The following annotated bibliography is an extensive, yet not exhaustive, list of published resources that may be helpful in developing and implementing respite care programs for parents and caregivers of children and youth with special needs. This listing was prepared by the National Foster Parent Association (NFPA) with support from Casey Family Programs. The listing presents the publications chronologically, with the most recent publications first and undated publications at the end of the list. A list of relevant website addresses is also included.


The findings of a respite care utilization study are reported. The study examines three models of intensive, in-home services for children experiencing psychiatric crises.


Assesses the effectiveness of a model of family reunification and attempts to identify those characteristics of families with children in care that were associated with reunification. The relationship between returning home and a number of risk factors was also examined.


Contents:

- Part I: Carers and care-recipients
- Part II: The impact of caregiving
- Part III: Supports and services
- Part IV: Implications

Based on a 1997 doctoral dissertation by E. J. Bruns, this article presents the results of a controlled, longitudinal study of respite care services for children experiencing emotional and behavioral disturbances, and the effects on their families. Results indicated that families who received respite care experienced significantly better outcomes than families who did not. This included fewer out-of-home placements, greater optimism about caring for the child at home, reductions in some areas of caregiving stress, and lower incidence of negative behaviors expressed in the community.


Describes a 3-year research demonstration project that examined the efficacy of three models of intensive in-home services as alternatives to hospitalization for children experiencing serious psychiatric crises.


Key components of an effective crisis support system are identified, including financial and practical support, emotional/psychological support, social support, professional training and development, task-focused problem-solving, respite care, and community support.


This handbook provides a guide to those interested in starting a respite care program or enhancing an existing program. Provides several suggested respite models.


Contents:
- The Demography of Disability and Chronic Illness Among Children. Henry T. Ireys, Scott Katz
• Families and Communities. Gary L. Albrecht
• The Impact of Disabling Conditions. Allen C. Crocker
• Public Sector Health Services for Children with Special Health Care Needs. Vince L. Hutchins, John E. Hutchins
• Overview of Health Care Financing for Children with Severe Developmental Disabilities. Herbert J. Cohen, Arnold Birenbaum
• Future Directions of Community-Based Service Systems for Children with Special Health Care Needs and Their Families. John C. MacQueen, Josephine Gittler
• Allocation of Health Care Resources. Tina Ciesiel Kitchin
• Legal Rights of Children with Disabilities. Josephine Gittler
• Family Roles: The Most Relevant Aspect of Family-Centered Care. Josie Thomas, Beverley H. Johnson
• Cultural Competency. Richard N. Roberts, John E. Evans
• Confidentiality Requirements in Integrated Programs. Lola J. Hobbs
• Child Abuse, Neglect, and Disabled Children. Susan Reichert, Richard D. Krugman
• Sexuality. Marilyn J. Krajicek, Elizabeth A. Cassidy
• Systems of Care for Children and Adolescents with Chronic Illness. James M. Perrin
• Public Policy Advocacy. Beverly Schenkman Roberts, Brenda G. Considine
• Interorganizational Collaboration. Margo I. Peter, Calvin C. J. Sia
• Community-Based Needs Assessment. Colleen Monahan
• Defining Goals and Shared Expectations: The Use of Model Standards to Enhance the Quality of Care. Susan G. Epstein, Ann B. Taylor
• Planning Health Education Programs for Self-Management of Pediatric Chronic Disease and Disability. L. Kay Bartholomew, Guy S. Parcel, Danita I. Czyzewski
• Case Finding. Anita M. Farel
• Developmental Screening/Surveillance. Forrest C. Bennett, Robert E. Nickel, Jane Squires, Barbara J. Woodward
• Developmental and Behavioral Assessment. Thomas R. Montgomery
• Case Management and Service Coordination. Robert F. Biehl
• Team Organization and Function. Cordelia C. Robinson
• Health Services. William C. Cooley
• Oral Health Services. Lynette A. Lancial
• Nutrition Services for Children with Disabilities and Chronic Illness. Marion Taylor Baer
• Genetic Services in the Care of Children with Disabilities. John C. Carey
• Mental Health Services. Suzanne M. Bronheim
• Early Intervention. Elizabeth S. Ruppert
• Preschool Programs: The Search for Quality Services. John T. Neisworth, Lisa A. Schneider
• Special Education. Eleanor W. Lynch, Douglas B. Fisher
• Transitions from Adolescence to Adulthood. Pamela Luft, Frank R. Rusch
• Vocational Preparation for Students with Disabilities. Carolyn Maddy-Bernstein
• Assistive Technology. Glenn E. Hedman
• Respite Care: Support for Families in the Community. Jennifer M. Cernoch, Elizabeth E. Newhouse
• Home Care for Children with Technologic Needs. Arthur F. Kohrman, Joanna Kaufman
• Transportation of Severely Disabled Children. Lawrence W. Schneider
• Conditions. Lisa T. Craft, Mark L. Wolraich


A "how-to" manual which serves as an introduction to the basics of establishing planned and emergency respite care. Designed to assist any interested community person in developing a respite care program. Includes information on funding, recruiting, training, program planning, collaboration, and evaluation. Provides models to follow based on a community's needs, resources, and unique characteristics. Models are presented for emergency respite (center-based and home-based models) and for planned respite (in-home and out-of-home models). Chapter headings are: (1) Needs Assessment; (2) The Planning Process; (3) Models; (4) Budget; (5) Collaboration; (6) Marketing; (7) Developing a Solid Funding Base; (8) Administrative Planning, Policies, and Procedures; (9) Staffing; (10) Daily Operations; and (11) Evaluation. Manual includes sample forms, and an extensive annotated bibliography.


Provides instructions and forms for agencies to use in interviewing adults and children with respect to establishing the need for services for children and families.

The efficacy of two New York programs to meet the needs of children with serious emotional disturbances was studied.


An overview of issues faced by families in the adoption of children with special needs. Implications for services systems include the need to increase adoption-sensitive services, to establish a statewide system of respite care, and to support adoption as a permanency plan when children are unable to live with birth families.


Examines the pre- and postadoptive service needs of families with adopted children. A survey of adopting families identified helpful services as financial/medical subsidies, respite care, and counseling and educational services.


Data about health and educational services were collected from families. The unmet needs and reasons for them are identified.


Presents a preventive project designed to provide respite child-care for low-income families under stress in a high-risk community. This action-research project focused both on preventing family deterioration and on promoting empowerment. Findings of interviews with the families served suggest that the respite care service was relevant to local needs.


This article describes a family support project that implemented a cost-effective, family-centered approach to the provision of respite care for children with complex medical needs. Focus is on the role of the social worker in developing and implementing the program.

Presents the principles of a "family-centered" approach to working with families, and describes a model for putting these principles into action. The manual is intended to be used especially for in-service staff development.


The authors state that with the right promotion and organization, faith communities can provide effective respite care. One church's respite care program is described, and steps to a successful respite program are outlined.


This article describes an innovative in-home respite care program for parents and caretakers of HIV+ children. Strategies to recruit, train, and supervise volunteer caregivers are outlined.


A review of the literature on respite care utilization, a description of a respite care program in Arkansas, and a report on a study of utilization initiated by the Arkansas Division of Mental Health Services.


Children's services and assistance for families caring for children and elderly relatives should include respite care, community and day care, residential care, employment flexibility, and income assistance for caregivers. Partnerships can promote shared responsibility by the entire community.


Children with serious emotional disturbance were placed in homes of professional parents with a goal of reintegration into their family of origin following treatment. Parents of these children noted they would be able to keep their child at home and function as treatment parents if given the same resources and supports as
professional parents. Also addressed are the policy implications of developing, implementing, evaluating, and disseminating community-based models of care that empower families.


Examines the policy/program needs raised with primarily white, middle class grandparents who provide regular care to their grandchildren. Their needs echo those raised by black grandparents, including participation in the child's medical care, the use of social service agencies, experiences with lawyers, the use of child and respite care, and the use of support groups.


Intended as a resource to program administrators interested in increasing their knowledge of the funding process. The manual provides a suggested training outline, a list of funding consultants, lists of state and federal resources, an annotated bibliography, and exercises for use in training.


A man describes the difficulties of placing his handicapped son in hostels and foster care, feeling that this decision gives his other children a semblance of normal family life.


Describes a project titled "Respite vs. Inpatient Care: An Experimental Study." The goal was to determine the efficacy and the relative benefit/cost ratio of a crisis respite alternative. Findings suggest that this alternative is as efficacious as, but less costly than, conventional hospitalization.


Data collected from families who used the services of a respite care program are used to examine relationships among child characteristics, coping resources, and satisfaction with family functioning.

Data from parents of children with motor disabilities due to cerebral palsy are used to examine their views on health and education services, social services, and the availability of respite care. Although most parents had access to a range of services, lack of information in the early years, fragmentation of services, and limited choices were identified as problems.


A manual describing the training process, providing suggestions for preparing, conducting, and evaluating the training. Includes examples of several evaluation forms.


Describes an innovative respite care program that incorporates a service credit system as an incentive for volunteers to participate.


This article discusses the findings of a 3-year study of respite care services for disabled children in England and Wales in light of the 1989 Children Act.


This monograph discusses interagency collaboration, and provides program descriptions of several collaborative programs. Identifies six essential ingredients needed for collaboration.


This book outlines the basics of organizing special events, and contains suggestions on how to approach philanthropists. Provides a step-by-step guide to direct mailing and information on door-to-door canvassing.

Provides information on the importance of collaboration, how to collaborate on the implementation of a family service center, and state and national action to support collaboration.


This article focuses on children with both a developmental disability and a chronic health condition. Family-centered case management services were established and interview data was obtained from mothers during the first month of the project and one year later. Findings indicate that maternal life satisfaction improved with program participation.


Provides an assessment of the understanding of the concerns, behavior, and needs of low-income child care consumers. Highlights insights and principles that should guide consumer education efforts. Introduction and Table of Contents retrieved December 29, 2001 from http://cpmcnet.columbia.edu/dept/nccp/publications/coned.html


Includes a wide range of information on parental attitudes and behaviors that will help readers understand the needs of families, especially low-income families that use child care. Table of Contents retrieved December 29, 2001 from http://cpmcnet.columbia.edu/dept/nccp/publications/cccbib.html

Outlines the Americans with Disabilities Act, and how to evaluate your program for compliance.


The effectiveness of respite care in reducing feelings of entrapment and resentment is examined. This case study suggests that empirical support for respite care can be used to promote social welfare policies and programs that are responsive to the needs of families pursuing caregiving functions.


This book provides an overview of the family dynamics of adoption, including assessment and treatment strategies. Also includes child psychiatric services for adoptive families.


This book examines the full range of alternatives for those who cannot become biological parents. It includes answers to questions about agency and international adoption as well as less familiar choices such as foster parenting, child and family mentoring, and special-needs adoption.


This program matches families with other community families willing to provide respite care for a child in their own home and other forms of contact that will support the child’s family. The program often helps parents avoid entering into crisis.


This manual provides program components and sample materials developed by the respitality demonstration sites.

This paper provides useful principles and background data for states to plan new child care initiatives, coordinate and strengthen existing programs, and improve sliding fee scales used with current state programs.


This manual focuses on helping parent groups replicate the Parents and Respite Trainers model in response to families identifying the need for respite care.


This book provides extensive information, from practitioners in the field, on the key aspects of strategic marketing. Includes information on developing a customer orientation, strategic planning and organization, developing and organizing resources, designing the marketing mix, and controlling marketing strategies.


Examines the application of risk management to child protection and welfare activities to reduce the risk of liability and resulting financial loss. The book addresses methods for minimizing losses, and explores insurance options for protecting the agency.


This manual focuses on developing respite care programs in rural areas.


Includes information on home care, respite care, and other services for terminally ill children.


This project aimed at preventing family deterioration while keeping young children in their own community during temporary family crisis. The main supportive strategies were a respite care and group service for vulnerable families.


An action-research project is described to illustrate unmet needs and the difficulties involved in developing appropriate group services. The project’s main goal was to prevent family deterioration by creating accessible, affordable respite care for families.


Data gathered from adolescent mothers reveal that those who receive respite care and financial assistance from their families also tend to receive such help from their child’s father, their peers, and community members. Further, family and peer support are significantly correlated with well-being.


Based, in part, on a survey of New York Area Agencies on Aging respite services, conducted in 1988 by the Long Term Care Unit of the New York State Office for the Aging. Principles are applicable to any respite program, including those for children and youth with special needs.

Efforts to foster children's well-being at the state level are discussed. The national context of the renewed focus on children's welfare is examined, and the work of Alaskan Governor Steve Cowper's Interim Commission on Children and Youth is described. Policy implications for the future are discussed.


Critical services for troubled children and families are not widely available due to lack of funding. Foster and respite care are stretched to the limit when they are available.


Two prevention-oriented policies in particular are discussed: respite care services to assist persons caring for elderly infirm family members, and family (parental) leave for new parents. The goals of previous family policies are challenged and recommendations made for more realistic approaches.


This book is primarily for evaluators and administrators who are involved in analyzing family services, with special attention to family preservation services. Program issues addressed include: defining the target population, the service delivery structure of family preservation services, methods of measurement and data collection, and program outcomes.


This publication is designed to assist policymakers and practitioners in their efforts to develop programs that serve families with infants and toddlers with disabilities, within the families' own cultural frameworks and individual lifestyles.


This monograph provides a philosophical framework and practical ideas for improving service delivery to children of color who are severely emotionally
disturbed. Emphasizes the cultural strengths inherent in all cultures, and examines how the system of care can more effectively deal with cultural differences and related treatment issues.


A description of a foster home recruitment project carried out in King County, WA, which attempted to raise community awareness about the need for placement for children with special needs, and to recruit and license homes for disabled foster children. A respite care brokerage system is also described.


A resource manual of training curricula for respite care providers.


The form, characteristics, and dimensions of respite programs currently in place are articulated, followed by a discussion of the resources needed to initiate a respite care program.


The focus of this bibliography is on families of children with serious emotional disabilities. The literature search conducted by the authors found little specific information on respite programs for children and youth with serious emotional problems. Therefore, respite care for other populations was included if it was relevant to the specific focus of the authors. Publications included in the bibliography date from 1978 to 1988.


This monograph resulted from a search for respite programs that serve families of children with serious emotional disabilities. Chapter headings are: (1) Rationale: The Need for Respite Care Services; (2) Varied Responses to Varied Needs: Locations and Types of Respite Care; (3) Respite Providers: Attributes and Training; and (4) Respite Care and Public Policy.

A review of the effects of childhood disability for the family and for society, which shows that disability has both positive and negative functions and that the negative functions are in large measure the outcome of a society that is structured primarily for those without disabilities. It is concluded that availability of resources is the most important determinant of family adaptation.


A detailed evaluative study of the Avon, England, family support scheme, which provides respite care to families of handicapped children. Also discussed is the preparation given to children for separation from their parents, stressing the possible ill-effects of separation and the need for careful matching and preparation of carers and children.


A handbook which offers a step-by-step approach to creating and sustaining a network of funding sources through a discussion of organizational tasks; a comprehensive overview of money available to nonprofits; how to secure funding from individuals, businesses, corporations, and foundations; and how to capitalize on the uniqueness of your organization to secure funding.


Discusses some of the crucial components of family-centered care. The book emphasizes that the health care professional must recognize, respect, and support the pivotal role that families play in the care of their children.


This article discusses the use of permanency planning procedures in substitute care systems. It is discovered that permanence is more readily achieved in agencies in which workers generally make use of many sources of information in planning, and less readily achieved in agencies in which workers frequently focus their contact with the biological parents on adoption. No relation exists between achieving permanence and the delivery to the biological family of such family supports as respite care.
Providing respite care to families who have a member with a disability is the focus of this book. The book is organized into three parts: (1) Rationale and Need for Respite Services; (2) Issues and Models for Delivering Respite Services; and (3) Evaluating Respite Services. The book contains 16 chapters contributed by a total of 25 authors.


The principle objective of this book is to describe respite care for families with severely disabled members. It was intended to serve as a catalyst for bringing about the expansion of respite care services. The book includes eight chapters: (1) Families in Need; (2) Respite Care as a Family Support Service; (3) What Research Tells Us About Respite Care; (4) Respite Care Programs in Action; (5) Legal and Fiscal Perspectives; (6) Respite Care Workers; (7) Respite Care as a Generic Service; and (8) Issues, Corollaries, Prospects, and Conclusions. The appendix includes procedures for establishing a respite care program.


The effectiveness of a community-based respite center's interventions in alleviating parental stress was evaluated. Data analysis reveals a significant reduction in all effective and overall measures of stress following respite care.


An expanded view of respite care is proposed that includes care for: (1) the family of the disabled child, (2) the internally stressed family/at risk child, and (3) the externally stressed family.


Four major approaches to providing respite care are identified. The advantages and disadvantages of each are discussed and recommendations made concerning the development of quality programs.

This article describes a training program designed to limit respite care staff turnover and burnout, as well as teach specialized skills.


Ten models of respite care are identified, and recommendations for improvement of the availability and quality of respite care services are made.


Intended for parents of children with special needs, this booklet provides information on how to acquire and keep respite care providers. Provides resources specific to the western Washington area, especially Seattle and King County.


A reference manual for training respite providers in Mississippi.


This guide assists agencies and communities who are attempting to make respite care available to families with children with special needs. It focuses on issues such as clarifying planning objectives, assessing the needs of consumers, and planning a course of action.


This brief manual summarizes the need for respite care, and provides basic guidelines for setting up a respite program.

Santa Rosa Children’s Hospital (undated). *The Respite Station Handbook*. San Antonio, TX: Santa Rosa Children’s Hospital.

A handbook designed to instruct parents in the requirements, application process, and respite care process of the Respite Station of the hospital.
United Cerebral Palsy Associations, Inc. (undated). For This Respite, Much Thanks...: Concepts, Guidelines, and Issues in the Development of Community Respite Care Services.

A somewhat dated, but nevertheless useful, booklet on designing respite care programs. Particularly useful are the descriptions of respite models developed and implemented by a number of state organizations. Includes a bibliography of the older respite references (i.e., 1970's).


A handbook which provides strategies and encouragement to families who may need respite care. The information is based on the experiences of families and staff members from the Respite Coordination Services Project.

WEB SITES:

http://wizard.ucr.edu/~wm/adamscamp.html

ARCH National Resource Center for Respite and Crisis Care Services. This site outlines the tools needed for bringing respite care to your community and provides a description of federal funding programs, a National Respite Locator Service, as well as links to state Respite Coalitions and Developmental Disabilities Councils.
http://www.chtop.com/archbroc.htm

http://www.upstate.edu/peds/efrdir/

Kris' Camp. A non-profit organization for special needs kids and their families, to provide therapy for special kids, and respite and support for the siblings and parents of special kids.
http://wizard.ucr.edu/~wm/kriscamp.html

Easter Seals Camping and Recreation. Information on accessible camping and respite programs throughout the country.
http://www.easter-seals.org/services/camp/index.asp
http://thearc.org/faqs/respite.html

The Arc of the United States is an organization for people with mental retardation and related disabilities and their families. This site provides links to respite-related sites and resources.
http://thearc.org/index.htm

The National Respite Network promotes the nationwide development of respite options. Provides information on services, training, and resources.
http://www.chtop.com/nrn.htm

The Respite Care site provides a definition of and information about respite care, suggestions for parents, resources, organizations, and family support projects.
http://www.autism-pdd.net/respite.html

Therapy/Respite Camps for Kids. This site provides information about various respite camps for children.
http://wmoore.net/therapy.html