



ARCH Products, Publications, and Resources

Fact Sheets, Issue Briefs,
Start Up Manuals,
Training Resources,
Webinars

November 2011

Introduction

During its more than twenty years of service, the ARCH Respite Resource Center has produced a myriad of products and resources to assist respite providers and community and faith-based organizations build, sustain and evaluate respite programs and services; to help family caregivers find and choose respite; to help state and local agencies develop statewide respite coalitions; and to educate the public and policymakers on the importance of respite. Many of these documents and resources are still timely and useful. With funding from the Administration on Aging, US Department of Health and Human Services, and in partnership with the Family Caregiver Alliance, ARCH is working to update many of these materials and create new ones in response to the training and technical assistance needs of the Lifespan Respite grantees and their many partners, including state respite coalitions and Aging and Disability Resource Centers. ARCH will continue to respond to the needs of the entire ARCH Respite Network, including family caregivers, and the public at-large as it develops new products.

The new and existing resources listed in this document are available online at the ARCH website www.archrespite.org. Most of the documents and resources are available free online and are downloadable directly from the website. A few of the lengthier documents are available for a fee at the ARCH Store <http://www.archrespite.org/arch-store>.

What are your Needs for Respite Training, Information and Assistance?

We continue to seek your input on needs for new products and services. Please let us know what your preferences and needs are at <http://www.surveymonkey.com/s/VTL5FNV>.

Thank you

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Consumer Information

A Consumer's Guide to Respite for Family Caregivers

<http://www.archrespite.org/consumer-information>

- Types of Respite
- How do I choose a respite program or provider?
- How do I choose an Adult Day Care Program?
- How do I pay for Respite?



Respite Locator Service (www.respitelocator.org): The National Respite Locator Service helps parents, family caregivers, and professionals find respite services in their state and local area to match their specific needs.¹

Fact Sheets

(Available as free downloads at <http://www.archrespite.org/productspublications/arch-fact-sheets>)

- 1. Crisis Nursery Care: Respite for Children at Risk of Abuse and/or Neglect.** Definition of crisis nursery services, information about six program models, and listing of resources and references for further information. [\[FS 1\]](#)
- 2. Respite for Children with Disabilities, & Chronic or Terminal Illness.** Definition of respite, information about seven program models, and listing of resources and references for further information. [\[FS 2\]](#)
- 3. Crisis Nursery Care for Infants and Children Who Are Medically Fragile.** Staffing, training, and medical services issues for crisis nursery care for infants and children who are medically fragile written by Jeanne Landeck-Sisco, Executive Director, Casa de los Niños. [\[FS 3\]](#)
- 4. Respite Care for Children with Developmental and/or Physical Disabilities: A Parent's Perspective.** Parent's perspective on keys to a successful respite program, written by Scott Miller, FSC Coordinator for West Virginia, and parent of a child with Down's Syndrome. [\[FS 4\]](#)
- 5. Respite Care for Children with HIV-Related Conditions.** Program considerations such as training, provider support and supervision, use of volunteers, and medical services, written by Jane Weiler, Director, Pediatric AIDS Respite Program, NY Hospital Cornell Medical Center. [\[FS 5\]](#)
- 6. Some General Principles of Charitable Nonprofit Fundraising.** Examination of funding basics and the role of boards; long range and strategic market plans; different funding strategies; and funding goals. Written by Beverly R. Hoffman, President, National Deferred Giving Trust. [\[FS 6\]](#)
- 7. Marketing for Charitable Nonprofit Organizations.** Discussion of marketing principles applied to nonprofit organizations. Emphasis on use of effective marketing in the competitive search for funding. Written by Beverly R. Hoffman, President, National Deferred Giving Trust. [\[FS 7\]](#)
- 8. How Fundraising Flows From Strategic Planning.** Explanation of the interrelationship between strategic planning, marketing, and fundraising. Includes a step-by-step strategic planning process. Written by Beverly R. Hoffman, President, National Deferred Giving Trust. [\[FS 8\]](#)
- 9. Respite Care for Children with Autism.** Description of the characteristics of children with autism with suggestions about provider training and child care provision. Written by Marie Taras, Director, Autism Support Center. [\[FS 9\]](#)
- 10. Creative Fundraising Activities.** Seventeen creative fundraising activities described with estimates of planning time, cost, and personnel required. [\[FS 10\]](#)
- 11. Respite Care for Children Who Are Medically Fragile.** Respite program options: general partnerships and resources; community and family needs assessment; licensing and standards; staffing; training; medical services and collaboration; innovative community-based respite support programs; resources and references, by Jennifer Cernoch, Director of the Texas Respite Resource Network. [\[FS 11\]](#)
- 12. Local Program Evaluation.** The basics of program, not outcome, evaluation. Provides step-by-step process including how to determine the scope of the evaluation, select appropriate evaluation methods, collect and analyze information, and report findings. Written by David B. Langmeyer, evaluation consultant and Gail S. Huntington, former ARCH Director of Research/Evaluation. [\[FS 12\]](#)
- 13. Developing Evaluation Questions.** Explanation of how to develop process, structural, activity, and outcome questions for effective program evaluation. Written by David B. Langmeyer, evaluation consultant and Gail Huntington, former ARCH Director of Research/Evaluation. [\[FS 13\]](#)

¹ **Disclaimer:** Please note that this database is provided for informational purposes only and is not all-inclusive. The fact that an organization is or is not listed in the database does not represent an endorsement or lack of endorsement for any purpose. We assume no responsibility for any claims arising from use of the online database. We do not check the background, references or any other aspect of the companies and individuals listed here. You must take responsibility for checking the background and qualifications of any respite provider you choose.

- 14. Evaluation Measures.** Explanation of the importance of carefully selecting measures for evaluation questions. Covers the question of how activities will be measured, who will complete the measure, selecting the measure, and ensuring confidentiality. Written by David B. Langmeyer, evaluation consultant and Gail S. Huntington, former ARCH Director of Research/Evaluation. [\[FS 14\]](#)
- 15. Developing the Evaluation Report.** Discussion of how to most effectively present evaluation data in written and verbal reports. Includes information about developing charts and graphs for visual presentation of numerical data. Written by David B. Langmeyer, evaluation consultant and Gail S. Huntington, former ARCH Director of Research/Evaluation. [\[FS 15\]](#)
- 16. Volunteers .** Discussion of the issues pertaining to workers' compensation, personal liability, and vehicle liability for organizations employing volunteers. Excerpted from Lai, M., Chapman, T., & Steinbeck, E. (1992). Am I Covered for...? A Comprehensive Guide to Insuring Your Nonprofit Organization (2nd ed.). [\[FS 16\]](#)
- 17. Risk Management.** Details the liability risk to programs and provides five steps for managing those risks. Points out the value of sound agency structure as a risk management tool, the need for a risk management policy statement, and ways to address parental concerns and confidentiality. Written by Becky Montgomery, planner, consultant, and trainer in child abuse and neglect issues. [\[FS 17\]](#)
- 18. Volunteer Respite: Valuable Resources *NEW!!*** How-to's of screening, selecting, placing, and training volunteers. Outlines various ways that volunteers can be utilized and provides tips for retaining volunteers over time. Highlights national and local volunteer respite programs. Written by Kelly Tipler, consultant and Chair, TN Respite Coalition. [\[FS 18\]](#)
- 19. The Child Care and Development Block Grant Program.** Provides a detailed description of this block grant program including eligibility, planning, payment, collaboration, and other considerations. Written by Kerry K. Healy, ARCH consultant, and Belinda Hardin, former ARCH Director. [\[FS 19\]](#)
- 20. Crisis Nursery Services: Responding to Parental Concerns.** Discussion of parental concerns and how programs can respond effectively to those concerns, thus building trust between the organization and parents. Written by Becky Montgomery, planner, consultant, and trainer in child abuse and neglect issues; Nancy Smith, ARCH Associate Director; and Belinda Hardin, former ARCH Director. [\[FS 20\]](#)
- 21. Families and the Grief Process.** Examination of grief and the emotions associated with it. Offers healing strategies for families and staff working with them. Written by Kathleen Braza, bereavement consultant. [\[FS 21\]](#)
- 22. Family Support Services.** Definition of family support, description of typical components of family support programs, in general, and specific to crisis nursery and respite programs. Written by Paul Deane, Director of Information Services, National Resource Center for Family Support Programs. [\[FS 22\]](#)
- 23. Siblings of Children with Special Health and Developmental Needs.** Discussion of typical concerns of sisters and brothers and how to create programs that address specific needs. Provides a checklist for organizations to assess sibling inclusion. Written by Donald Meyer, Director, Sibling Support Project. [\[FS 23\]](#)
- 24. Advisory Boards and Boards of Directors.** Distinguishes between the roles and responsibilities of advisory boards and boards of directors. Offers tips on the recruitment, training, and retention of board members. Written by Sue McKinney-Cull, ARCH Regional Coordinator and Nancy Smith, Associate Director of ARCH. [\[FS 24\]](#)
- 25. Helping Each Other Help Others: Principles and Practices of Collaboration.** Definition of collaboration and other shared resource efforts. Discusses the characteristics of effective collaborative efforts. Written by Arthur T. Himmelman, consultant. [\[FS 25\]](#)
- 26. Crisis Nursery Services: Responding to Ongoing Family Crises.** Discussion of the need for planned crisis nursery services to assist families with chronic or ongoing crises. Points out programmatic and staffing considerations for such service as well as the need to build a relationship with child protective services. Written by Jeanne Landdeck-Sisco, Executive Director, Casa de los Niños. [\[FS 26\]](#)
- 27. Sticky Figures: Using a Needs Assessment.** A thorough examination of the process of developing, implementing, and documenting a needs assessment. Various data collecting methods are examined in detail. Written by David B. Langmeyer, evaluation consultant. [\[FS 27\]](#)
- 31. Understanding the Temporary Child Care Act.** Provides legislative background for the Temporary Child Care for Children with Disabilities and Crisis Nurseries Act of 1986 (as amended). Describes programmatic impact and details legislative chronology. Written by Jennifer Cernoch, Texas Respite Resource Network, Jill Kagan, National Respite Coalition, and Nancy Smith, Associate Director of ARCH. [\[FS 31\]](#)
- 32. Respite for Foster Parents.** Discusses value of respite for maintaining and enhancing foster family placements. Offers unique program considerations, foster parent concerns, and tips for respite provider recruitment, screening, training, and retention. Written by Marilyn Barney, Director, Project HARP, Judy Levin, Supervisor for Family Support Services of the Bay Area, and Nancy Smith, ARCH. [\[FS 32\]](#)
- 33. Respite as a Support Service for Adoptive Families.** Highlights eight core issues affecting all adoptive families. Presents information to help respite programs address the unique needs of children who are adopted, their adoptive families, and respite workers serving this population. Written by Brenda Goldsmith, Director of Adopt-A-Rest at La Hacienda Foster Care Resource Center. [\[FS 33\]](#)
- 34. Respite for Families with Children Experiencing a Serious Emotional Disturbance.** Finding respite services for a child with challenging behavioral issues, can be difficult for families. This fact sheet discusses the definition and characteristics of emotional disturbance, issues for families, program considerations including the referral process, the matching of respite providers and families, liability, training, and evaluation, as well as the need for state involvement in program planning. Written by Judith Sturtevant, Director of Vermont Federation of Families, and Sandra Elliott, former Director of Family Respite Services of Overlook Center, Inc. [\[FS 34\]](#)
- 35. Developing and Implementing Rural Respite and Crisis Nursery Programs.** Respite programs in rural locations have unique issues and challenges. Sandra Morris, a Training and Development Specialist at the Montana University Affiliated Rural Institute on Disabilities, discusses

the unique qualities and challenges of rural programs, the recruitment and training of local respite providers, the search for funds, transportation issues, and the building of community trust. Written by Sandra L. Morris, a training and development specialist at the Montana University Affiliated Rural Institute on Disabilities. [\[FS 35\]](#)

36. Abuse and Neglect of Children with Disabilities. Over 10,000 copies of this factsheet have been distributed nationally. Nationally known author, Nora Baladerian, makes clear the interrelationship between child abuse and neglect and disabilities. Pointing out that not only are children with disabilities at high risk for abuse and neglect, but that children can become disabled through abuse and neglect. She looks at methods of prevention and challenges to effective intervention, and makes strong recommendations for anyone working in the field with children. [\[FS 36\]](#)

37. Family Preservation and Support Services. An in-depth examination of legislation contained in the *Omnibus Budget Reconciliation Act of 1993, P.L. 103-66*. An overview of the legislation is provided as is a thorough discussion of the nature of family preservation and family support services. In addition, the steps involved in accessing the funding available through this legislation are provided. [\[FS 37\]](#)

38. Providing Respite at Conferences for Children with Special Needs. More and more conference planners understand the value of offering respite services to families attending their conferences. Written by Susan Bridges Robertson, who has direct experience in offering respite at a large national conference, this comprehensive factsheet covers logistical concerns, liability issues, staffing questions, meals, registration basics, budget issues, and evaluation. [\[FS 38\]](#)

39. Respite Services for Families with Adolescents at Risk of Abuse or Neglect. An often forgotten population in the field of respite, teens and their families in crisis can greatly benefit from temporary relief. Program design, services for parents, and services for adolescents are discussed. Written by Jill Edwards-Sutton, Child and Family Services Director with Mid-Michigan Community Action Agency. [\[FS 39\]](#)

40. Caregivers Grieve, Too! Respite providers can experience all levels of grief when working with families under extreme stress. Bereavement Consultant, Kathleen Braza, discusses how to recognize grief, what to do with "unfinished business," rituals that can help when someone dies, and healing strategies for everyone working in this field. [\[FS 40\]](#)

41. Soothing Those Jangled Nerves: Stress Management. Discussion of the impact of stress on individuals, the symptoms of stress, myths about stress, and strategies for living with stress. Written by Nita Norphet Thompson, Coordinator for the Head Start Region IV Resource Access Project, and Sue McKinney-Cull, Product Development Specialist for ARCH. [\[FS 41\]](#)

42. Preventing the Spread of Disease: Tips for Providers. A thorough discussion of universal health precautions from the perspective of those providing direct care to children. Specific strategies are addressed for preventing the spread of infectious disease, including HIV/ AIDS. Written by Maggie Edgar, ARCH Regional Coordinator. [\[FS 42\]](#).

43. Protecting Staff and Children from the Spread of Disease: A Guide for Program Directors and Managers. This fact sheet provides program administrators with information and guidance related to the spread of infectious diseases in programs serving children. Issues relating to training, universal precautions, and confidentiality are covered. Specific strategies are addressed for preventing the spread of infectious disease, including HIV/AIDS. Written by Maggie Edgar, ARCH Regional Coordinator. [\[FS 43\]](#)

44. Recruiting and Retaining Respite Providers. Finding and keeping care providers is a challenge for all respite programs. This concise fact sheet offers strategies for both. Written by Susan Workman, Director of the Family Tree Crisis Nursery project at San Juan College in Farmington, New Mexico, and Kerri Bates, coordinator of the program. [\[FS 44\]](#)

45. Respite Services to Support Grandfamilies **NEW!!** Many of the challenges facing grandfamilies who have become the primary caregivers for relative children are unique. This fact sheet, written by staff of the Generations United, covers these unique considerations and offers suggestions for support, funding opportunities, and examples of respite programs that provide appropriate options for grandfamilies. Written by Ana Beltran, Special Advisor to Generations United's National Center on Grandfamilies, and Jaia Peterson Lent, Deputy Executive Director at Generations United in Washington, DC in collaboration with Maggie Edgar, ARCH Senior Consultant, and Jill Kagan, ARCH Program Director. [\[FS 45\]](#)

47. Children with AD/HD and Their Families. Attention Deficit/Hyperactivity Disorder is the most commonly diagnosed child psychiatric disorder in the United States and accounts for at least half of all referrals to child counseling centers. Written by Marissa Lewis, former Information Specialist for the ARCH National Resource Center. [\[FS 47\]](#)

48. Organizational Survival After Federal Funding for Children's Crisis Care and Planned Respite Programs. Planning to continue program activities after federal funding ends needs to begin as soon as the grant is received. Several case studies are reviewed for the lessons they offer. Written by Marissa Lewis, former ARCH Information Specialist. [\[FS 48\]](#)

49. Children with Prenatal Drug and/or Alcohol Exposure. Dealing with the problems of these medically fragile children poses a challenge for respite and crisis care providers. Jeanne Landdeck-Sisco, Executive Director of the Casa de los Niños, the first crisis nursery in the U.S., talks about the health conditions of drug-exposed infants, their developmental patterns, and techniques for working with these children. [\[FS 49\]](#)

50. Cultural Responsiveness in Family Services. To fully achieve the goals of respite and crisis care and other family support services, it is essential that all aspects of program operations, staff development and training incorporate and support cultural responsiveness. The shift to cultural responsiveness and multicultural programming will require change, risk-taking, training, courage, and coordinating a variety of new and different resources. Written by Shirley Pinder Cook, M.Ed., a private consultant with more than twenty years of experience providing educational and social services to diverse populations in a variety of work settings across the country. [\[FS 50\]](#)

51. Respite, Crisis Care, and Family Resource Services: Partners in Family Support. This fact sheet is intended to encourage collaboration among *respite, crisis care, and family resource* services. Collaboration among these services broadens and diversifies their funding base. In

1996, the Temporary Child Care Act (TCCA) and the Community Based Family Resource Program (CBFRP) were consolidated into the Community Based Family Resource and Support (CBFRS) program (the TCCA had provided start-up funding for *respite* and *crisis care* services, and the CBFRP had provided funding for *family resource* services). The newly formed CBFRS program promotes the development of statewide networks and provides funding for *family resource centers*, *respite* and *crisis care* services and other related family support services. [\[FS 51\]](#)

52. Finding Federal Funds for Respite and Crisis Care Services. This fact sheet provides basic information about each of the federal programs that provide funding to states that they could, if they chose to, use to fund respite and/or crisis care programs. [\[FS 52\]](#)

53. Respite and the Faith Community (updated, June 2010) *NEW!!* In the early years of our nation, faith communities often provided the only existing social services, such as education and healthcare. Over time, however, this social involvement slowly diminished. As government increasingly met society's social and economic needs, faith communities began to limit their focus to society's spiritual needs. Today that focus is changing again, as a growing number of faith communities seek to serve not only the spiritual needs of their congregations but also the many different social needs in the larger community. [\[FS 53\]](#)

54. Adult Day Care: One Form of Respite for Older Adults. Adult day care centers, also known as adult day services, have been providing respite for caregivers for more than twenty years. In 1978, there were only 300 centers nationwide. By the 1980s, there were 2,100 centers, and today there are about 4,000 centers nationwide, according to the National Adult Day Services Association (NADSA). NADSA reports that the need for such centers has "jumped sharply to keep pace with the mushrooming demand for home and community based services." [\[FS 54\]](#)

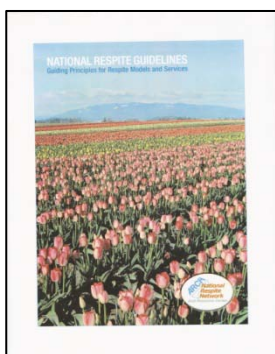
55. Respite for Persons with Alzheimer's Disease or Related Dementia. Alzheimer's disease is a brain disorder, a distinct disease, that results in progressive failure of the person to remember, think, reason, perceive, and make judgments. Eventually the brain shuts down all vital functions, and death occurs. At present, there is no cure. Alzheimer's is a type of dementia. [\[FS 55\]](#)

56. Results of ARCH 2001 Survey of State Respite Coalitions. From an historical perspective, planned and crisis respite are relatively new services for families caring for a dependent family member. Although respite programs were developed in the 1960s, most States still report a serious shortage of respite for families in need. This nationwide shortage of respite programs, coupled with the realization that there is strength in numbers, planted the seed that has led to the growth of State respite coalitions. [\[FS 56\]](#)

57. Respite for Adults with Mental Health Disorders. *NEW!* Written by Diane Elmore, PhD, MPH, Associate Executive Director of the Public Interest Government Relations Office at the American Psychological Association (APA), this fact sheet is meant to assist state agencies, Lifespan Respite grantees and their collaborators, and respite providers by increasing their understanding of the unique needs of family caregivers providing care for adults with mental health needs. Such insight and direction will help State Lifespan Respite programs and others develop strategies to increase respite quality, access, and capacity for this population through partnerships with community-based services and enhanced provider recruitment and training efforts. It is also intended to offer resources for family caregivers seeking to expand respite opportunities for themselves and others. [\[FS 57\]](#)

Guides and Start Up Manuals

<http://www.archrespite.org/arch-store#guides>



***New!* Free Download**

National Respite Guidelines, 2011

Authors: Maggie Edgar, MSW, Senior ARCH Consultant and Monica Uhl, MA, Partnership for People with Disabilities, Virginia Commonwealth University

The guidelines provide a summary of principles addressing quality indicators for all respite models and services. They can act as a checklist for respite providers to review as they address service delivery issues. The guidelines are intended to be used by respite 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 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](#). 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.

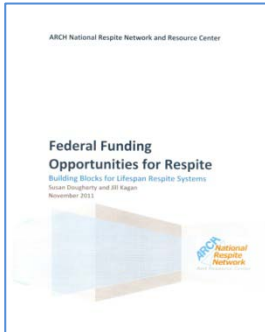


New! Free Download

Participant-Directed Respite Guidebook, October 2011

Developed by the National Resource Center for Participant-Directed Services for the ARCH National Respite Network and Resource Center. Authors: Suzanne Crisp, Elizabeth Maguire, Isaac Selkow, and Erin Singer at NRCPS.

The guidebook is offered as a resource for programs, including State Lifespan Respite Programs that provide respite and are interested in developing and implementing participant-directed respite, especially through voucher programs. Included are: overview materials that provide content information regarding participant direction, examples from two states that currently implement participant-directed respite programs using a voucher system, important tax and financial information, and resources for additional materials.

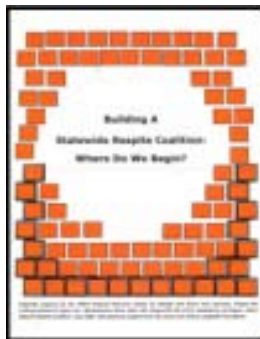


New! Free Download

Federal Funding Opportunities for Respite: Building Blocks for Lifespan Respite Systems

Authors: Susan Dougherty and Jill Kagan

The guidebook provides basic information about each of the federal programs that provide funding, or could potentially provide respite funding. It is meant to be used by State Lifespan Respite programs and their partners to help identify funding sources and maximize and streamline their use. These funding sources could: 1) be the building blocks for the state's Lifespan Respite systems; 2) help serve the unserved; 3) help build respite capacity and quality and help recruit and retain respite workers; and 4) identify the individuals who administer these funds for future collaboration and partnerships. It should also be useful to community and faith-based programs and other local public and private entities that are looking for potential sources of funding to help build new respite programs or expand or sustain current efforts, as well as for family caregivers or those who assist them, to help identify sources of funding that could be used to pay for respite. Numerous potential funding sources for respite certainly do not suggest that funding is even close to sufficient to meet the need, but it does suggest the need to coordinate such efforts with a plan to maximize their benefits.



Free Download

Building a Statewide Respite Coalition: Where Do We Begin?

While respite coalitions have different forms and names, they share a common goal: to promote and improve respite services within their state. Within every group, members provide a support system for each other and assist in making the most of opportunities and solving problems that are too big for one person or agency to manage. This guide is intended to assist those states or groups that are considering forming coalitions by providing the tools necessary to begin building a state respite coalition. Although the focus is on *respite* coalitions in particular, the material can be used for building any coalition. It can be used as a general reference or as a workbook for team members as they progress through the development of a coalition. The workbook was updated in 2009 to include additional references, more state examples, and the latest information on the Lifespan Respite Care Act and implications for State Respite Coalitions.



Free Download

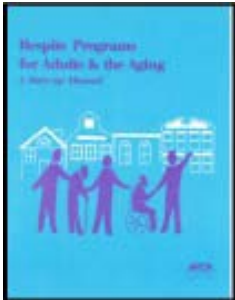
ARCH Respite Coalitions: A Compendium of Fact Sheets

These fact sheets, updated in 2010, are used widely by state respite coalitions and others to educate their members and prospective members, family caregivers, funders, legislators and other policy makers about the resources they have available to provide assistance within their own states (each fact sheet has been formatted to stand alone as a separate document). Newly forming respite coalitions may also find the information helpful as they develop their own structure and activities. Each fact sheet contains the following information: Start-Up Process and Coalition History; Structure; Staff; Funding; Membership; Meetings and Communication; Major Activities; Available Documents (Bylaws, Strategic Plans, Surveys, Brochures, etc.); and State Contact Information.



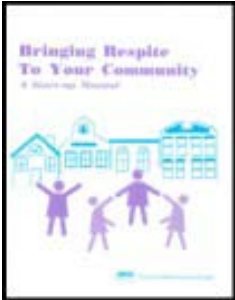
Risk Management: A Training Guide

A simple, straightforward forward approach to a complicated topic. Two attorneys from the American Bar Association Center on Children and the Law, Robert Horowitz and Marcia Sprague, co-authored this resource guide, which includes potential resources, an annotated bibliography, numerous overheads and handouts, and suggested exercises for use in training. 59 pages; \$10.00.



Respite Programs for Adults and the Aging: A Start-up Manual

This 258-page manual contains all of the topics addressed in the original manual (*Bringing Respite to Your Community* -- see above). Examples, forms, and resources relevant to services for adults were substituted for those in the original document. \$25.00 + \$6.00 shipping.



Bringing Respite to Your Community: A Start-up Manual

This manual gives step-by-step instructions on how to begin a respite care program. The 332-page book includes chapters on needs assessment, the planning process, program models, budget, collaboration, marketing, funding, administrative policies and procedures, staffing, daily operations, and evaluation. Included are sample forms, policies, job descriptions, and other resources that can help existing programs reevaluate the design of their current services. \$25.00 + \$6.00 shipping.



Free Download
National Respite Guidelines, 1994

The original National Guidelines were prepared to assist service providers in developing quality services for children, and to help families have some means of discerning the quality of their options. The guidelines do not attempt to set standards or requirements, but merely to assist states and local communities in developing quality respite services that meet the diverse needs of families. Programs must consult with state, county, and/or local licensing agencies to make sure they comply with licensing or certification rules that apply to the type and location of the services. Respite can be provided in a variety of settings and these guidelines are intended to cover general principles that apply to all of them. Contributions to these guidelines have been made by families, respite providers, administrative personnel, licensors, nurses, social workers, educators, government agency personnel, and others. See National Respite Guidelines, 2011, above.



Free Download
Funding for Adult Respite

The need for respite and crisis care continues to grow as older adults live longer and longer. This document provides basic information about Federal, State and other sources of funding for respite and/or crisis care programs for older adults. Potential funding for adult respite and crisis care services can be found in Federal and State statutes. Most often, Federal statutes require that funds flow through States or State designated entities.



Public Awareness Guidebook

A 24-page guidebook for crisis nurseries and respite care programs on strategies for increasing public awareness of the availability of services through press releases, and media public service announcements. Sample press releases, telephone contacts, and more; \$5.00.



Securing a Stable Funding Base: A Training Guide

While materials abound on this subject, none so succinctly lays out the issues related to funding. Referring to the classics in the field of funding, this guide book simplifies the subject and offers suggestions for trainings. Written by Sue McKinney-Cull, ARCH Product Development Specialist/Regional Coordinator; 55 pages; \$10.00.



A Step-by-Step Guide to Successful Training

A trained staff is essential for effective delivery of safe and quality services. This guidebook has been developed to help trainers create and implement interactive, quality training experiences. It contains ideas for visual aids and other props and guidance on how to evaluate the training. 41 pages; \$10.00

Evaluation Materials

<http://www.archrespite.org/program-evaluation>



This 150-page guide with CD is available from ARCH for purchase online.

During the past several years, planned and crisis respite programs across the United States have field tested tools for measuring program outcomes. Under contract with ARCH, the tools were developed by Dr. Ray Kirk of the University of North Carolina, and revised by Casandra Firman ARCH Outcome Evaluation Specialist, and are published in the ARCH guidebook, *Evaluating and Reporting Outcomes: a Guide for Respite and Crisis Care Program Managers (2002)*. The need to demonstrate program outcomes is critical in today's climate of limited and more competitive funding.

Respite programs, both planned and crisis, must be able to clearly and compellingly demonstrate that their programs are achieving worthy outcomes—outcomes related to the improvement of quality of life, and outcomes related to saving tax-payer dollars on more costly interventions such as foster care, nursing homes, or other institutional care.

Phase 1 Field Test Results

The ARCH National Respite Network and Resource Center launched an Outcome Evaluation Initiative in 1998 to develop instruments, in the form of surveys, for measuring the efficacy of planned and crisis respite programs. This report describes the field-testing process, outcomes of

the field-testing, and subsequent recommendations for instrument revisions. (Please note that this is a 46-page report. On a 56K modem, it will take several minutes to download.)

Phase II Field Test Results

The ARCH National Respite Network and Resource Center launched an Outcome Evaluation Initiative in 1998 to develop instruments, in the form of surveys, for measuring the efficacy of planned and crisis respite programs. After being field tested and revised, the instruments were field tested again in 2002. Just over 1,000 caregivers from 43 sites participated in the second field test by responding to the surveys. The surveys asked questions designed to examine how respite affected such things as caregiver stress, health and family relationships. Phase II data indicate that respite has an overall therapeutic effect on caregivers and their families. Following the Phase II testing, the instruments were revised based on feedback from participants and published in *Evaluating and Reporting Outcomes: A Guide for Respite and Crisis Respite Program Managers* (ARCH, 2nd ed.).

Research and Survey Studies

<http://www.archrespite.org/arch-store#guides>



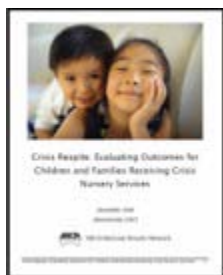
Free Download **Study of Four Lifespan Respite Programs**

In 2004, ARCH endeavored to secure the most current information about the existing State Lifespan Respite Programs by conducting state surveys and follow-up interviews. While only four states had implemented State Lifespan Programs (OR, NE, WI, OK) by that time, several salient findings emerged from early lessons learned. These four programs became best practices upon which the current national Lifespan Respite Care Program was crafted.



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

The Child Welfare League of America (CWLA), the ARCH National Respite Network and Resource Center (ARCH), and Casey Family Programs (CFP) National Center for Resource Family Support collaborated to lay the groundwork for the development of best practice standards for planned and crisis respite services. This report describes the survey's findings; documents approaches to funding, administering, and delivering planned and crisis respite services to families, as described in the case studies; and makes preliminary recommendations on expanding and enhancing these services to support families and caregivers nationwide.



Free Download **Evaluating Outcomes for Children and Families Receiving Crisis Nursery Services**

The ARCH National Respite Network and Resource Center conducted the Crisis Nursery Program evaluation to examine relationships between crisis respite care and (1) incidents of reported child abuse and (2) days of involuntary out-of-home placements. The evaluation also explored the differences in outcomes between crisis respite used as a secondary prevention service and as a tertiary prevention service. Four crisis respite programs were studied, the programs each located in a different county in a western state, operate as a collaborative, and follow a common service delivery model. The evaluation was conducted over 25 months, from June 14, 2004 to July 31, 2006.

Posters and Videos



Respite: A World of Relief

Family love and care is essential for human survival. Even the strongest love can be stretched to the breaking point when a family must provide for year-round, 24-hour care for a loved one. Through interviews with family members and program staff, this video offers the viewer an intimate look at the needs of families for support services, particularly respite care. The 15-minute video is intended to draw attention to, and educate the public and policy makers about, the needs of families for support services, and to promote the concept and benefits of respite care for families and for the community at large. VHS or DVD, \$25 plus \$6 shipping.



Small Poster, 8½" by 11", glossy paper:
"Asking for Help is a Sign of Strength"

Toolkits, Issue Briefs, and Topical Resources

(available as free downloads)

Tools For Collaboration (2010)

Background and Resources for building effective partnerships for Lifespan Respite systems.

http://www.archrespite.org/images/docs/Webinar_Collaboration_Background3.pdf

Lifespan Respite "101" Toolkit (2009)

<http://www.archrespite.org/ta-center-for-respite/webinars-and-resources/webinar-lifespan-respite-101>

- ***AoA Lifespan Respite Fact Sheet***
The US Administration on Aging prepared this fact sheet in 2009 to provide background on the newly implemented Lifespan Respite Program and to provide AoA's vision for the program.
- ***Comparative Table of State Lifespan Respite Programs***
The Lifespan Respite Care Act was modeled on state Lifespan Respite programs in OK, WI, NE and OR that were already up and running, with AZ passing Lifespan Respite legislation in 2007. Each program focuses on a coordinated method for respite service delivery and funding, yet each program has unique characteristics. This comparative table provides an easy look at the differences and similarities between these model state programs and allows other states to choose which characteristics they might want to incorporate into their own state Lifespan Respite Program
- ***Application as a Collaborative Tool***
For States to receive a federal grant to implement a Lifespan Respite Program, they must compete for funds by completing an application to be submitted to the US Administration on Aging. The Lifespan Respite law requires very specific information be included in the application. Compiling this information for the application will require research, documentation, and planning, which presents opportunities for state respite coalition, Aging and Disability Resource Center, and state agency collaboration early in the implementation process. This fact sheet provides details on what is required by law for the application as well as suggestions for how each partner could be most helpful with any or all of the application requirements.
- ***Building Blocks for Respite: Federal Funding Opportunities***
This issue brief summarizes federal funding information from previous ARCH products including [Funding for Adult Respite](#), and updates it to provide brief descriptions of possible federal funding resources for states to support respite services for all ages and disabilities. This information is useful to state agencies and state respite coalitions trying to identify potential partners/respite resources at the state level, as well as important information for respite providers and others seeking funding for their own programs or for the family caregivers they serve.
- ***Model State Lifespan Respite Programs***
This fact sheet provides a summary of the original ARCH study, Statewide Lifespan Respite Programs: [A Study of Four State Programs](#) with updated information on the status of and contact information for the original four Lifespan Respite states, as well as Arizona's recently implemented program.
- ***Lifespan Respite Legislative History***

Public Law PL109-442, Lifespan Respite Act of 2006.

Section-by-Section Summary of the Act.

Congressional Record of House and Senate Floor Statements on Passage of Lifespan Respite Care Act (December 2006)

This document provides the actual transcribed Congressional Floor Statements of key Senators and House Members as they debated final passage of the Lifespan Respite Care Act in 2006. These floor statements, which carry the weight of law, provide critical information on Congressional intent for how the federal government, as well as states, is expected to implement Lifespan Respite programs.

House Energy and Commerce Committee Report on Lifespan Respite Care Act (September 2006)

The House Committee report is the only Congressional Report in the legislative history of the Lifespan Respite Care Act. It carries the force of law and elaborates on Congressional intent, especially related to who is to be served by state lifespan respite programs and how the program is to be administered at the state and federal levels.

Lifespan Respite Grantee Updates (reprinted from FCA-ARCH Training/TA Centers Newsletters)

<http://www.archrespite.org/ta-center-for-respite>

A four-part article on the ongoing activities of nine of the first twelve FY 2009 State Lifespan Respite grantees and their stakeholders to implement Lifespan Respite systems.

More Tools for Lifespan Respite Grantees/Partners

<http://www.lifespanrespite.memberlodge.org/LifespanTools>

- Sample Job Descriptions
- Sample Needs Assessments
- Examples of Respite Registries
- Voucher Guidance and Sample Tools
- Performance and Evaluation
- Lifespan Respite: Who, What, When, Where and How? (PPT Presentation)*

Respite Provider Training/Credentialing Resources

For more resources, see <http://www.archrespite.org/ta-center-for-respite/training-ideas>

Respite Provider and Other Direct Care Training, Certifications

Arizona The Direct Care Workforce (DCW) Initiative is a public-private partnership that seeks to promote a stable and competent direct care workforce to meet the growing care needs in Arizona and provide support for families in their efforts to care for their loved ones at home and in the community. For more information, go to http://www.azdirectcare.org/About_Us.html

Maine has developed on-line training for respite providers that is part of their certification program. You can access the training by going to <http://www.respiteforme.com/become-a-certified-provider/index.php>. This web-based training program is specific to the requirements of the State of Maine. There is an on-line skills assessment at the end of the course.

The Connecticut Association of Foster and Adoptive Parents (CAFAP) has been contracted by the Department of Children and Families to train, and study families or individuals interested in becoming authorized respite care providers. Contact CAFAP at 1-800-861-8838 or visit www.cafap.com for more information.

Respite Care Association of Wisconsin publishes the *Respite Care Provider Training Manual* which provides a curriculum designed to help develop basic competencies in providing respite care, and meets Wisconsin's Standards for Supportive Home Care Providers and the standards applicable to Medicaid Waiver Funded Non-Institutional Respite Care. To download an order form for the manual, see <http://www.respitecarewi.org/docs/TrainingManualForm.pdf>.

Autism Society of America: Use **Generations & Autism Connect**, developed by Easter Seals and its national partners, to enhance the learning of individuals, especially older adults, who will be volunteering with children with autism. Generations & Autism Connect is a modular training curriculum. Each module contains a PowerPoint presentation, a script for the presentation, and supporting handouts. Pre-post tests are provided for each of the modules. These tests can assess participant learning from the didactic instruction.
Contact: Patricia Wright, 233 S Wacker, Suite 2400, Chicago, IL 60606, 312.551.7226; pwright@easterseals.com

SafeGuards of Ontario, Canada has launched a new open-entry, self-paced online course designed to prepare individuals to work in respite support situations. The course was designed to prepare individuals to work in respite support situations and also to provide a basic level of training for current respite workers. Those who are already working in the field may find it useful to take the course to explore areas they are less familiar with to ensure they have a full understanding of all the skills required. They also offer a course for those working with children with autism. Certifications earned may only be applicable in Canada. To link to the Respite Training Portal, <http://www.respitecourse.ca/>

Provider Training Advocacy and Clearinghouse Information

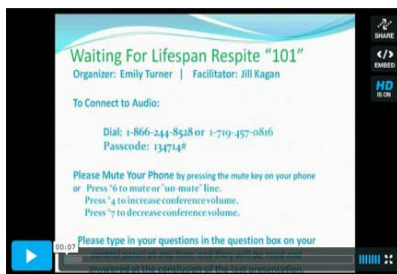
The Direct Care Alliance is an advocacy organization working to improve benefits and working conditions for all direct care workers. They also offer a personal care and support credential. The national Direct Care Alliance Personal Care and Support Credential is a competency-based test for personal assistance workers in home and community-based settings. <http://www.directcarealliance.org/>

National Direct Service Worker Resource Center has resources and best practices on training and recruiting direct care workers. One document emerged from a Leadership Summit on Building Capacity and Coordinating Support for Family Caregivers and the Direct Service Workforce convened by the Centers for Medicare and Medicaid Services (CMS) in September 2010. The leaders in attendance at the Summit ultimately articulated 12 common goals, each with specific policy recommendations. For a copy of the report, see http://www.archrespite.org/images/docs/CMS_LeadershipSummitApr28.pdf

PHI State Data Center. In collaboration with the DSW Resource Center, PHI has created this database of state profiles of the direct service workforce. For state-by-date workforce information, <http://phinational.org/policy/states/>

PHI Training and Organizational Development Services offer a series of downloadable training curricula, slides, evaluation forms and other training materials on topics such as abuse and neglect prevention training, fall prevention, and personal care assistance. <http://phinational.org/training/resources/phi-curricula/>

Webinars



Lifespan Respite 101 **(March 2010)**

This webinar and its resources provide an introduction to Lifespan Respite, including lifespan respite legislation, the US Administration's (AoA) role in implementation, best practices in State Lifespan Respite Programs, and information to help you plan for a Lifespan Respite System in your state.

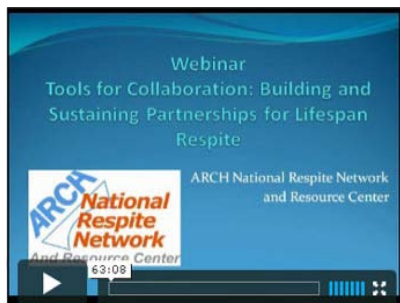
<http://www.archrespite.org/ta-center-for-respite/webinars-and-resources/webinar-lifespan-respite-101>



Respite in the Faith Community **(June 2010)**

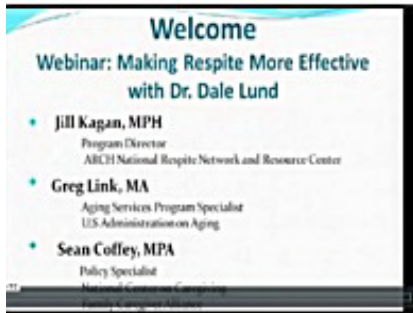
The shortage of respite providers continues to be a significant barrier to respite access in many communities. At the same time, government funding for social services is shrinking. Turning to the private volunteer sector for assistance makes increasing sense. The faith-based community has a long history of supporting family caregivers through respite and can offer assurances to family caregivers who are often reluctant to ask for help or mistrustful of other outside agencies.

<http://www.archrespite.org/ta-center-for-respite/webinars-and-resources/webinar-respite-in-the-faith-community>



Tools for Collaboration: Building and Sustaining Partnerships for Lifespan Respite **(August 2010)**

At the heart of Lifespan Respite is the concept of collaboration. Throughout the Lifespan Respite Care Act, and in the federal program guidance, references are made to collaboration and coordination among various stakeholders at the federal, state and local levels. This webinar will explore the history, successes, and challenges of collaboration among state agencies, state respite coalitions, and Aging and Disability Resource Centers. While the lessons to be learned will be most useful for those directly involved in planning and implementation of State Lifespan Respite programs and state respite coalitions, others working in social service, long-term services and supports, and health systems will benefit as well. <http://www.archrespite.org/ta-center-for-respite/webinars-and-resources/tools-for-collaboration>



Making Respite More Effective (June 2011)

Dr. Dale Lund discusses practice and policy suggestions that might enhance caregivers' use of respite time and discusses how to measure outcomes related to respite time-use. In 2009, Dr. Dale Lund presented at the National Respite Conference in California on respite time-use suggesting that family caregivers' use of respite time was a determining factor in the extent to which the family caregiver benefits from the respite received. While Dr. Lund has been researching the benefits of respite for many years, his recent study published in the *Journal of Applied Gerontology* (February 28, 2011) found that employed caregivers were generally more satisfied with respite time-use than nonemployed caregivers. Dr. Lund is also a coauthor of the very thoughtful guidebook for family caregivers, ***RESPITE SERVICES: Enhancing the Quality of Daily Life for Caregivers and Care Receivers*** (updated, 2010 in English & 2011 in Spanish). Presented by the Family Caregiver Alliance and the ARCH Technical Assistance Centers on Caregiving and Lifespan Respite. <http://www.archrespite.org/ta-center-for-respite/webinars-and-teleconferences/making-respite-more-effective>



Marketing Respite to Family Caregivers: Moving Beyond Awareness (July 2011)

Successful Lifespan Respite programs build public awareness and encourage family caregivers and others to action on behalf of respite. But before you book that billboard space, write that pharmacy bag ad, or record your radio PSA, it's important to be clear on who you want to reach, what you want them to do, and why they might not already be doing it. Alicia Blater, the North Carolina Lifespan Respite Project Director, who worked for 10+ years in public relations and marketing, will walk us through the basics to prepare us to be more successful at implementing the subtleties of messaging and marketing. Alicia will talk about the benefits and barriers our target audiences may be experiencing as they see and hear messages about caregiver services, and present one possible approach to help you develop your own messages. This is especially critical for respite, which is already encumbered by misunderstandings and limited exposure among family caregivers, professionals and the public. This webinar will be most useful for Lifespan Respite Grantees and their partners. <http://www.archrespite.org/ta-center-for-respite/webinars-and-teleconferences/webinar-marketing-to-family-caregivers>

National Respite Coalition Policy Documents

Benefits and Cost Savings Due to Respite Fact Sheet

http://www.archrespite.org/images/Cost_Fact_Sheet_08-11.pdf

Complete Lifespan Respite Care Act Legislative History (2203-2006), including public law, congressional record statements and floor debate, committee reports, amendments

<http://www.archrespite.org/national-respite-coalition> (scroll down)

National Respite Coalition Policy Statements, Testimony, Funding Requests

<http://www.archrespite.org/national-respite-coalition> (right-hand menu)

Congressional and Organizational Letters of Support for Lifespan Respite Care Program

<http://www.archrespite.org/national-respite-coalition> (right-hand menu)

