family member. It is important for communities and respite providers to assess and identify existing respite service options. Communities can then enhance the continuum of respite services, and develop and provide new respite options to better address the breadth of family caregiver needs. Community planning and collaboration ensures that respite services are effectively developed within the context of the family's community and its unique characteristics. If available, planning can also be done in collaboration with the State Lifespan Respite Program funded through the U.S. Administration on Aging.

Surveying Community Resources and Family Caregiver Needs

Programs conduct a survey of community resources and needs when planning and providing respite services. This process serves to gather information, educate the community about respite service options, and foster collaborative relationships.

- ☞ Respite programs periodically conduct a comprehensive survey of community resources through phone calls, email, mailings, and meetings to determine what services are currently available within the community and what gaps and needs exist.
- ☞ A broad array of community organizations are included in survey outreach activities such as: state and local respite and/or caregiver coalitions, human service agencies, parent groups, disability organizations, schools, health agencies, child and adult day care centers, family day care providers, adult family homes, assisted living facilities, nursing homes, recreation programs, summer camps, group homes, residential programs, local government, colleges and universities, hospitals, clinics, shelters, substance abuse treatment programs, crisis intervention agencies, businesses, and religious, cultural and community service organizations.

Planning for an Array of Community Respite Options

Once it is clear what community respite services are available and what gaps exist, then respite programs plan their service development to meet specific needs.

- ☞ Community service coordination and collaboration is built into respite program development and service delivery plans. Communities plan an array of respite service options to meet the changing and diverse needs of family caregivers.
- ☞ Information is maintained on all agencies providing respite services.
- ☞ Information is maintained on all funding and payment sources for respite care options.

- Information is solicited and maintained on all agencies providing additional services to families caring for someone with special needs and/or families in crisis.
- Each respite program provides other community agencies with relevant information about their program, such as the population served, program description, and referral procedures.

Community Collaboration

When planning and providing services, respite programs collaborate with other agencies and human service organizations to enhance service provision and program evaluation.

- Service options are developed that meet the needs of family caregivers who are unserved or underserved and which interface effectively with existing service systems, programs, and natural supports.
- Respite programs engage in interagency collaboration to enhance the array of respite services, thus providing family caregivers with appropriate choices and options.
- Respite programs consider collaboration on training, funding, sharing technical expertise and support, and the development of multiple community service options.

Marketing and Fundraising

Respite programs develop plans that include marketing and fundraising goals. The ability of an organization to continually adjust its services to meet consumer needs is key to its survival.

- Marketing and fundraising activities reflect the respite program's mission, goals, objectives, and action plans.
- Respite programs have a well developed promotional campaign as a result of their marketing efforts.
- Promotional campaigns educate the community on the benefits of respite care. (For further information, see Blater, 2011 <http://www.archrespite.org/ta-center-for-respite/webinars-and-teleconferences#marketing>)

Evaluation

Program evaluation and consumer satisfaction are important in measuring successful service delivery, to identify unmet respite needs, and to identify areas of needed improvement. Evaluation data serve as a critical tool to maintain and improve quality respite services. (For further information see Firman & Kirk, 2002 and Cook, 2010.)

Monitoring Respite Program Success

Program evaluation serves as a useful tool to monitor the success of the program in relation to its mission and goals, and can be used to provide "objective" detailed documentation of accomplishments which is useful for attracting consumers, furthering collaboration and obtaining funding. Evaluation starts when respite services begin and continues throughout the duration of

the program, as it is useful in improving services and service delivery. Evaluation information is also critical to the funding source, and is carefully planned to answer key questions. Ultimately, respite programs strive to include strategies to constructively assess caregiver, care recipient, and family outcomes of the services and share “best practices” with other respite providers, audiences, and stakeholders.

- ☞ Respite programs systematically conduct evaluations of their service delivery.
- ☞ Respite programs incorporate evidence-based or evidence-informed evaluation measures, as appropriate.
- ☞ When needed to enhance respite service evaluation, respite programs form partnerships with state and community agencies (e.g., institutions of higher education, state agencies) to collaborate on needs assessments and program evaluation.
- ☞ Minimally, the following data are collected and evaluated on a regular basis:
 - ✦ Consumer satisfaction with services and consumer benefits (e.g., using a pre and post survey)
 - ✦ Units of service (i.e., numbers of care recipients and families served; hours/days of care)
 - ✦ Service location (e.g., home, community, hospital, group home)
 - ✦ Ethnicity, family composition and primary language of families
 - ✦ Requests for service
 - ✦ Unmet service needs and waiting lists
 - ✦ Costs of services
- ☞ Ideally, respite programs evaluate the following:
 - ✦ Reasons family caregivers are seeking services
 - ✦ Impact of services on family caregiver stress and quality of life
 - ✦ Impact on caregiver interpersonal relationships
 - ✦ Caregiver work-related secondary benefits
 - ✦ Family caregiver requests for service changes, expansion, and new service development
 - ✦ Family caregiver involvement in services
 - ✦ Staff satisfaction
 - ✦ Program cost-effectiveness
 - ✦ Achievement of program goals and benefits
 - ✦ Impact of the services on the community
 - ✦ Special activities (e.g., public awareness, fundraising)
 - ✦ Provider and volunteer training is assessed in terms of skill levels as well as satisfaction with the training.



RESOURCES

Note: The following resources are intended to supplement and enhance information within the Guidelines. Resources are loosely arranged as to how they relate to the various sections. Because many of the articles could be referenced in several sections of the Guidelines, the authors attempted to place them in categories based on the larger emphasis within the article. Some resources, although relevant, did not fit into discrete categories and are therefore categorized as ‘General.’

Family Caregivers

Family Caregiver Involvement

ARCH National Respite Network and Resource Center. (2010). *ABCs of Respite: A Consumer’s Guide for Family Caregivers*. Chapel Hill, NC: Author. Retrieved from <http://www.archrespite.org/consumer-information>

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Stockwell-Smith, G., Kellett, U., & Moyle, W. (2007). Why carers of frail older people are not using available respite services: An Australian study. *Journal of Clinical Nursing, 19*, 2057-2064. doi:10.1111/j.1365-2702.2009.03139.x

Strunk, J.A. (2010). Respite care for families of special needs children: A systematic review. *Journal of Developmental & Physical Disabilities, 22*(6), 615-630. doi:10.1007/s10882-010-9190-4

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Family Diversity

Al-Kandari, H.Y., & Al-Qashan, H. (2010). Maternal self-efficacy of mothers of children with intellectual developmental disabilities, down syndrome, and autism in Kuwait. *Child and Adolescent Social Work Journal, 27*, 31-39. doi:10.1007/s10560-009-0189-6

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Respite Systems

National Direct Service Workforce Resource Center. (2011). *Building capacity and coordinating support for family caregivers and the direct service workforce, common goals and policy recommendations emerging from the CMS leadership summit (9/16-9/17/10) on the direct service workforce and family caregivers*. Washington, DC: Author.

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Thurgate, C. (2004). Home from home: Evaluation of a respite service in Kent. *Paediatric Nursing*, 16(7), 20-22.

Respite Care Models

Meltzer, J., & Bennett Johnson, S. (2004). Summer camps for chronically ill children: A source of respite care for mothers. *Children's Healthcare*, 33(4), 317-331.

Whirrett, T. (2002). *Adult day care: One form of respite for older adults* [ARCH Fact Sheet #54]. Retrieved from www.archrespite.org/productspublications/arch-fact-sheets#FS_54

Respite Care Providers

(qualifications, recruitment, hiring & retention, volunteers, training, supervision)

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Olson, N., & Whirrett, T. (rev. 2002). *Recruiting and retaining respite providers* [ARCH Fact Sheet #44]. Retrieved from www.archrespite.org/productspublications/arch-fact-sheets#FS_44

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Wilkes, L., Beale, B., & Cole, R. (2006). Aunties and uncles co-operative family project ltd: Volunteers making a difference in the lives of children and parents. *Contemporary Nurse*, 23(2), 291-302.

Quality Care

(access to services, information and referral, privacy/confidentiality, safety, nutrition, hygiene, universal precautions, medical emergencies)

Beale, H. (2002). Respite care for technology-dependent children and their families. *Paediatric Nursing*, 14(7), 18-19.

Edgar, M. (1996). *Preventing the spread of disease: Tips for providers* [ARCH Fact Sheet #42]. Retrieved from www.archrespite.org/productspublications/arch-fact-sheets#FS_42

Edgar, M. (1996). *Protecting staff and children from the spread of disease: A guide for program directors and managers* [ARCH Fact Sheet #43]. Retrieved from www.archrespite.org/productspublications/arch-fact-sheets#FS_43

Wolkowski, A., Carr, S.M., & Clarke, C.L. (2010). What does respite care mean for palliative care service users and carers? Messages from a conceptual mapping. *International Journal of Palliative Nursing*, 16(8), 388-392.

Providing Respite

(individualized, appropriate activities, care continuum, family directed)

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Chan, J.B., & Sigafos, J. (2000). A review of child and family characteristics related to the use of respite care in developmental disability services. *Child & Youth Care Forum*, 29(1), 27-37.

Dellinger-Wray, M., & Uhl, M. (1996). *A Practical Guide to Respite for Your Family*. Richmond, VA: Partnership for People with Disabilities, Virginia Commonwealth University.

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MetLife Mature Market Institute. (2010). *The MetLife National Study of Adult Day Services: Providing Support to Individuals and Their Family Caregivers*. Washington, DC: Author. Retrieved from www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-adult-day-services.pdf

Parahoo, K., Campbell, A., & Scoltock, C. (2002). An evaluation of a domiciliary respite service for younger people with dementia. *Journal of Evaluation in Clinical Practice*, 8(4), 377-385.

Administration

Program Administration

(advisory committee/board, policies/procedures, risk management)

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General

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