



Respite Care Services for Families Who Adopt Children With Special Needs: A Synthesis of Demonstration Program Final Reports

*This synthesis was made possible by the Children's Bureau, Administration for Children, Youth and Families, Administration for Children and Families, U.S. Department of Health and Human Services. The conclusions discussed here are solely the responsibility of the authors and do not represent the official views or policies of the funding agency. Publication does not in any way constitute an endorsement by the U.S. Department of Health and Human Services. Suggested citation: U.S. Department of Health and Human Services. (2002). *Respite Care Services for Families Who Adopt Children With Special Needs: A Synthesis of Demonstration Program Final Reports*. Washington, DC: National Clearinghouse on Child Abuse and Neglect Information.*

Post-adoption services are essential to support families who have adopted children with special needs, especially medically fragile children and children with physical or emotional disorders. One of these services is respite care—temporary care for the children that can provide a break for the families from the daily demands of caring for their children or respite during times of emergencies.

To enhance and expand respite care services, the U.S. Department of Health and Human Services has periodically selected Respite Care Services for Families Who Adopt Children with Special Needs as one of the priority areas for funding in its annual Adoption Opportunities discretionary grants programs. Nineteen respite care projects were funded in this priority area in 1990, 1991, 1994, and 1995. Other respite care projects have also been funded under the priority areas of Post Legal Adoption Services and Field Initiated Demonstration Projects.

To share the knowledge gained from these projects with others in the field, this report synthesizes information from the final program and evaluation reports of 8 of the 19 projects. The information presented here was current at the time these reports were written between 1994 and 1999. Project descriptions, challenges and lessons learned, accomplishments, and recommendations are summarized in the following sections.

1. PROJECT DESCRIPTIONS

The eight projects synthesized in this report were conducted in Alabama, Arizona, New Jersey, the Northwest region of the United States (a multi-state project serving six States), Oregon, Pennsylvania, South Carolina, and Texas. Contact information and an overview of project components are provided in the appendices.

Each project demonstrated a unique effort to improve or expand respite care services in their target area to families who had adopted children with special needs. One project developed a replicable training curriculum for providers and families, while seven delivered respite care services.

Respite Care Provider Recruitment. Various recruitment methods were used by the projects, but the most successful method of recruitment for many projects involved adoptive families referring people they already knew to become respite providers. Many of these potential providers were “natural helpers,” relatives or friends of the adoptive families who were already providing some child care services for the adopted children. In addition, all of the projects recruited respite care providers who were

previously unknown to the families—people who agreed to participate in training and provide respite services. As part of these efforts, some projects recruited providers from the ranks of foster parents, adoptive parents, and prospective adoptive parents because these families had already received training in issues such as child development and behavior management.

Provider Training/Licensure. All projects provided some level of pre-service training for providers, and most provided some type of ongoing or in-service training. While all projects provided training for newly-recruited providers, many also trained natural helpers who had been referred by adoptive families. Some projects trained providers and families together.

Target Population. Most projects offered services to families who had adopted children with a variety of special needs, but some targeted children with specific needs such as developmental disabilities or severe physical challenges. In addition to serving families in which adoptions had been finalized, at least half of the programs also offered services to families who had not yet finalized their adoptions. Some programs served only families who had adopted through the local public agency, while other programs served families who had adopted through public or private agencies. Target geographic areas for the projects ranged from a single city, to regions within a state, to statewide, to a multi-state region.

Recruitment of Families. Numerous methods were used to recruit families for the projects. These included letters sent to prospective families, word of mouth from adoptive families already participating in the program, presentations at parent support groups, requests that adoption agency staff market the program to their families, public service announcements, and articles in newsletters and newspapers.

Respite Services Offered. Of the projects that provided respite services, all provided hourly services and special events such as family retreats and group outings. Some projects also offered weekend respite and weeklong camps. Most provided both in-home and out-of-home respite services. Unique offerings included residential respite and tutoring-based respite.

Project Management/Administration. Three projects were headed by university-affiliated programs, three by public child welfare agencies, and two by local private organizations. Most involved some form of collaboration; for example, one project collaborated with a neighborhood faith-based organization. Another utilized volunteers from parent support groups to manage the services. Some projects contracted with vendors to provide services.

Information Dissemination. Most projects presented information at state and national meetings and conferences and developed brochures about their projects. Two projects produced training manuals that can be used by others, and one produced a resource book of respite providers.

Evaluation Activities. Almost all projects reviewed program documentation and noted accomplishment of the project's tasks and objectives. Most projects conducted surveys and/or interviews of families about their experiences, needs, concerns, satisfaction, and/or assessment of the program's impact on them. Two projects also interviewed staff about their experiences with the program.

2. CHALLENGES AND LESSONS LEARNED

Every program noted challenges. In reviewing these reports, it appears that many of the challenges may have been avoided if pre-program needs assessments had been conducted (only two

programs noted that they had conducted needs assessments). Needs assessments can reveal the characteristics of targeted families that must be addressed as well as their needs for type, duration, and location of services. Needs assessments might also examine and identify previously successful or unsuccessful strategies to recruit and train providers and families. This information can help to ensure that a new program is designed to meet the needs of its target population and that its intended strategies are based on knowledge of “what works and doesn’t work.”

In addition, many programs experienced challenges in conducting rigorous evaluations that could produce useful data about a program’s effectiveness. These challenges affected the programs’ abilities to state their accomplishments with certainty.

A summary of the programs’ identified challenges and lessons learned is presented below.

Provider Recruitment, Training, and Licensure. Two programs noted difficulties in these areas. One program was not as successful as they had hoped to be in recruiting prospective adoptive parents as respite providers. They believe prospective parents were more focused on identifying a child they might adopt than they were in providing temporary care for children from other families. A difficulty in scheduling training sessions to accommodate natural helpers was noted. One program acknowledged that the lengthy, stringent licensing process they utilized may have resulted in fewer providers, but they believe that it also resulted in higher quality providers. One multi-state program noted challenges in complying with various State licensing requirements and adopted strategies to address this. These strategies included recruiting existing foster and adoptive parents who were already licensed; structuring the duration and type of services such that they did not require use of licensed providers; having adoptive parents choose, hire, and pay their own providers; and getting legal advice for the agency regarding liability issues in training respite care providers.

Recruitment of Families. Five programs noted challenges in this area. In almost all cases, challenges included families’ reluctance to use services. Common reasons included not understanding what respite is, not being comfortable with providers they did not know, not wanting to seem inadequate, and doubt about others’ ability to handle their child. Some adoptive parents had confidentiality concerns; some did not want the type of services offered by the program; and some wanted to stay with their natural helpers. In many cases, families’ concerns were based upon their belief that respite care is a service provided only in emergencies and that their use of the service might reflect poorly on their ability to parent their child with special needs. Programs noted that these concerns need to be addressed early and often, and that it can take up to a year to build trust between the families and program staff. Some programs strengthened efforts to educate families about respite, emphasizing that it is a supportive service rather than a service reserved solely for crises. Some programs worked through trusted community agencies to build a relationship with families.

Service Provision. Two programs noted difficulties with services being offered that did not meet families’ needs. Both reported that they offered in-home hourly services and families wanted longer periods of service. One program also noted that the location of out-of-home services at a camp was not convenient for families.

Program Management/Administration. Two programs noted challenges with this aspect. One developed a system that was run by parent groups, which, while successful in some areas, posed challenges to accomplishing tasks such as provider recruitment and training, licensing and liability, and referrals and matching. Some parent groups partnered with an agency to address these challenges.

Another program had difficulty establishing a contract with a provider agency and had to spend considerable time identifying and negotiating a contract with a new vendor.

Evaluation Activities. Four of the programs that attempted to survey families about their experiences with the program noted low response rates from families. This resulted in findings that could not be deemed statistically reliable. Follow up phone calls helped improve response rates in one program. Another program discussed difficulties of matching pre- and post-test surveys due to attrition of families from the program. Another program noted that administration of the surveys by project staff was inconsistent.

3. ACCOMPLISHMENTS

Each project noted its significant accomplishments in various areas. While all projects were successful in completing their identified tasks, some were particularly successful expanding or enhancing services in their area, establishing an infrastructure within which to operate, producing replicable training models, or influencing State policy. These accomplishments are summarized here.

Service Provision. Most projects documented the number of families and/or children served, number of providers recruited, and number of hours of service provided. Of the projects that documented these accomplishments, the number of families served ranged from fewer than 20 to more than 80, the number of providers trained ranged from fewer than 20 to more than 130, and the number of respite hours provided ranged from 7,000 to more than 41,000. (The project that provided more than 41,000 hours was using an existing foster care respite care agency as its lead agency.)

Target Population. One program noted that by serving foster-adopt families who had not yet finalized their adoptions, they were serving a group that was otherwise not eligible for any other respite services under existing funding guidelines. (They were not eligible for foster care funds because they were considered to be in the adoption system, but were not eligible for adoption funds because the adoptions were not finalized.)

Satisfaction. Four programs assessed families' satisfaction with the program. Although not statistically reliable, families in general were satisfied with the providers' and children's interactions.

Impact of Services on the Family. Five programs assessed the impact of the services on the families served. Although not statistically reliable, results indicated that many families felt some relief from child care responsibilities, that the services had helped to improve family relationships, and that their family's stress level had been reduced. Families that participated in a tutorial-based program said the services helped improve their children's behavior and academic work. Some families indicated that the respite services had prevented adoption disruptions.

Program Management/Administration. One program noted that it had successfully developed a parent-run system with a high degree of parent ownership. Another program attributed some of its successes to the collaboration with a neighborhood faith-based organization.

Information Dissemination. One program successfully developed and disseminated a training manual for providers and families. The manual, now in its second printing, is entitled "The AFIRM Project Respite Training Manual."

Policy. One program testified before the State legislature and helped to pass the Oregon Lifetime Respite Care bill, which established an infrastructure to coordinate respite services through the State. Another program helped establish a statewide workgroup that was developing state policy to entitle all adoption subsidy children to 12 paid days of respite per year.

4. RECOMMENDATIONS

Based on their experiences, respite care grant project staff offered a number of recommendations that they believe will contribute to successful respite care programs for families who have adopted children with special needs. Their recommendations are summarized here.

Providers. Programs should conduct ongoing recruitment efforts throughout the life of a program, provide ongoing pre-service and in-service training, include natural helpers in training, recruit providers who live close to families' homes when in-home services are offered, and recruit more providers with specialized skills such as sign language.

Families. Programs should educate families about the nature of respite care, clarify their understanding of the service, and be responsive to their concerns. As one program stated, these activities should be done "early and often." Assessment of families' respite care needs should be done prior to designing the program's services.

Services. Services should target families' identified needs and appropriately address the types of special needs children in the target population (e.g., medical fragility, emotional or behavioral disability, or older children), and should be provided in a manner that families desire (e.g., in-home and/or out-of-home, hourly and/or weekends). Services should include group activities for children and families, and siblings of the adopted children with special needs should also be served.

Program Management/Administration. Allow ample time for starting-up, establishing trusting relationships among agencies, and negotiating contracts with vendors. This includes ensuring that the provider agency can serve the target population and provide the necessary services, and consider using a community-based agency rather than a government agency because some families have a mistrust of government agencies. Many programs emphasized agency collaboration. Other recommendations included engaging parents in program design and management and avoiding legal problems with liability issues.

Public Awareness. Raise awareness among adoptive families and the public about the need for respite care services for families who have adopted children with special needs.

5. SUMMARY

The adoption community recognizes that respite care is an essential post-adoption support service for families who have adopted children with special needs. The knowledge gained from prior demonstration programs can assist others in the field who are developing or enhancing their own programs. Future grantees can build on the lessons learned from the eight programs summarized here.

Appendix Project Information

The following information was current at the time the final project reports were written; it may have changed since then. Not all information was available from each project's report.

Project Name: Respite Care Services for Families Who Adopt Children With Special Needs
Lead Agency: Chauncey Sparks Center for Developmental and Learning Disorders, University of Alabama at Birmingham
Area Served: Birmingham, Alabama
Project Period: 1991 – 1994
Contact Person: Dale Brantley or Betsy Edwards
Contact Phone: (205) 934-5471

Provider Recruitment

- Recruited providers previously unknown to the families (including foster parents) and natural helpers
- Most effective strategy was word-of-mouth from adoptive parents; other strategies included presentations at meetings, networking, and articles in newsletters and newspapers

Provider Training/Licensure

- 40 providers trained
- Pre-service and in-service training offered
- Trained providers previously unknown to the families, natural helpers, and staff together

Target Population

Adoptive and foster-adopt families with children who had all types of special needs, especially developmental disabilities/mental retardation

Recruitment of Families

Letters to families receiving subsidies and contact through agency staff

Respite Services

- 75 children served
- 13,797 respite hours provided
- In-home and out-of-home services provided
- Hourly, weekend, and week-long camps

Program Management/Administration

Lead agency was a University Affiliated Program (UAP)

Information Dissemination

Presentations at meetings and conferences; articles in newsletters, newspapers, and magazines; published materials

Evaluation Activities

Interviews with families, providers, and staff

Project Name: Adopt-A-Rest Project
Lead Agency: La Hacienda Foster Care Resource Center, Inc.
Area Served: Tucson, Arizona
Project Period: 1991 – 1994
Contact Person: Brenda Goldsmith
Contact Phone: (205) 934-5471

Provider Recruitment

Recruited providers previously unknown to the families, including prospective adoptive parents

Provider Training/Licensure

- 27 providers trained
- In-service trainings offered
- Pre-service training similar to that required for foster parents

Target Population

Adoptive and foster-adopt families with children who had all types of special needs

Recruitment of Families

Mailings and personal contact with project director

Respite Services

- 85 families served
- 41,771 respite hours provided
- Hourly and weekend respite
- In-home and out-of-home respite
- Parent and teen support groups
- Family events

Program Management/Administration

Lead agency was a private, non-profit respite care agency

Information Dissemination

Created a brochure, presented at conferences and meetings, submitted articles for newsletters

Evaluation Activities

Surveyed families regarding their satisfaction with services, the impact of services on them, and their needs for respite care

Policy

Established a statewide work group to develop state policy that would entitle all adoption subsidy children to 12 paid days of respite per year

Project Name: CHARM - Child Home-based Adoption Respite Model
Lead Agency: Department of Human Services
Area Served: Northern region of New Jersey
Project Period: 1994 – 1996
Contact Person: Jacqueline Rose
Contact Phone: (201) 742-0063

Provider Recruitment

Not identified in final report

Provider Training/Licensure

Not identified in final report

Target Population

Families with children who had all types of special needs

Recruitment of Families

Referrals of families from adoption agencies

Respite Services

- Hourly in-home services and group events
- Tutorial-based respite services

Program Management/Administration

Lead agency was public child welfare agency

Information Dissemination

Not identified in final report

Evaluation Activities

Surveys of families and staff; documentation of tasks completed

Project Name: Respite Care for Special Needs Adoptive Families
Lead Agency: Northwest Resource Associates/Northwest Adoption Exchange
Area Served: Northwest region of the United States with sites in Anchorage, Alaska; Boise, Idaho; Reno, Nevada; Portland, Oregon; Salt Lake City, Utah; and Seattle, Washington
Project Period: 1991 – 1994
Contact Person: Norma Nelson
Contact Phone: (206) 292-0082

Provider Recruitment

- Recruited providers previously unknown to the families (including foster and adoptive parents) and natural helpers
- Contact through parent support groups and agency staff

Provider Training/Licensure

- 136 providers trained
- Offered training to natural helpers
- Pre-service and in-service training offered

Target Population

- Families who had children with all types of special needs
- Public and private agency adoptions

Recruitment of Families

Contact through parent support groups and letters to adoptive parents

Respite Services

Hourly, out-of-home services

Program Management/Administration

- Lead agency was private regional adoption exchange
- Lead agency collaborated with volunteers from parent support groups in each site to manage local projects
- Parent support groups often collaborated with local adoption agencies to conduct some tasks (such as licensing)

Information Dissemination

Presentations at conferences and meetings, articles in newsletters and newspapers, brochure

Evaluation Activities

Documentation of project tasks completed

Project Name: Project AFIRM (Adoptive Families' Individualized Respite Model)
Lead Agency: Child Development and Rehabilitation Center, University Affiliated Program, Oregon Health Sciences University
Area Served: Oregon
Project Period: 1995 – 1999
Contact Person: Will Foran
Contact Phone: (503) 494-8364

Provider Recruitment

Not identified in final report

Provider Training/Licensure

130 providers and 180 families trained

Target Population

Not identified in final report

Recruitment of Families

Not identified in final report

Respite Services

Developed a model of respite care and a replicable training curriculum (project did not provide respite services)

Program Management/Administration

Lead agency was a University Affiliated Program (UAP)

Information Dissemination

Development of the AFIRM Project Respite Training Manual for national distribution

Evaluation Activities

Documentation of tasks completed

Policy

Staff testified before State legislature and helped to pass Oregon Lifetime Respite Care Bill

Project Name: Partners In Time
Lead Agency: Institute on Disabilities/University Affiliated Program, Temple University
Area Served: Philadelphia, Pennsylvania
Project Period: 1991 - 1993
Contact Person: Adam Brunner
Contact Phone: (215) 204-3196

Provider Recruitment

- Recruited older adults as providers
- Recruitment through senior centers and churches in families' neighborhoods

Provider Training/Licensure

- 18 providers trained
- Pre-service and in-service training

Target Population

Families who had adopted children with disabilities

Recruitment of Families

Presentations at meetings and support groups, mailings to families, articles in newsletters and newspapers, public service announcements, and stipends to adoption agency staff to recruit families

Respite Services

- 14 families served
- Hourly services and family events

Program Management/Administration

Lead agency was a University Affiliated Program (UAP)

Information Dissemination

Not identified in final report

Evaluation Activities

Interviews with families, providers, and staff; survey of families

Project Name: We Care - A Community's Response to Respite Families
Lead Agency: South Carolina Department of Social Services
Area Served: South Carolina
Project Period: 1995 - 1999
Contact Person: Don Adams
Contact Phone: (803) 898-7107

Provider Recruitment

- Recruited providers previously unknown to the families, including residential care providers
- Contact through local minority faith-based agency and adoption agency

Provider Training/Licensure

74 providers trained

Target Population

- Families with children who had all types of special needs
- Families who had adopted and families in the pre-finalization phase of adoption
- Adopted children with special needs and their siblings

Recruitment of Families

Recruitment through local minority faith-based agency and local adoption agencies, mass mailings to families, presentations at meetings, and articles in newsletters

Respite Services

- Served 86 families with 152 adopted children and 51 siblings
- More than 7,000 respite hours provided
- Out-of-home services
- Hourly, weekends, camps, and group events

Program Management/Administration

- Lead agency was local public child welfare agency
- Contracted with local faith-based agency and local service organizations for services

Information Dissemination

- Presented at conferences and meetings, distributed a brochure, placed articles in newsletters and newspapers, created a newsletter, and created a respite resource booklet

Evaluation Activities

Review of tasks completed

Project Name: HAART - Helping Achieve Adoption Respite Together
Lead Agency: Texas Department of Protective and Regulatory Services
Area Served: San Antonio, Texas
Project Period: 1995 - 1999
Contact Person: Judy Pavone
Contact Phone: (512) 438-3151

Provider Recruitment

- Recruited providers previously unknown to the families and natural helpers
- Word-of-mouth, articles in newsletters, and recruitment sessions at universities

Provider Training/Licensure

- 20 providers trained
- Trained providers previously unknown to the families, natural helpers, families and staff
- Pre-service and in-service training provided

Target Population

- Families who had adopted and families in the pre-finalization phase of adoption
- Families who had adopted through the public child welfare agency

Recruitment of Families

Presentations at parent support groups, mailings to families, and articles in newsletters

Respite Services

- 38 families with 89 children served
- 15,651 respite hours provided
- In-home and out-of-home services
- Hourly, weekends, week-long camps, and group events

Program Management/Administration

- Lead agency was public child welfare agency
- Contract with private, non-profit provider agency for services

Information Dissemination

Not identified in final report

Evaluation Activities

Surveys of families, Parent Stress Index for families, review of program reports, training evaluation forms