


HU6/25.2/W37/1997
c.i

our only copy

We Have the Answers Here

COLORADO STATE PUBLICATIONS LIBRARY
HU6/25.2/W37/1997 local
Erickson, Mary/We have the answers here



3 1799 00030 7165

Child Care Options

The Respiteers

*Regalo de Tiempo
The Gift of Time*

Project Support

We Care 4 Kids

A Little Peace of Mind

About the Author

Mary Erickson, who completed this evaluation, has worked with and on behalf of individuals with developmental disabilities and their families for 20 years. Her work has included serving as a direct service provision and as a Planner with the Colorado Developmental Disabilities Planning Council. In addition to consultation services, Mary Erickson works as a Certified Music Therapist with a private practice in Denver and is an instructor at the Naropa Institute in Boulder, Colorado.

WE HAVE THE ANSWERS HERE

**An Evaluation Of Community Pilot Projects And
Local Behavioral Training For
Colorado's Respite Care Grant**

**"Promoting Community Connections And
Family Directed Respite Options in Colorado"**

**Funding for this project was provided to the Colorado Department of Human
Services, Division of Child Care, by the U. S. Department of Health and Human
Services, Administration for Children and Families through Grant #90-CN 0132**

**Division of Child Care
Colorado Department of Human Services
1575 Sherman Street, First Floor
Denver CO 80203**

**by
Mary Erickson**

TABLE OF CONTENTS

	Page
Introduction	2
The Issue	2
What Was Done About This?	2
What Are The Results?	2
Background	2
Evaluation Methodology	5
Demographics	6
The Budget	6
Goals Of The Six Community Projects	7
Respite Pilot Projects In Six Local Communities	10
Alamosa: Regalo de Tiempo--A Gift Of Time	10
Canon City: We Care 4 Kids	11
Denver: Project Support	12
The Association for Community Living in Arapahoe and Douglas Counties	12
The Rocky Mountain Adoption Exchange	13
The Colorado Office of Resource and Referral Agencies	13
The Kelly Foundation	13
The Mental Health Association of Colorado	13
One Day	13
The Work and Family Resource Center	13
Ft. Collins: Child Care Options	13
Lakewood: The Respiteers	14
Littleton: A Little Peace of Mind	15
Behavior Training Sessions	17
The State Intent Of The Grant for Behavioral Training	17
Outcomes	18
Difficulties	18
A Different Approach	18
The State Perspective	19
Family Involvement	19
Community Capacity Building	20
Handbooks	21
Family Access To Respite Resources	22
Sharing Information About The Projects	23
Strengths and Weaknesses Of The Community Pilot Projects	23
Why Did The Community Pilots Work?	23
What Were The Limiting Factors?	24

Innovations	26
Local Models Of Respite	26
State Models Of Respite.	26
Products Developed By Pilot Projects	27
Unexpected Successes.	27
What Lessons Were Learned?	28
Goals Can Be Accomplished	28
Barriers To Be Overcome For Future Efforts.	29
Respite Is Still A Number One Need	29
Community Building Has Challenges	29
State And Federal Requirements Pose Problems	29
Behavior Trainings Could Be More Successful Using A Different Approach	30
Support Grassroots Groups	30
Few Responses To The Requests For Proposals	31
Providers Need Support	31
More Public Education Needed	31
Address Volunteering Challenges	31
Will Community Respite Continue After Federal Funding Ends?	32
Parent Coordinators and Project Directors Speculate.	32
Suggested Next Steps	32
Recommendations For Communities	32
Recommendations For The State	33

INTRODUCTION

"The myth about community is that we think we need one more piece in the puzzle, or the missing link, but we have the answers here."

Pilot Community Project Director

The Issue

Colorado knows that respite, temporary relief for families, is the number one need of families who are raising children with disabilities. Colorado also realizes that families know best what they need and can work in their local communities to bring about change.

What Was Done About This?

- Federal funds were secured and six local communities received grants for pilot projects to build respite support for families who have children with disabilities ages birth to 18.
- The entire project included parents and family members from the beginning, in planning stages, and through implementation and evaluation.
- Support for families with children with challenging behaviors was available to communities.
- Handbooks that address families' respite concerns and needs were written and disseminated widely.

What Are The Results?

- Respite capacity was increased.
- There is a foundation on which to build respite options for families through community support.
- Families have voices that were heard and are still being heard.
- Families have more options for respite.
- Families are more knowledgeable.
- There are suggestions for future directions.

Background

In August 1993 the Division for Developmental Disabilities, within the State Department of Institutions, applied to the federal government for a grant to develop respite options for families who had children, ages birth to 18, with disabilities. The grant began in Colorado on September 30, 1993, and continued for three years. The federal dollar amount awarded each year was \$200,000. The State was required to match these funds.

During the three years of the grant there was reorganization within the state system. The grant is now housed in the Child Care Division, within the Department of Human Services. The original Project Director, Cynthia Trainor, continues in that position with the grant. Matthew Solano is the Program Assistant.

The basic purpose of the project is to assist public and private agencies in Colorado and families of children with disabilities, mental health needs and chronic or terminal illnesses in promoting community connections and the expansion of family-directed respite options.

The objectives of the grant were to:

1. Increase available respite options in Colorado and build community capacity to provide respite to families currently without adequate options.
2. Develop an ongoing statewide respite training capacity to address common issues and needs.
3. Increase family access to respite resources.
4. Develop and disseminate information statewide and nationally about new models, innovations and improvements in respite developed through the grant to maximize the sharing of information, increase cost-effectiveness and ensure the ongoing viability and expansion of respite.

Steering Committee

Overseeing the grant is a Steering Committee composed of parents, family members, project directors, parent coordinators and agency personnel who represent the diverse ethnic and economic backgrounds of the individuals needing respite in Colorado. The committee has 24 members, 17 of whom are parents of children with disabilities, with mental health needs, or who have chronic or terminal illnesses. The Committee has one member with disabilities. Committee meetings were bi-monthly at the beginning of the grant and then quarterly to share information from all sites and to get updates from the state office. The Committee assisted in implementation of the community development and community-building pilot projects. The Committee continues with ongoing project monitoring, evaluation and modification by overseeing the project and making suggestions for improvement throughout.

Request For Proposals (RFP)

Partial completion of the second part of Objective one, "...build community capacity to provide respite to families currently without options," allowed interested local community groups anywhere in the state to apply for funding through the state's competitive bid process. The grant proposal specified there would be two cycles of bidding. The first cycle could potentially fund a community pilot project for two and one half years and the second cycle 6 months later, could potentially provide funding to a community project for two years.

The bidding process involved sending out a Request For Proposals. In the first cycle 250 RFP's were sent out to interested groups in the state. Twenty responses were received. A review committee of people knowledgeable on the subject, including parents and some people from the State Steering Committee, rated the RFP's and recommended that four local groups receive funding for their projects. The first four local pilot projects were:

1. The San Luis Valley Comprehensive Community Mental Health Center in Alamosa for the "San Luis Valley Respite Care Project," Judy McNeilsmith, Project Director,
2. The Family Support Council of Developmental Opportunities, the Community Centered Board serving people with developmental disabilities in Canon City for the "We Care 4 Kids Respite Project," Leslie Meyer, Project Director,
3. Denver Options, a Community Centered Board serving people with developmental disabilities in Denver for "Project SUPPORT," Kathy Sinnot, Project Director, and
4. The Kelly Foundation, a private foundation, in Lakewood in Jefferson County for "The Respiteers" project, Patricia Hennessey, Project Director.

In the second cycle 120 RFP's were sent out, and 5 responses received. Two more pilot projects were funded and the above listed projects were given renewals.

1. The Association for Community Living in Arapahoe and Douglas Counties, and the City of Aurora in Littleton for the "Focus On Respite Opportunities," Nancy Baesman, Project Director, and
2. The Disability Cooperative in Ft. Collins for the "Respite Care Community-Building Pilot Project," Barbara Stutsman, Project Director.

Completion of Objective two, "Develop an ongoing statewide respite training capacity to address common issues and needs" was addressed through a Request For Applications (RFA's) process. These RFA's were to train local service agency personnel and parent teams to enhance community respite capacity for children with challenging behaviors. This RFA was also sent out to 250 groups or individuals statewide. In the first round, 4 responses were reviewed, and two funded; and in the second round, 5 responses were reviewed, and 2 funded. While not necessarily intended, results of this process funded four of the groups selected as community pilot projects. They are: Alamosa, ACL Arapahoe/Douglas, Denver and Ft. Collins. A fifth site, Lamar was later awarded a grant also, since the Denver project was discontinued.

Evaluation Methodology

An independent evaluator was hired to review the community pilots and the behavior sites. The evaluator first reviewed the state grant application and progress reports to the federal government, and the local grant applications and progress reports to the state.

Questionnaires to be used in the evaluation were developed cooperatively by the evaluator, the state staff, and members of the State Steering Committee including parents. The questionnaires were designed to gain information from the local Project Directors, local Parent Coordinators, families who had received respite through the pilot projects, and families who had been involved in the behavior training.

The questionnaires for each local project were completed using face-to-face interviews with Parent Coordinators and Project Directors. Some of the questionnaires for families were completed in person and some by telephone. The telephone was used for two reasons: 1) it was the family's preference, and 2) some families were not available during the site visits and needed to be called at a later date. The Parent Coordinators of each local project identified the families to be interviewed, and received their permission. Sixteen parents were interviewed. Interviews with six identified parents were not included because they could not be reached after 5 attempts at different times of the day and evening. Confidentiality was maintained by referring to respondents by number only. Two families who were contacted did not complete the questionnaire because they had not used the recommended respite providers. One parent said it was because she found respite support from her church. The other parent said she heard that by the time she called, the providers would no longer be working or had moved and she probably would not be able to get in touch with them.

The evaluator interviewed members all of the local Advisory Boards. The interviews ranged from meeting with the entire Board at a regular meeting, to talking with one parent who is a Board member, to meeting with a few Board members. Two interviews were by telephone.

The evaluator interviewed five providers by telephone. The evaluator also interviewed Mike Green, Bernie Maly, Charles Perez, and Joe Schiapacasse who were the trainers involved in the behavioral trainings..

The evaluator was unable to determine how many families received respite as a result of this project, and therefore could not determine the percent of parents who received respite were interviewed. This is because specific data on numbers of families contacted and referred for respite during these projects was not kept at each of the sites. However, the evaluator feels the family interviews present a representative sample of those who received respite as a result of the projects.

Demographics

The local projects represented both urban and rural areas of the state including: two small towns, one small city and three areas in metro-Denver.

The number of parents interviewed were: Alamosa, four; Canon City, eight; Ft. Collins, three; and Lakewood, one. Twelve interviews were by telephone and four were face to face involving 15 mothers and one father. The number of children in each family ranged from one to eight. Fifteen of the families had one child with disabilities and four families had two children with disabilities. Eight families included both parents, one family was blended with children from previous marriages of both the mother and father, and seven families had only a single parent. Two families were Hispanic and 14 were white.

The children with disabilities who received respite ranged in age from two years to 18 with the average age of 8. One child was adopted and the others were biological children.

The children's disabilities included physical, developmental, learning, multiple birth defects, severe medical and behavioral problems, cerebral palsy, muscular dystrophy, attention deficit-hyperactive disorders and global developmental delays.

Ten of the families received services from their Community Centered Board, three families received services from their Community Mental Health Center, two received support from Social Services, and five families received services from Part H because their children were under three years old.

Five of the six projects supported families of children who were terminally ill; and all six projects supported families of children who were chronically ill.

The Budget

Federal dollars available to Colorado each year were \$200,000. An average of 50% of that money, or \$100,000, per year, was allocated for the local pilot projects. The remaining funds supported trainings, travel, the Steering Committee activities, publications and distribution/dissemination of project information.

A small amount of federal dollars were also made available to Colorado for the behavioral training assistance each year. The behavioral trainers were not paid but their time was used for an in-kind match. The federal monies were for travel, per diem, printing and incidentals.

Goals Of The Six Community Projects

Alamosa: Regalo de Tiempo--The Gift Of Time

Completed	Goal
✓	To serve Alamosa and Rio Grande Counties beginning in year one and adding Costilla, Conejos, Mineral and Saguache Counties in year two.
✓	To increase the available respite options to families, and enhance community capacity to provide respite care to families who currently do not have adequate options.
✓	To improve community collaboration and coordination.
✓	To enhance family involvement in developing a system of care that is culturally sensitive.
✓	To provide peer to peer technical assistance and training to 4 community pilot projects during the second year.
✓	To assess the success of the Respite Care Project and develop a process to disseminate information to others.
✓	To establish a means to continue the project after federal funding.

Canon City: We Care 4 Kids

Completed	Goal
✓	To develop ongoing dialogue between providers, users and communities to address common issues and needs.
✓	To increase the network of peer supports available to families.
✓	To increase family options for respite resources by expanding the number of specially trained providers, to find respite for kids with special needs and to provide funds in the three counties for respite. (Custer County did not participate.)
✓	To develop an ongoing evaluation system to define problems, innovations and improvements in the tri-county system.
✓	To increase active parent involvement and leadership.
✓	To develop the concept that diversity enriches the community and that natural supports are desired outcomes for all cultural/ethnic orientations and people of all abilities.
✓	Develop financial support for the continuation of We Care 4 Kids after September 1996.
✓	Peer to peer technical assistance for the second phase, parents will be consultants.
✓	Evaluation.

Denver: Project Support

Completed	Goal
	To develop at least 75 new respite options for families, which will include cooperative options, and care within the child's home or the home of the respite provider. A coordinator will be hired. Denver Options will contract with the Denver Family Network to coordinate a respite cooperative.
	To increase the competence of respite providers insuring that all providers receive training on CPR, First Aid, seizure disorders, understanding children with developmental disabilities and 4 other pertinent topics.
	Families throughout the Denver community will have increased access to respite services. A computer software mapping system will be purchased so families can be connected with resources. The Coordinator will develop a data base of providers with their location and information about them. Parents can then call the Coordinator and get the names of two or three providers to call. Families and agency personnel will also be trained to use the data base.
✓	The coordinators will develop an evaluation tool and disseminate surveys.
	The staff will develop and disseminate a training curriculum related to children with complex medical needs.

Ft. Collins: Child Care Options

Completed	Goal
✓	Recruit and train respite providers. There will be a pre and post test for each provider and at the successful conclusion of the training the provider will receive a certificate.
✓	Employ a project coordinator to match providers and families. The coordinator will maintain a data base of providers, support families with information on how to interview potential providers, determine appropriate compensation, help families access funds to pay for respite. The coordinator will also provide mediation for any disputes between families and providers and meet regularly with Child Care Options staff and trainers.
✓	Train two groups of providers during the first year.
	During year two recruit volunteers to take over provider training. (Paid trainers were to mentor volunteers.)
✓	Partner with two large summer programs to promote inclusion in Loveland and Ft. Collins.
✓	Participants in training will complete evaluations.
✓	Project Coordinator will track usage of providers by families, and have satisfaction surveys for families to complete.

Lakewood: The Respiteers

Completed	Goal
✓	Foster supported inclusive community through awareness, volunteers, and recognition. The volunteer providers will be called Respiteers and will carry picture identification cards which will get them 10% discounts at participating businesses. Volunteers will be honored with awards.
✓	Increase collaboration and coordination between families, agencies and the community.
✓	Build comprehensive training program including behavioral, medical, and recreational aspects.
✓	Assure quality control and continuation.
	Create Respiteers of America.

Littleton: A Little Peace of Mind

Completed	Goal
✓	Advisory Board for the project will develop a mission statement and determine the direction of the project. It will be 75% family members, will have decision making power and will be in charge of the concept and growth of the project.
✓	One stop shopping for families and a single telephone number, for families to obtain respite providers, training and information.
✓	Computer data base of respite options for agencies and families to have a central point to input information and to get information.
✓	One stop shopping for agencies, organizations and community.
✓	Give families access to dollar resource information.
✓	Identify family's strengths and needs.
	Identify provider's strengths and needs.
	Identify agencies' strengths and needs.
✓	Training for family, churches, groups, clubs, professional providers, and neighborhood teens.
✓	Assistance for parents to interview and train providers.
✓	Community awareness to determine community capacity.

RESPITE PILOT PROJECTS IN SIX LOCAL COMMUNITIES

Alamosa: Regalo de Tiempo--The Gift of Time

The San Luis Valley Comprehensive Community Mental Health Agency with Marie Henderson as Project Director, and Belinda Toth, as Parent Coordinator, successfully changed the lives of many families in a 5-county area through this project.

An Advisory Committee was developed to oversee the project. It included individuals who collaborated together for the first time: the Family Center in Blanca, Blue Peaks (the Community Centered Board), probation officers, people in nursing services, special education teachers, professionals from Valley Industries, Developmental Opportunities, the Board of Cooperative Educational Services (BOCES), and the Health Care Program for Children with Special Needs. Three of the 10 Advisory Board members were Hispanic.

There were no respite providers for families to call before the project. Through this project 16 respite providers were identified, and are listed by name, telephone number, training, experience and the areas they are willing to serve. The parents who want respite call to obtain the list of providers, screen them, choose the provider they want, and reimburse them for services. Spanish speaking providers are available.

Some of the providers are college students majoring in special education or psychology at Adams State College in Alamosa. These students received credit for their participation as respite providers.

A resource directory, "Human Services Resource Brochure of San Luis Valley," was created and is available to families. The Directory was widely distributed through schools and other agencies including Part H which is a program and support for families who have children birth to three years old.

Many recreation options for children with disabilities were developed because of this project. Prior to the project there were very few. Project personnel worked with Splash and Swim to make the indoor pools in Ft. Garland and Blanca accessible for individuals with disabilities. Equipment, life-vests and a lift were secured for the pools. A local business donated cement for the ramp into the pool. Eighty-four children and adults celebrated the completion of this part of the project with a swim day. Snow skiing at Wolf Creek was provided for 20 children with disabilities during school time. There are plans in the works for skiing at Purgatory next year. A future goal is to make the local movie theaters accessible.

"Mental health connected me with this project, and made me feel welcome, and assured me I deserved respite."

Mom

Public Service Announcements were on the radio telling about this project and educating the community about the needs of children with disabilities.

As of October there are no funds now to support the parent coordinator, but the Community Centered Board, Mental Health Agency and the San Luis Valley Kids Council will continue to provide support for families who need respite. Agencies in the area are really pulling together to support funding of direct services. The Mental Health Center came up with \$2,500 for the project. Also, the family preservation/family support project La Gente and the family center will support families who fall through the cracks due to definitions of disability and eligibility issues. The project is being housed at the Blanca/Ft. Garland Family Center. The main challenge of the future will be to obtain more providers and keep them involved.

Canon City: We Care 4 Kids

"Information is available about respite. It's like insurance, it raises the comfort level. It's a mental support."
Parent

The Fremont County Family Center, which is billed as "A Friendly Place For Families" is where this respite project began. "We Care 4 Kids, Encouraging Parents To Take A Break!" covers Chaffee and Fremont Counties. The Project Director is Leslie Meyer and Misty Herzer is the Parent Coordinator.

Where did families in this area previously go for respite? They had no where to turn. This project has provided options for families. They know the project is a part of the Family Center and know when they call, they will get support.

Care Finder, a computer Software program is used to keep necessary information up to date. Each family who calls in for respite is now in the data base with their demographics and needs. One hundred child care providers and 60 licensed day care homes are also in the computer. By collaborating with the Family Center, training was available to the providers. The abundance of providers is gratifying.

"Respite is not a vacation, it's something you need."
Parent

How did the news about project get out? Articles in local newspapers, features in the Family Center Resource Fair Newsletter, distribution of fliers all over town, and word of mouth made it happen. Developing a mailing list of all families who have been in touch with the project, and sending information and newsletters to them was one accomplishment of the project.

When families call for respite they are given three providers from which to choose. Funding for respite is provided on a sliding scale based on the Women's, Infants and Children's program.

In addition, "The Parent AND Provider Handbook," an information source for families using the respite care system, was developed. Tee shirts with the project logo were used to raise awareness and promote the project in the community.

An Advisory Board of 12 members worked with the project. Nine of the members are parents. Dialogue at least monthly was necessary between the coordinator, advisory committee, the Family Center, KIDS Always Win and the Family Support Services Council.

Fremont and Chaffee Counties have applied for and received an interfaith grant through the Robert Wood Johnson Foundation, for the continuation of respite for families. In Fremont County six churches have come together to make this happen.

Denver: Project Support

The respite grant in Denver was awarded to Denver Options, the Community Centered Board. The original Project Director resigned soon after the project started and Nancy Hodges became the Project Director. There was a collaborative effort with the Denver Part H group in writing the project proposal, however, Denver Options assumed the implementation responsibilities.

During the first year of the grant, four different Parent Coordinators were hired. Due to personnel problems, none of them worked for very long. The plan was to develop new respite options and provide trainings for the new providers. It is unclear whether either of these occurred. A proposed respite cooperative was not developed. Families needing respite were served by the existing system. A software package to build a data base, that would be available for family use in finding respite providers, was purchased but not installed nor customized for use. A handbook for families with children with intense medical needs was developed, but not disseminated because Project SUPPORT was not able to make changes needed to meet the intent of the grant. One parent on the Advisory Board felt there was a lack of team work, people got frustrated and left the Board. The approach needed to have more parent involvement and leadership.

Extensive technical assistance and support were provided to this project by grant staff and members of the Steering Committee, but Denver Options was not awarded a final year of funding due to non-performance. In making the decision not to award the final year of funding the Committee agreed that respite issues still needed to be addressed in the metro area. Therefore the general consensus was to support the following mini-projects in Denver during the final grant year.

The Association for Community Living in Arapahoe and Douglas Counties is developing respite resources in two counties adjacent to Denver County. One key product of this project is a set of respite resource materials designed to give families information and guidance to find and use respite services (see description of A Little Peace of Mind page 15). This agency will provide these materials to families in Denver County and will provide training to interested parents on how to utilize the materials.

The Rocky Mountain Adoption Exchange, a non-profit agency, is finding new parents for children whose parents are dying of AIDS. They will provide respite services

for the adoptive and birth parents if the children are either HIV/AIDS affected or have a disability. The agency has targeted 21 children for these services.

Colorado Office of Resource and Referral Agencies (CORRA) is providing funds to Denver County families to obtain professionals to train respite providers on technical issues related to their specific children. For example: child care center staff could be trained on g-tube feeding procedures for a specific child, or time with a behavioral consultant could be provided for a day care home provider working with a child with challenging behaviors.

The Kelly Foundation is providing emergency respite services for families in Denver County. A Denver County case management agency has been made aware of the availability of these funds.

The Mental Health Association of Colorado is using two approaches to get respite for families of children with mental health needs in Denver. One is to provide funds directly to families with children at imminent risk of out-of-home placement. The other is to work directly with local recreation centers to include children with serious mental health needs in recreational activities. They are also coordinating training to be provided by the ACL of Arapahoe and Douglas Counties to assist families in developing their own respite options.

One Day is a private, non-profit agency that provides family support services to AIDS affected families and operates a child care center for children with HIV/AIDS. Funds are being utilized by this agency to develop and implement a Baby Buddies program that pairs a trained volunteer with a child with HIV/AIDS as a companion and respite provider for the family. The agency is training and matching 20 volunteer Baby Buddies.

The Work and Family Resource Center is the local child care resource and referral agency for Denver County which provides referrals for temporary child care to families of children with disabilities. They have acquired training materials and videotapes about inclusive child care for children with disabilities and will make this information available to child care providers in Denver through the Resource Center's lending library.

In summary, even though the original Denver project did not succeed, there are many positive impacts from the seven mini-projects.

Ft. Collins: Child Care Options

The Disability Connection is a respite project serving all of Larimer County. The project's name is Child Care Options. The Project Director is Barbara Stutsman, and Linda Teahon is the Parent Coordinator.

"The only respite option in town was to take our children to a facility. Now I can have respite in my home and not drive my daughter anywhere."

Parent

Before the project there was only one place in Ft. Collins to take your child for respite. There were no respite providers who would come to a family's home. Now there is a list of 12 new providers who will come to families' homes. Therefore, families have choices; they can have respite at home, or away from home. The providers also care for all children in the family, not just the child with disabilities. When a family calls for respite, they are given the names of three providers. The family chooses their own provider.

The project also focused on building respite by increasing inclusive settings for recreation and before and after school care. In Ft. Collins at several elementary schools there are Base Camps that provide before and after school care. There was inclusion training for 40 employees of the Base Camp. Children with disabilities are readily accepted into Base Camps. In two schools there was specific training to support children with behavior problems.

"I wanted someone more than a baby sitter, someone who had knowledge and did not just follow my child around. This provided what I wanted."

Parent

In the summer there are respite day programs from 7 A.M. to 6 P.M. The Recreation Therapist was trained in inclusion at the Chilson Center in Loveland. If parents are in the Center taking classes, they can drop off their children with disabilities for care.

Through this project, collaboration happened for the first time with the following groups: Foothills-Gateway Family Support Council and Family Support Program, and Larimer County Mental Health Center.

Respite for families will continue through many efforts. The project is working closely with the Women's Center which is the local child care resource and referral agency. The Center offered money for training at the school-based programs and for families with children with developmental disabilities in order to have full use of the service collaboration. The Center will also provide a list of every provider who has training or experience with children with disabilities; and will note which providers take drop-ins. In addition, the project has combined with other groups and churches. That new group has applied for and received an interfaith volunteer caregiver grant through the Robert Wood Johnson Foundation. The plan includes developing volunteers to provide respite.

Lakewood: The Respiteers

The grant to Jefferson County was awarded to The Kelly Foundation in Lakewood, which is in the metro-Denver area. Their project is "The Respiteers." The original Project Director resigned from the project after the first few months and Bud McGrath, Director of the Kelly Foundation agreed to be Project Director. The project had some set backs at the beginning and during the change of directors, but success was achieved. Many volunteers now provide respite to families.

The volunteers who provide respite are called Respiteers. A thorough process was developed to support people who showed an interest in becoming a Respiteer. An extensive training manual was developed and volunteers are informed when trainings are being offered. People wanting training can pick and choose the parts of the training that will meet their needs. When families call for respite, they are connected with a Respiteer who is trained and available. If further training is needed specifically for their child, the family provides further training. A video camera is available for these purposes.

There are about 43 Respiteers. Each Respiteer gives at least 12 hours of respite a month that could serve one or two families. Respiteers make a commitment to work with a family for 6 months or one semester. Many of the Respiteers decided to work with children who have mental health problems, even though that required more training. It works best if we get to know the volunteers well before they are connected with a family, so the volunteer's interests and talents can be put to best use. After 20 volunteer hours an award is sent to the Respiteer. Two weeks after a Respiteer begins, a member of the Advisory Board calls to see how things are going. Funds for emergency respite were also available.

Some businesses agreed to give services or merchandise to the Respiteers. However the large response that was expected did not happen. Businesses are more likely to give in-kind support like free printing to the project.

Finding and training the Respiteers was a much more difficult challenge than anticipated. Success came slowly but more volunteers for respite were secured in the last few months of the project than in the previous two years.

The advisory board for the project is 55% parents. Collaboration between the local mental health agency and the Community Centered Board occurred for the first time because of this project. Families with children who have a dual diagnosis of mental illness and developmental disabilities were able to get respite because of this project. Because of this project, the two agencies considered the children in a new way, not focusing only on their labels.

The Kelly Foundation was a key player in developing the Jefferson Volunteer Caregivers project funded by the Robert Wood Johnson Foundation. Through these efforts the Respiteers and a small volunteer-oriented charity have motivated two large publicly funded service providers to make a commitment to volunteer support for families.

Littleton: A Little Peace Of Mind

"A Little Peace of Mind" is the respite project of The Association for Community Living (ACL) in Arapahoe and Douglas Counties and the City of Aurora. Nancy

"Family members on the Advisory Board have learned power and will not give up. Their momentum is contagious."

Project Director

Baesian is the Project Director and the Parent Coordinator.

The focus of this project is the empowerment and support of parents and families to develop, and to own their respite options. The driving force of the project was the Advisory Board which is 90% parents. The Board made the decisions and adapted the original project to what they believed would work best for families. Countless hours have been spent by volunteers to make this project happen.

A notebook, "A Little Peace Of Mind," was created and designed by the Advisory Board. This book has most, if not all, of the information a family would want to have in one place about their child with disabilities. The first draft of the notebook was reviewed by eight focus groups. With the information from those groups, the process started over again and every page was changed to incorporate every suggestion. The Notebook is in two parts, Personal Profile and Family Checklist. The sections included are, At Your Fingertips, All About Me, Daily Living, Activities, Special Needs, Home Life, Provider Information, Getting Around and Anything You Want To Add. One hundred and seventeen families are now ready to use the book and to train their providers.

Forty providers have been added to the data base and the building process continues. Letters were sent out to 1,800 para-professionals in the schools asking if they were interested in being respite care providers. The response from the first mailing was small, so the letters were sent again. Fifty eight provider surveys were returned. In order to obtain more providers, posters and book markers have been made to recruit providers from colleges and universities where they were disseminated.

"Respite gives families who have kids with disabilities time...to take a break, spend time with other family members, renew old friendships, or maybe just take a nap."

ACL Committee

Seven hundred and fifty surveys were sent to parents who might be interested in respite. The survey was to gather information and to ask if the parents would attend a meeting. Approximately 70 surveys were returned. Then a group of volunteers called the families who did not respond and asked, "Are you interested?" As a result of this effort, 60 families attended the meeting and received notebooks.

One successful part of the project that was not planned was the purchase of camcorders and pagers that families can borrow. If families are hesitant to leave their children, they can borrow a pager for the time they will be away. Families can borrow the camcorder to make a video for providers, or to make a video of themselves so the child can watch it in their absence and perhaps not be as anxious.

"A Little Peace of Mind Is Respite Care" is a video made during the project. The brief video ends with the question: "Want to know more?" It is available free of charge.

The project also collaborated with the Work and Family Resource Center which maintains a data base of information about available care providers for any child. Now the data base includes information specifically about respite providers for families of children

with disabilities. The public libraries in Douglas and Arapahoe Counties have information about developmental disabilities. The larger libraries have files concerning respite.

Neighborhood Cluster Groups grew out of the momentum of the project. This was another facet of the project that was not planned. The first Cluster Group had 50 people in attendance and of them, 30 signed up for continuing involvement as group leaders. The Cluster Groups will be located in regions served by local high schools, with one Group at each school. They'll ask for meeting space at the school and support from the school. It is a parent and consumer driven group. The Cluster Groups will be the first contact for many parents. The Cluster Groups will do much more than respite to support families. The current Project Director will coordinate the Cluster Group leaders.

On September 10 Nancy Baesman, the Project Director, was informed that this project was the winner of the 1996 Mr. and Mrs. Alex Ziring Award of the National Association of Retarded Citizens (ARC). This is a distinguishing services award presented annually to confer national recognition on a chapter of ARC that provides exemplary, unique, innovative, or special programs which have positive impact on the lives of people with developmental disabilities and their families. The presentation of the award was on November 15, 1996.

BEHAVIOR TRAINING SESSIONS

Often families who have children with behavior challenges are not able to get any respite. Training for local behavioral teams, by behavioral consultants, was available for those communities that were interested and made application. Alamosa, Denver, Ft. Collins, Littleton and Lamar requested and received support through this part of the project. Subsequent to completion of the first training group it was decided that each project would determine its own training agenda.

The State Intent Of The Grant For Behavioral Training

The state design was to provide training and technical assistance to local community teams. The plan for the training was to focus on a collaborative community effort, including parents, that would expand natural respite supports for families of children with disabilities. The community teams would support individual children, their families, potential respite providers and the community in the provision of respite. The teams would be composed of parents, professionals and para-professionals interested in the training. The teams would use the train-the-trainer model. In this model the behavioral consultants train the original team, and that team in turn trains other interested people in the community. The teams would be ongoing in each community.

Outcomes

Three of the communities planned to get a team started with between one and four trainings per site. All the teams were composed of parents, professionals and para-professionals. Some of the trainings were opened to anyone who was interested. When an open meeting was held in Alamosa there were 35 people in attendance. The Project Director estimates that 60 people benefited from the trainings.

Following a training in Ft. Collins mapping helped one family. Mapping is working with a family to chart the supports they have, the supports they need, and how to obtain them. Technical assistance and consultation were provided by the behavior consultants for committees involved in the Littleton project. As a result of one training in Denver there is now a collaborative group of providers that continue to meet regularly and discuss how to support families.

Difficulties

The difficulties encountered in implementation of the behavioral trainings were because of the following circumstances. One state employee who helped design the trainings was not able to continue involvement. In Ft. Collins the families who needed the support were in crisis and could not attend the trainings because they could not get respite for their children. The information and Requests For Applications (see page 4) that were sent out about the trainings were confusing and people were uncertain about what was being requested.

"Parents feel ashamed and isolated because of their child's problems. They don't feel they can go out in public and are still looking for the support they need."

Parent

Training in and of itself using the train-the-trainer-model did not seem to work. This model expects a big time commitment over a period of many months from team participants. First the participants get the training and then they train others. The trainings would have been more beneficial if parents and children could attend together so there would be practical application and experience.

There are many families who still don't have the necessary resources and support for their children with behavior problems. Many schools don't know whom to call for help. Some children are kicked out of school and off buses because of behavior problems.

A Different Approach

Having learned from the previous behavior trainings, the current training in Lamar will approach it in these ways. They are taking the case study approach. Three or four families who want the training and have children with challenging behaviors will be chosen. Collaboration on the project will be a group of parents; and staff members from

the Mental Health Agency, the Board of Cooperative Educational Services (BOCES), the Community Centered Board, and the Prowers County Nurse Association. This group will work together with the behavior consultants who do the training. The approach will be community based. Support, including child care, will be available for involved families from the planning to the conclusion. This collaborative group will decide how many trainings they want, and in what format. Parents will meet and work together with agency staff members. Community mapping (see the above section on Outcomes) will be available. The intent is to insure that the people on the local team make a commitment to families in need of respite.

THE STATE PERSPECTIVE

The state had overall objectives for this grant, in addition to the local community respite and behavioral trainings. Objectives included: family involvement throughout all parts of the grant, local community capacity building, handbooks about respite and children who are medically involved, a study of liability issues, increasing family access to respite resources and sharing information statewide and nationally about innovations and improvements in respite.

Family Involvement

Were the projects family directed?

- ◆ Yes, the percentage of family members on local Advisory Boards ranged from 55% to 90%. One exception was Project SUPPORT.
- ◆ Four out of the six local Advisory Boards made all grant decisions.

Did the community projects meet the expectations of the families?

From the families' perspective:

- ◆ All 16 parents interviewed said the respite provided through these projects was what they wanted and needed, when they wanted it, and where they wanted it. Nine chose to have it at home.
- ◆ Ten families interviewed said the respite received was frequent enough.
- ◆ Thirteen said it was affordable, but three said it was too expensive.
- ◆ Ten families said they had choices of a respite provider.
- ◆ Ethnically diverse families said they felt respected. One bilingual, Hispanic Mom had a Spanish speaking respite provider and she appreciated that.
- ◆ Families believe they will continue to have ongoing respite resources available in the community.

From the Parent Coordinators' perspective:

- ◆ The project had a good, even the best possible, impact on families.
- ◆ The paper work was brief and not confusing for families. In some instances there was no paperwork only information by telephone.
- ◆ All coordinators felt the respite provided was based on the families' needs and not on their children's labels.
- ◆ More resources are available, and they are available for more than one time, to support families.
- ◆ We get good feedback about the project from parents and providers.
- ◆ We found providers where there weren't any before.

"Family directed options mean the family chooses when, where, for how long, and with whom their child has respite. The options are based on respect for family choice and not on the child's label."

The State Steering Committee of the Grant

Community Capacity Building

How did the community projects build community capacity?

Families' perspective:

- ◆ Children are more visible in the community because of this project. The public is becoming more aware of families' needs, and a tremendous network of support is developing in the community. This is only the beginning.
- ◆ Donating space for this project in an agency that is already established gave respite more visibility in the community.

"Friendship is a thing most necessary to life, since without friends no one would choose to live, though possessed of all other advantages."

Aristotle

How were you able to connect families with natural supports?

Parent Coordinators' and Project Directors' perspective:

- ◆ We secured providers who live in the community and who were interested in working with families.
- ◆ We publish directories of what's available in the community for the families, train providers and connect them with families, and secure volunteers from the community.
- ◆ We use a computer program to keep family information and resource information available. Then when a family has a need we can connect them, for instance, to after school programs and recreational centers that are inclusive.

Do you feel you have more respite support from your community and more natural supports because of this project?

Families' perspective:

- ◆ Fifteen said yes and one didn't know.

Handbooks

Three self-help handbooks were developed during this project: When Do I Get Some Time For Me; Love, Care, Technology and Other Ingredients; and Where Is Respite? The books are available free of charge and may be copied for further dissemination. All 3 handbooks supported the work of the local projects.

When Do I Get Some Time For Me was written by Cynda Arsenault who is a professional writer and the mom of a child with disabilities. Over 2,500 copies have been distributed statewide; 1,500 through the Colorado Developmental Disabilities Planning Council. The book is also available in Spanish. Two hundred copies were printed in Spanish and 120 have been distributed. The book is on the Colorado Meeting Place, which is a free-computer-network for parents and individuals with disabilities. Future plans are to get it into the computer systems of the large public libraries in the state.

"Respite is getting away long enough to find yourself again."

Parent

The Parent Coordinators and Project Directors are familiar with the book, have distributed it, and have copies available in their offices. They think the best parts of the book were the cover, the sample medical forms, and the resource list with telephone numbers. Parents told one coordinator the book was great and it helped them. This book was written to show parents how to create their own respite and how to empower them. However, no matter how helpful it is, some coordinators feel parents just don't have the time to read it.

The previous statement is substantiated by the response from families when asked about the book. Only 3 of them were sure they had seen it and said it is difficult to set aside time to read so many pages. The families who did not remember seeing it said they have too much to do. Getting the book and taking time to read it is not a priority.

The author says it is written as a resource guide, to refer only to the part of it you need at the time, and is not meant to be read from cover to cover. The distribution of the book, or the marketing of it, seems inadequate. Perhaps a how-to-use-this-book session could have been held for those distributing it so they could inform parents on how to get the most from it.

Where Is Respite is a book put together through collaboration. One thousand copies were printed and over 900 have been distributed.

"Respite helps people in need, those who can't control their circumstances at the moment."

Parent Coordinator

These books were distributed through the local project offices, and through established mental health and developmental disabilities agencies. A similar comment as stated about the previous book is the same for this one. Parent Coordinators feel it is

overwhelming and parents don't have time to read it. Only two families had seen this book. Again, instead of giving a number of books to busy people to distribute, give instructions to those distributing it and show in what instances the books can be a positive resource for families.

Love, Care, Technology and Other Ingredients was written by Barbara Brent, a professional and an individual with disabilities, and Dalice Hertzberg a registered nurse. The book was written for families of children with medical support needs, and for respite providers who are interested in giving parents a break. It is also intended to give children a new opportunity for friendship and fun. One hundred and forty of these books were printed and 120 have been distributed.

From the information we have from families, these books were not that helpful for them, nor would books be a priority for them in future projects.

Family Access To Respite Resources

This project collaborated with the Colorado Office of Resource and Referral Agencies (CORRA) the statewide agency managing the state's child care resource and referral services. Before this grant there were zero respite providers identified in the state who would accept children with developmental disabilities. By September 1996 there were 1,832 potential respite providers. CORRA also has a group of America Corps volunteers to increase supply and quality of child care that includes youth buddies. This approach encourages middle school adolescents in child care to reach out to peers with disabilities. These youth buddies could become respite providers.

Colorado Options For Inclusive Child Care (COFICC) is a unique model that takes training to providers on a one-on-one case basis. Existing licensed child care centers are asked, if you have an opening would you consider drop ins, and children with developmental disabilities if we provide the training for you? It is an individualized approach for each family where there is team work with the provider and the parent. This approach has provided wonderful success with day care centers.

Comments from Parent Coordinators:

- ◆ All Coordinators have contacted their local CORRA office, five were successful in getting a working relationship established even though some of the beginnings were rough.
- ◆ Licensed day care providers need training about children with disabilities so that inclusion can occur.

"It's time out, a break
of your choice."
Parent

Sharing Information About The Projects

Information about the pilot projects has been shared in these ways:

- ◆ Articles about respite in agency, church and college newsletters.
- ◆ TV interview that has been aired five or six times.
- ◆ Speaking about the project at every meeting you attend in your community.
- ◆ Recruiting volunteers, and obtaining them through advertisements in a free, weekly newspaper.
- ◆ Going to meetings at churches, service organizations and other agencies and groups.
- ◆ On the Colorado Meeting Place.
- ◆ Talk about it everywhere I go.
- ◆ Master's Class at local college.
- ◆ Kiwanis Club.
- ◆ Chamber of Commerce in Denver.
- ◆ Resource Fairs.
- ◆ Epilepsy Foundation in Denver.

"The Chamber of Commerce had many questions. The person who introduced me was living it and didn't know it...his wife is very sick."

Project Director

STRENGTHS AND WEAKNESSES OF THE COMMUNITY PILOT PROJECTS

Why Did The Community Pilots Work?

Families

- ◆ The project belongs to the families and they are invested. Family members are involved as Board members, and as local Project Coordinators. Families' voices were listened to. Extended family members can actually get paid for respite care.
- ◆ The project addresses children with all disabilities and not just children with developmental disabilities as defined by the state. (The state definition says children with developmental disabilities have cognitive impairment.) In this project there was less labeling, and devaluing of children and families, than there is when you receive services from the state system.
- ◆ Volunteers are priceless, they contribute many hours and charge nothing to the families. Their energy and enthusiasm are contagious.
- ◆ The financial support from the project made respite available for many families.

Collaboration

- ◆ Collaboration in local communities that had not happened before included these groups: Recreation Centers, Day Care Centers, Community Centered Boards, Family Support Councils, Mental Health Centers, Part H, Public Health Nursing Services, schools, doctors and pediatricians, Family Resource Centers, CORRA, Mile High Down Syndrome, and the Autism Society.
- ◆ Collaboration from one local project site to another began at the State Steering Committee meetings.
- ◆ Parents and professionals are involved together and they need each other.

Financially

- ◆ The Project Directors and Parent Coordinators say that the amount of money spent on the projects provided many benefits for families.
- ◆ Federal grants require a local match. All six projects easily obtained the required 10% match. All match was in-kind.
- ◆ For the amount of money available for the community projects, two said it went as far as expected, two said it went farther than expected, and two said it did not go as far as expected.

Providers

- ◆ Some providers came forward because of classified advertisements in the newspaper, and some were recruited from school para professionals.
- ◆ The projects provided the local community a place to try out new ideas.
- ◆ The provider is enthusiastic and has become a part of the family.

Outreach

- ◆ Word of mouth.
- ◆ Advertise in campus newspaper and student employment.
- ◆ State employment office in the local area.
- ◆ Six minute video is available and ends with, "Want to know more?",

"When the provider charged an extra \$2.50 an hour for my other child, I could not afford it."

Parent

In Every Aspect

- ◆ A good sense of humor.
- ◆ It's fun to share ideas, to plan, and it's exciting to see it come together.

What Were The Limiting Factors

The Name

- ◆ Call it child care, not respite.

Families

- ◆ Have one program to care for all children and one that respects their feelings.
- ◆ Families need more respite time on a regular basis, like one night out a week.
- ◆ Difficult to determine who has the greatest need when all families can't get respite.
- ◆ Family voices are not listened to in all communities.

Financially

- ◆ The contracts were very slow getting signed and through the state process so projects could not start as planned. In one project the first year ended up being only 4 months long.
- ◆ Working capital at the beginning of the projects, and quicker reimbursements during the projects are needed.

- ◆ It's difficult to figure who, what, and how much it will cost when starting a project like this even though you have a plan.
- ◆ Many families can't afford respite and \$7.00 an hour is definitely too much for a family to pay.
- ◆ How to keep it going? Fund raising is a huge challenge that was not addressed early enough in the project.
- ◆ All projects could have used more money for a variety of reasons.
- ◆ Approval of carry over funds from one year to the next came too late because of needed federal and state approval.
- ◆ More money could have been used for direct respite care.
- ◆ The required federal budget categories didn't match the local operating budget and this caused confusion at times.
- ◆ Personnel problems up front in another project caused much money to be spent with no furthering of the project.

Providers

- ◆ Limitations for some providers are: they want more respite business, they have not had training, they have no referrals yet, they have concerns about liability (i.e.: if they are doing respite at their home and the television gets broken, or something is missing from their home, what to do?), large distances from one town to another are difficult when a provider needs training in a distant town, and then there's not enough work in their town, and there's not enough business for a respite provider to be fully employed.
- ◆ Recruiting providers and getting them to stay is a challenge.
- ◆ Volunteer providers were supposed to get 10% discount at local merchants. Great idea that was difficult to implement.
- ◆ Use of college students as providers is difficult during summers, vacations away from school, and after graduation.
- ◆ Providers are not always available when families' need them. Overnight child care can be tough to arrange.

Project Directors

- ◆ Three of the six project directors who wrote the community grants left their positions before the project was fully operational. That put the projects off-track. In two of the three instances, the projects got "on track" and were completed.
- ◆ Mental health agencies were not involved in all communities.
- ◆ It's very difficult to develop the community if you're not there. In the town where the parent coordinator lived and worked things went well, but the other towns in that county, and the other counties didn't work as well.
- ◆ More Child Care Centers need to accept children with disabilities.
- ◆ There was too much paper work required of the coordinators.
- ◆ State Steering Committee meetings should have moved out of the Denver area. Breaking into smaller groups at the meetings would have been more beneficial.
- ◆ Parent coordinators did not get to meet regularly as a group.
- ◆ Not all families were served because of lack of resources and providers.

Public Education

- ◆ The public needs more knowledge about families with children with disabilities and their need for respite.

Volunteers

- ◆ Volunteers in this project work harder than in some other volunteer positions. Give them more support. Overachievers die hard.

Ethnic Diversity

- ◆ Need to figure out how to truly reach ethnically diverse families that we don't know about.
- ◆ Build a collaborative, supportive network of ethnically diverse folks.

INNOVATIONS

Local Models Of Respite

- ◆ One volunteer connected with one family and gave a 6 month commitment for respite.
- ◆ Parents receive a list of providers that includes names, telephone numbers and short biographies of each.
- ◆ Giving families who are interested three providers to call. **Families make all the decisions**, and negotiate pay per hour.
- ◆ Meetings where respite is provided allow the families to meet providers and providers can get to know children.
- ◆ Use of a **computer software system** with families and providers in the data base.
- ◆ Use of **camcorders and pagers** to give families peace of mind when they're gone.
- ◆ One child can go to **judo classes** with other children from town. In addition to learning judo, he learned behavior control and his Mom had a break.
- ◆ **After school programs**, recreational programs, child care and support in the community, and Mom's Day Out now accept children with disabilities.
- ◆ There was **community outreach and response**: donated logo, copies, brochure design and printing. Video-interview on TV Channel 41, free advertising to all residents through a coupon book, free advertisements in local newspapers, and donations for the swim program.

"There is trust built with the provider now and she even knows sign language."

Parent

State Models Of Respite

- ◆ **Parent control**--families have power to take control.
- ◆ A **modular training** concept for providers that allows them to choose the parts of the training that will be beneficial to their work.

- ◆ **A model notebook, designed by parents**, about each child and family that can be left with the provider.
- ◆ **New providers** who had not worked with children with disabilities before, were identified.
- ◆ **Providers have become natural supports**. Some children go out into the community with providers.
- ◆ **Families who have children with disabilities have choices** as other families have.
- ◆ **Volunteers** were community members, many of whom had not been with children with disabilities before this.

Products Developed by Pilot Projects

- ◆ "All About Me" **Notebook**.
- ◆ Huge, comprehensive **training manual** for all Respiteer volunteers.
- ◆ A library of **training video tapes** that Respiteer volunteers can watch at their convenience.
- ◆ **Resource books** and directories developed in 4 of the 6 projects.
- ◆ "A Little Peace Of Mind Is Respite Care" **video**.
- ◆ **Handbook** on how to recruit, train and keep volunteer providers.
- ◆ A **packet of information** on behavioral training.
- ◆ **Medical training materials**.

Unexpected Successes

- ◆ **Adoptive homes** were found for two children who were in foster care.
- ◆ One Project Director received a Christmas card from a make-up artist who was a volunteer, saying **thank you** for bringing a son and his father into her life.
- ◆ The mother of a boy with asthma wanted her son, who was feeling sorry for himself, to meet another child with disabilities. The connection was made and the boys are **best friends** now.
- ◆ In **Greeley**, a place not involved with the project, community organization is underway. They are using information from these pilot projects to start their own respite program.
- ◆ **Volunteer youth in churches** are very excited because when they volunteer now it is not to mow another lawn or paint another wall, it is to provide care for a child with disabilities.
- ◆ Social Services in one community now knows more about **family needs** because of this grant.

"One family had not been away for one-and-a-half years and because of this project they got a week-end off."

Parent

WHAT LESSONS WERE LEARNED?

Goals Can Be Accomplished

Parent Coordinators and Project Directors say:

- ◆ **Local projects reflect their communities.**
- ◆ **Family members had a voice in their projects.**
- ◆ **Families had choices and control of the respite they received.**
- ◆ **Families now realize they have power.** They learned they can be trainers.
- ◆ **Families have knowledge.** They know how to get respite.
- ◆ **Families are more comfortable** knowing someone is available even though they may not call upon them. It's feels like a kind of insurance.
- ◆ **Everyone is an owner.** Parents choose their providers. Providers agree to be a part of the project.

"Respite for the whole family, all of the children, not just the one with disabilities. Yes!"

Parent

Families are in agreement:

- ◆ They received respite because of this project.
- ◆ The respite was with a provider they chose.
- ◆ The families have more support because of the respite.
- ◆ The respite was based on the family's needs and not their child's label.

Families also say the respite they received:

- ◆ **Is a social support**, and it kept Social Services away.
- ◆ **Brings people together.**
- ◆ **Families connect to the community** and not to an agency.
- ◆ **Should be ongoing.**
- ◆ **Came as a blessing.**
- ◆ **Came from a united effort**, and parents were listened to.
- ◆ **Came through when they really needed it.**
- ◆ **Helped since there was no extended family near** and they **had no respite options before.**
- ◆ **It's the best support, they have...**someone to call when the child gets sick and they don't know what to do.

BARRIERS TO BE OVERCOME FOR FUTURE EFFORTS

1. Respite Is Still A Number One Need

The need is still there. Respite continues to be what families with children with disabilities need the most. Families report that respite reduces their stress level, helps them feel refreshed to continue to provide care for their child, improves family relationships, and gives them time to deal with urgent and daily family matters. Will this community-supported respite continue? Many families received respite because of this

"Respite is wonderful and I hope it will always be there, in my home with my choice of provider."

Parent

project, something has started. None of the projects were the same because they served individuals. However, many of the efforts worked well. Will these efforts be nurtured successfully in each community and continue to grow and produce?

2. Community Building Has Challenges

The grant talks about building community but community was not defined. Would community be the family's community, a geographic area, a social group, neighbors, or some other group? Local groups were asked to develop a community and then complete the grant. Community development is a time-intensive process in itself. An understanding of community and the development process is needed. For future grant funding know that a "community" cannot form quickly and instantly take off. The idea is captivating, but the vehicle to accomplish the work isn't immediately available, it needs time to develop.

3. State And Federal Requirements Pose Problems

The community respite grants were overly designed from the beginning because of tight federal rules and short deadlines. These rules and deadlines forced community projects to be up, running, evaluated and self sufficient in two-and-a-half years. The state proposal to the federal government and the six local pilot projects had ambitious plans that were difficult to complete in the amount of time allotted. The main problem, mentioned in the previous section, was that the "community" was not yet formed. In the future maybe a broader, more open ended model could be offered for local people to build on. Perhaps a plan that thinks one-family-at-a-time, rather than community, would have been less overwhelming.

Another difficulty was the reimbursement method used by the State. The projects first had to spend the money; second, send verification of funds spent; and third, wait to be reimbursed. This wait could be up to six weeks. If the project was with a large agency there was no problem. However small agencies found it very difficult because the "cash flow" is minimal. This discourages small, grassroots organizations from applying, or re-applying for funds.

4. Behavior Trainings Could Be More Successful Using A Different Approach

Problems seemed to arise during the implementation of the behavior trainings. The behavior trainers found they were working more on community building, and community relations than they were on behavior training. The families who needed training and respite often could not attend because there was no one to care for their child with behavior problems.

The behavioral training component needed to be clearer about the intent. It seemed backwards to add behavior training after the respite grant was going. Was it focused on respite or behavior, or a combination? In the future blending the training with the broader pilot projects could help determine clear behavioral training goals and steps to reaching them from the beginning of each project within the established structure.

One perception was that the local people didn't own the behavioral training piece. It wasn't theirs, it came to them from someone else. Maybe the training was too intimidating because of the amount of information presented in a short amount of time.

In developing future behavioral training teams it is suggested that: 1) time be spent with folks who want information and want to change, 2) a cadre of six people statewide, available to train, 3) one of the local team members participate as a co-trainer after the first session, and 4) technology isn't the only answer.

Consider also the large time commitment it takes for the train-the-trainer-model. A person first must be trained and then in turn train others. If this is clearly spelled out ahead of time, then people would know if they have the time to be fully involved. Perhaps if there had been designated local leaders who would focus only on the organization and support of the behavior teams, they would have flourished.

5. Support Grassroots Groups

If we truly want to build community and support families one way would be for a grass-roots group to receive grants. Advance funding that could be provided with a waiver of State rules would help to make this happen. The current reimbursement method keeps many groups from applying.

"It's easier for a community to support a child than it is for parents to fit their child into the professional model of services available. "

Parent

There are many parent leaders in many communities. Give them the support they need to apply for and receive a project grant. Have more parents than professionals involved and work for collaboration with equal voices from all.

6. Few Responses To The Requests For Proposals

There were very few responses to the 2 rounds of RFP's in relation to the number sent out (see page 3). Perhaps requirements by the state system were overwhelming, or there was too much required for the amount of time and money offered. Follow up surveys should be done with groups who may have been interested but did not respond.

7. Providers Need Support

Providers needed more support in some cases and wished for some support in other cases. Plan to support providers in the future. Ask the providers what are their barriers to successful respite, and address them. In one area providers stopped due to a lack of demand. Determine if ongoing training and support are needed.

8. More Public Education Needed

Project people and families talked about the need for more education about respite and about families who have children with disabilities. The deficit is not in educating people or getting the word out, but rather in relationships. Try different approaches. For instance, invite a family to dinner at your home. Then you will begin to know each other. Relationships are valuable educational tools.

"I used University students who are Occupational Therapy majors and need an experience like this as part of their training."
Parent

9. Address Volunteering Challenges

Volunteering is an excellent solution when it works. Determine specific challenges that come with getting and keeping volunteer respite providers from the people who have done it. Then develop the plans and supports to overcome the barriers.

WILL COMMUNITY RESPITE CONTINUE AFTER GRANT FUNDING ENDS?

Parent Coordinators And Project Directors Speculate

1. It will be business as usual

Most of the parent coordinators are sure that the projects will continue no matter what. One community is not sure because they may not have providers after the grant. It will be full speed ahead in most instances. The software program will continue to be available. There will not be respite funding directly to families, but provider's names will still be available. The core group developed in each community is committed to continue with support for families.

2. *They will use more volunteers*

The project that used volunteers plans to train more volunteers in order to serve more families. They will also involve the Jeffco Volunteer Caregivers to secure a volunteer coordinator to keep it going.

3. *They will secure other grants*

All the project directors are actively seeking other grants in order to support a paid coordinator. With a three-year record of administering a successful project, they now have a strong case for securing another grant. Many of the projects are developing interfaith groups in order to secure a grant. One project will become an Information and Referral service with the same Parent Coordinator running it.

4. *Collaboration will continue to be part of respite*

The communities that have a family preservation/family support program will take on this project. New groups of people like senior citizens and retired nurses will be contacted for involvement. One mental health agency will provide resources for respite.

"Respite is having someone you can trust, who has good training, without costing your mortgage."

Parent

SUGGESTED NEXT STEPS

Recommendations For Communities

Close the gaps that we know about

- ◆ Have **emergency respite** in home and out of home.
- ◆ Provide a **24 hour respite house** where children can be dropped off without planning ahead.
- ◆ Expand inclusive **before and after school care** options.
- ◆ Establish **summer and holiday programs** and activities.
- ◆ Secure **transportation** to and from respite and community activities.

From experience, start future community projects with these things in mind

- ◆ Start day one knowing where **future funding** will come from.
- ◆ **Include more parents** in the infra-structure.
- ◆ Know how to **market** the program.
- ◆ Have a **secretary** to do paper work and data collection, rather than the coordinator.
- ◆ **Realize the process of creating community respite is often slow and difficult** to live through but the results are worth it.
- ◆ Obtain providers that are involved in their **communities**.
- ◆ Have more **training** available for providers and families as needed and requested.

Future priorities suggested by families and project persons

- ◆ Recruit and train **volunteers** because families can't afford \$5-7 an hour.
- ◆ **Develop parent support networks.** Parents need to talk together, all children need to play together, not only those with disabilities.
- ◆ Have a **mentor program** for children with mental health issues.
- ◆ Reach out and include families who do **home schooling.** They need respite too.
- ◆ **Get information about respite available in all libraries.**

Recommendations For The State

- ◆ **Increase age limit** to include children of any age.
- ◆ **Develop a vision** for the next 5 months and 5 years. What do we really want, and how will it happen?
- ◆ **Recreation** for all children in all communities is needed. Develop a "Respite Ranch" and other recreation options.
- ◆ Provide **direct respite funding** to families to facilitate the development of their respite network.
- ◆ Tackle the big one now, **full time child care is needed for many families.**
- ◆ **Have a pool of money** for families to access. Families would pay what they could and the pool makes up the difference.
- ◆ Continue this support for **children with physical disabilities, mental illness and developmental disabilities.** It really works well and serves at-risk families.

