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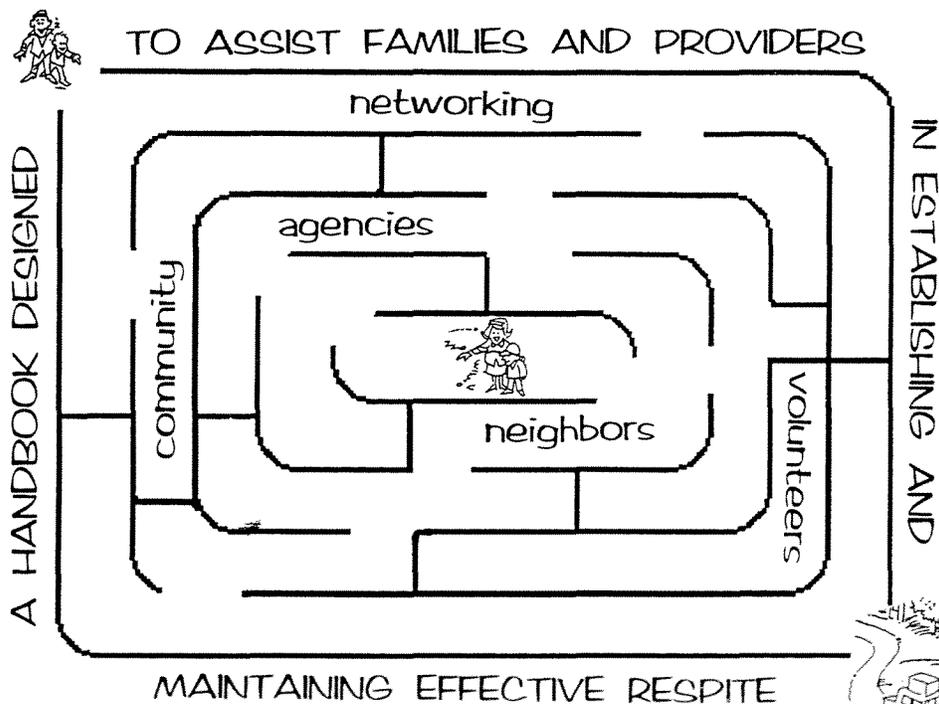


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WHERE IS RESPITE?

(res-pit: an interval of rest or relief)

The Art of Finding Temporary Care for Children and Youth with Special Care Needs



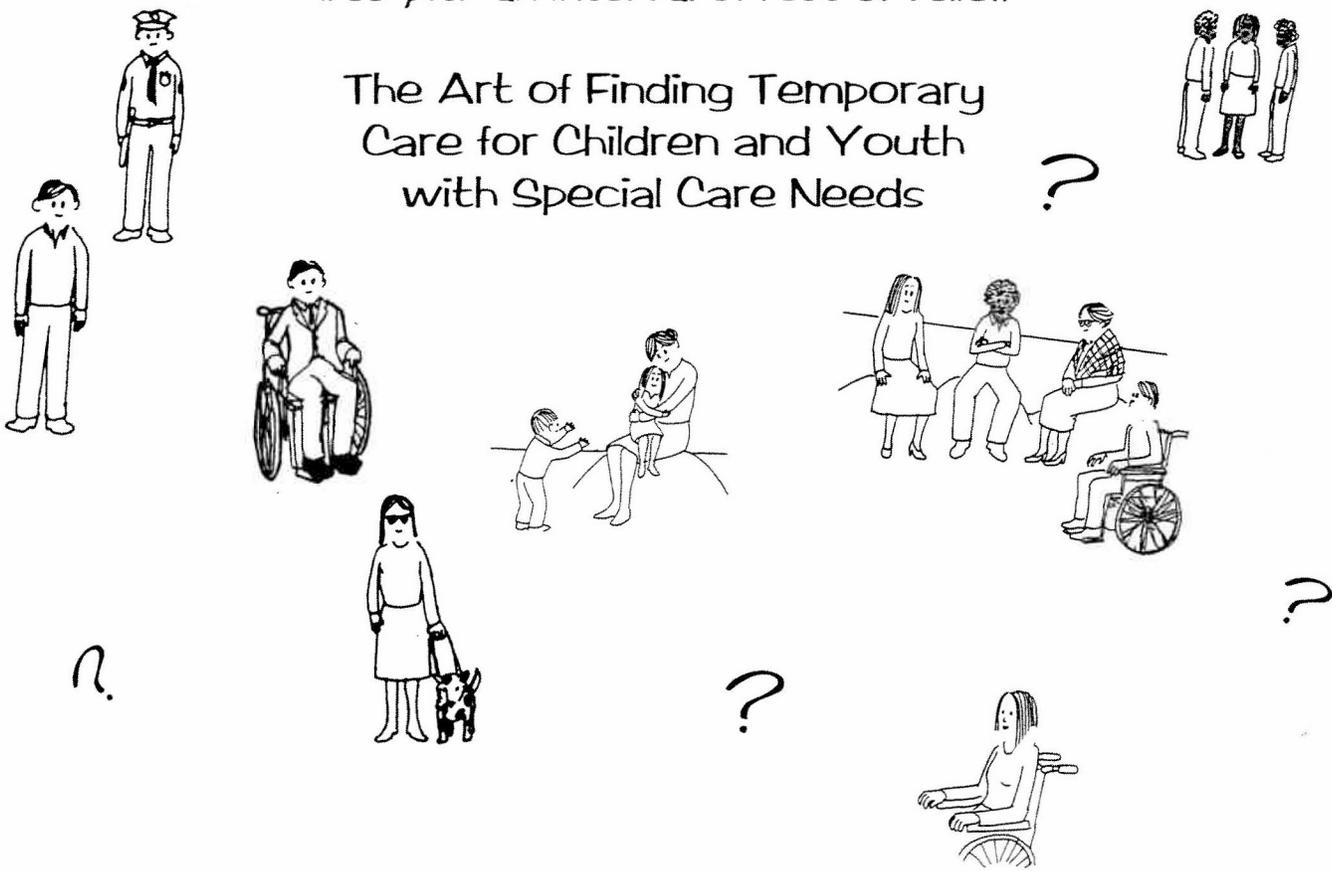
The Division for Developmental Disabilities
3824 W. Princeton Circle
Denver, Colorado 80236
(303) 762-4550

Promoting Community Connections and Family-Directed Respite Options in Colorado

WHERE IS RESPITE?

(res-pit: an interval of rest or relief)

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Care for Children and Youth
with Special Care Needs



Funding for this project provided by the Department of
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Promoting Community Connections and Family-Directed
Respite Options in Colorado

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Preface

Where is Respite? is a handbook about respite care in the State of Colorado. It is designed to be used by the following:

- Families of children and youth with special care needs who desire to utilize respite care
- Providers of respite care
- Any individual or organization that wants to learn more about respite care

The "Overview" chapter at the beginning of the book provides an orientation to the concept of respite care. The following chapters describe various models of respite care and processes for making respite care a reality. The concept of respite care is not new. It relies not only on formal but also informal processes. Thus networking, coalition building, and creativity take on special importance as we begin to make respite happen through out the state.

A grant was awarded in the fall of 1993 to the state of Colorado to create respite care alternatives and to increase the availability of respite care for families with children with developmental disabilities, mental illness or children with a chronic or terminal illness in both rural and urban settings. In order to expand the information contained within each chapter, appendices are located at the end of each chapter as well as illustrations and examples of forms, and other specific information related to the chapter.

Where is Respite? explains the various elements which contribute to the creation of respite options and the essential ingredients for successful respite partnerships among families, the child and the provider of respite care. The result is intended to be a "user friendly" set of materials which present the basic values and principles underlying respite care with a strong preference for the use of natural supports. These materials are not intended to be a substitute for sound judgment, but a complement to sound practices.

Where is Respite? defines five models of respite care. These brief descriptions will give you basic facts about each type of care and some of the pros and cons to consider. No particular type of respite care is inherently better than the others.

Families should be given choices in the types of respite options because individual circumstances and needs will vary. In any case, the type of respite matters less than the *quality* of care provided.

In order to expand the availability of the information contained in this handbook, we urge agencies who receive a copy of *Where is Respite?* to make additional copies for distribution as widely as possible. For this reason, the respite steering committee and the sub-committee both recommended that no copyright be attached to this handbook. We heartedly encourage that copies be made and shared with others in order to increase the circulation of the information contained herein.



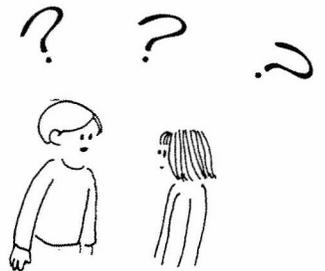
Acknowledgments

Heartfelt thanks are extended to members of the Respite Steering Committee for the State of Colorado for having the wisdom and foresight to spearhead this effort. It was their determination to meet the pressing need of Colorado families for accessible and affordable respite care statewide that led to the development of this manual. Through their forward thinking they identified and recommended needs to be addressed in the grant proposal; to Cynthia Trainor, Project Director, and Janet Wood for their hard work in completing and writing the grant proposal to the federal government. Grant #90-CN-132, "Promoting Community Connections and Family-Directed Respite Options in Colorado" was awarded in the fall of 1993, for a period of three years.

The completion of this handbook would not have been possible without the contributions of many people and organizations. Deepest thanks go to members of the special respite subcommittee who were directly responsible for contributions to the handbook and to the agencies who so generously shared their talents with us. They devoted their time, energy, expertise and knowledge of various collaborative systems involved in the development of this material. Merriam Smilley, Division for Developmental Disabilities, coordinated the subcommittee and was responsible for pulling together the material and writing the drafts for review. Subcommittee members who participated in the development of the handbook are: Neila Achter of the Colorado Office of Resource and Referral Agencies, Inc. and parent; Cynda Arsenault, author and parent; Jennifer Baggerly, Family Support Coordinator; Jefferson County Community Centered Board; Mary Garman, parent; Jo Lynn Osborne, Association for Community Living of the Foothills and parent, Pam Rodden, Division for Developmental Disabilities and parent, Agnes Sonnenfeld, parent; and Shelley Watson, Respite, Inc.

Finally, thanks must be extended to a number of others who also contributed their time by reviewing drafts at various stages of completion and making valuable comments and recommendations: Merriam Smilley, sub-committee chairperson; Cynthia Trainor, Division of Child Care, Respite Steering Committee chairperson; Janet Wood, Office of Health and Rehabilitation Services; Matthew Solano, Division for Developmental Disabilities and Jennifer Burnham, Office of Child Care Services/CORRA.

OVERVIEW



WHAT IS RESPITE?

Respite care is a broad term referring to the temporary care of a child with disabilities (or any child who has special care needs), for the purpose of offering relief to his/her family. Respite may be provided by friends, neighbors, relatives, volunteers, skilled care providers, licensed child care or professionals in the child's home or in another location. Respite care may be provided for an hour, a day, a week-end, a week, or several weeks. It should not be viewed as necessary only for emergency or crisis situations but incorporated into daily life. Respite care is care provided by people who care and are willing to learn any special care required for children.

Respite care means "time off" for parents. It means that the child is cared for by a concerned, well-trained respite provider while parents relax, go shopping, attend a meeting, visit a friend, go out for dinner, take a weekend trip or take care of themselves in some other way.

Respite care is a support to the family, not only to the child who is the usual focus for other supports. It is a support that allows time to re-energize, deal with an emergency, or engage in personal, social or routine activities and tasks that otherwise may be neglected, postponed, or curtailed due to the demands of caring for a child who has special care needs. Two primary objectives of respite care include supporting the continued presence and participation of a child with a disability within the family and giving parents a "break" from the continuous tasks and pressures of caring for a child with special care needs.

Respite care can take many forms and may have many different looks. In some instances, respite care is provided in the home. In other instances, respite care is provided in someone else's home, with a volunteer while participating in regular community activities or by community organizations. Many models and creative variations of respite care exist and can be developed or arranged by agencies, parents and the community to provide effective care.

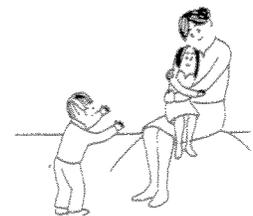
WHY IS RESPITE IMPORTANT?

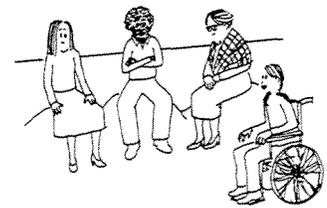
All parents need time away from their parenting responsibilities. Parents of children with disabilities may need this time off even more than other parents do. The extra demands made on parents by a child with special medical, physical, emotional and/or educational needs make respite care a necessary part of that family's life. Yet, many parents say they feel guilty about seeking and using respite care. They feel they should be able to manage all of their child's care, and that if they seek help they will be shirking their responsibility. Some parents feel that if they seek respite care, they may be considered inadequate parents. This is definitely not so. Time spent away from the child with special needs is very important for the parents, the child, and for the rest of the family. They need to have time to nurture themselves, to pursue personal interests and other relationships. This contributes to good physical and emotional health and allows families to continue successfully caring for their children at home. Respite care helps in the prevention of "burnout". A healthier mental outlook and balance are more likely to be maintained in families utilizing respite.

As children grow, most increase in independence and seek more and more time away from parents. This increased independence should also happen for children with special needs. In many cases, this normal, natural transition does not happen without specific planning.

Respite care is not the answer to all the needs of the child and family. It is only one of many options and/or strategies needing to be available from which families can choose on the basis of their changing needs. Respite is essential because if it is NOT utilized, children may end up needing out-of-home placement. Respite care may also diminish the risk of abuse and neglect caused from "burnout". The goal of respite care is to provide the most normal and natural type of support necessary to help the family maintain the child in their home and to maintain a healthy, nurturing and functional family life for all family members.

Children need to be kept in the most natural family-centered settings, which means their home, their natural environment and local community. Emphasizing these ideas will allow for the most individualization for the child. The chances are greater for respite care to be successful for the child and the family, if the family is in control and they have choices that support this basic premise. Family-centered respite care allows the child to be in familiar surroundings in the home and in their local community.





CRITICAL FACTORS AND VALUES

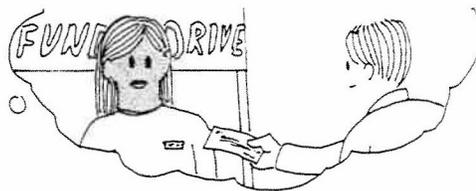
The qualities important for respite care providers are that they be caring, demonstrate open communication, be responsible and respectful to others, as well as sensitive and creative in caring for a child. Respite care providers may be parent cooperatives, a neighbor, or volunteers. They may be paid for their work through an agency serving a number of families or through a licensed child care provider. In any case, they should be provided the information they need in order to safely and effectively work with families with children who have special needs. This can be done in a formal training or informally on an "as needed" basis.

A three-way partnership must be developed between the child with a disability, the parents and the provider of respite care. Good providers will gain an appreciation for what families experience and understand what it is like to live with a child who has physical, developmental or emotional needs. They will recognize the struggles and pain families experience as well as their flexibility, resilience, courage and endurance. It is helpful for the provider to give feedback to the family, provide emotional support and acknowledge that each family member has his/her own needs. Family members provide information to the provider and participate in open communication regarding needs, routines and preferences.

Respite providers will acknowledge from the onset that children and families are unique. Respite care will be effective if the provider listens in a non-judgmental way to the child and their parents. A certain level of informality must be established to break down any barriers or perceptions that families may have regarding the provider's role. This will only be accomplished when the provider is seen by the family as truly an ally. The process of building a partnership takes time and has to be paced by the family. When the interaction between the family, the provider, and the child is comfortable and sharing of information is the norm, it is very likely that all involved will know that "partnership" has been accomplished.

Once this partnership has been developed, the establishment of ongoing utilization/contact will be easier. The child and their family will increase in confidence that they can meet the challenges they face. Providers need information in order to develop a view and attitude which is sensitive toward parents and the stages families go through in dealing with their child's disability. If respite care providers are going to be effective, they must be aware of these issues and find ways to respond to them with sensitivity. It is most useful to view the parents as the experts. Parents are the people who know the most about their child and family. Parents can be the most positive, most useful resource to the provider.

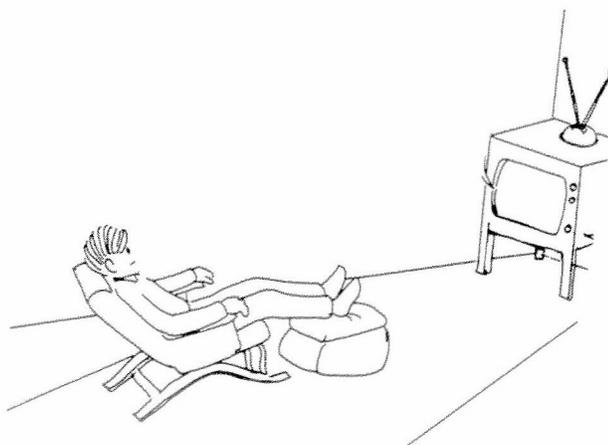
NATURAL SUPPORTS



Respite Care provided by natural supports includes services that are not primarily intended for respite care. However, they do provide parents a "break". These are sometimes referred to as "secondary respite services" and include organizations such as the boy scouts and girl scouts, schools, school programs, licensed child care centers, camps, religious groups, civic and community organized activities and other activities routinely available to the general population. Particularly as a child grows older, it is natural to be more involved in community activities rather than solely dependent on care providers as "baby sitters".

When viewing these resources as providing respite for families of children with disabilities, the issue may be assurance that all children have access to them. If children are excluded because of behavioral, physical, or other difficulties, then programs can often be easily adapted so the children can be included. Involving children in community programs and activities can be a way for parents to receive some respite time. The following are some of the advantages of using natural community supports:

- It is more natural and a part of the lives of all children, not just children with disabilities, and therefore increases inclusion.
- There may be socialization experiences and learning opportunities.
- Community inclusion tends to increase the community's willingness to be supportive.
- There will be an opportunity to participate in community and family activities that are not designed specifically for children with special care needs but are designed for all children in the community.





RESPIRE CO-OP



The family co-op model is based on the exchange system. Parents and/or family members agree to provide respite care to other families in return for respite care for their own family member. The idea usually begins in a neighborhood or small town or community. The simplest form of respite care co-op involves two families who exchange a similar number of respite hours. Sometimes the exchange may be agreed upon for other types of services than respite care. A family needing respite may exchange house-sitting, meal preparation, or home maintenance with another family. Families may make these arrangements informally or they may sign up with a sponsoring organization or community group.

Co-ops of different types have been operating in the community providing "win-win" situations for a long time. Respite care co-ops have been established within communities by families wishing to work together to maintain quality care that is easily accessed, without dollars attached. They can provide flexibility, in that a family could use the respite care co-op for just an afternoon and/or an evening out, or they could go on vacation for an extended time. With the co-op model, families learn to make respite care a part of their daily living. It can be a way to manage family stress and exhaustion that can be part of raising a family. The respite care co-op is more than respite care. As families take turns caring for each other's children, they often become a support group to one another. Family members find it very helpful to know and talk with other co-op families. Along with providing respite care and supporting each other's respite needs, families begin to cooperate in handling problems and finding resources. Ultimately the respite care co-op can be a way for families to expand their community.

Regardless of the type of co-op, safety checks and training are not required and no oversight is provided by regulatory agencies.

Possible Advantages:

- The co-op can be designed to meet your community's needs.
- It enables families who need a break to exchange other skills for respite.
- Families who do not have a child with disabilities are encouraged to participate.
- This is an excellent model for families in more rural areas.
- The child remains in their own community or neighborhood.
- This is a "no cost" way of receiving respite care.
- All children in the family are eligible for the co-op.

- Families become comfortable leaving the children in the care of another family because trust and predictability can be established.
- There is more opportunity to meet other children from families that have family members with special care needs and/or who do not have family members with special needs.
- Friendships have more chances to develop.
- Participants can be selected at the discretion of current participants.

Possible Disadvantages:

- A reciprocal commitment on the part of the family is required.
- A number of families are needed to participate or there may not be an adequate amount of flexibility and/or availability of respite care.
- Distance may be great between families.
- Hours traded will be similar only if families participate.
- Keeping the information and training updated may be time consuming.
- Scheduling training for new families after initial training of co-op members has been completed can be difficult.
- Someone must be responsible for tracking hours used and given by each family in the co-op.
- Careful interviewing and screening of persons and/or families interested in participating is a vital precaution.

Different Types of Respite Co-ops:

- **Neighborhood co-ops** may already exist and may include children with or without disabilities.
- **Informal community networks** may take many forms. Generally, they are neighborhood or small community centered. Frequently, families who participate know one another or have mutual friends.
- **Inclusion co-ops** bring together families in the community who want to include all children. This type of co-op would acknowledge and address individually the needs of the children receiving care. Having a child with special care needs would not be a barrier. Typically, families in an Inclusion Co-op would be families seeking a diverse experience for their children.
- **Agency coordinated co-ops** may be operated for all children or may be specifically for children with only certain types of disabilities and are coordinated and supported by a centralized agency.

Recruitment and Selection:

- Contact the Resource and Referral System office (see **Appendix VI B, page 40**).
- Find out what is already available in your community. Contact the local "Welcome Wagon", the Community Centered Board (see **Appendix IV A, page 22**), the Community Mental Health Center (see **Appendix IV B, page 23**), or MOPS (Mothers of Pre-Schoolers) **(303) 733-5353**. If what you want does not exist, search out other parents with similar interests and develop it.
- Contact parents through parent groups, Interagency Councils (see **Appendix III B, page 17**), churches, synagogues, service organizations, and clubs.
- Encourage the community to come together to brainstorm ideas of meeting community respite needs.
- Post times for organizational meetings at grocery stores, libraries, churches, synagogues, recreation centers, etc.
- Place articles in newsletters and local newspapers. This way of recruiting should be accompanied by interviews, screening of applicants and background checks, especially if the person is not known to the family.
- Make contacts through the schools.
- Contact parents of children in the neighborhood.



STATE AND FEDERAL REQUIREMENTS:

This is a legally exempt style of child care. There are no requirements for licensing by either state or federal agencies.

Families and providers may contact their local health department and fire department for information regarding requirements that may be applicable to the particular situation.

Families and providers may contact their homeowner's or renter's insurance company for information regarding coverage applicable to the situation.

COMMUNITY & RECREATIONAL PROGRAMS -- OPPORTUNITIES USED FOR RESPITE CARE

Most communities have some type of community and recreational programs for their youth. Although not traditionally thought of as respite, these programs can be a wonderful source of activities and social time for children with disabilities. A side benefit is that parents who use respite and get to have a break, or time away from their child.

Possible Advantages:

- Friendships
- Recreation
- Health and fitness
- New skills
- Opportunities for all ages
- Great for older kids--a chance to meet kids their own age and participate in age appropriate activities
- Potential for developing additional supports among community members
- Programs are already in place
- Once set up, can provide long term opportunities
- Increased independence for the child
- The child "has a life" of his/her own rather than always needing to be "cared and provided for"



Possible Disadvantages:

- Requires education of the people who run the programs
- Needs to be based on the individual child and his/her particular interests and abilities
- May be met with resistance or rejection before the right situation is found
- Most programs charge a fee to participate, plus additional costs might be required for supports, materials, activities

Some of the following programs listed here (such as City Recreation Department or YMCAs) may already offer programs for people with disabilities. This might be in the form of separate classes for specific needs and interests, and/or providing support for people to take part in regular program activities (see **Appendix III A, page 14**).

There may also be specialized programs such as therapeutic horseback riding, dance or theater for people with disabilities, Artreach, Special Olympics, etc. Some churches or religious organizations offer special religion classes for children with disabilities (see **Appendix III B, page 17**). These specialized services can be found in the yellow pages or through your local agencies serving people with disabilities. Non-profit organizations such as Easter Seals and the American Lung Association hold specialized summer camps.

However, don't limit yourself to only "special" programs when you are exploring community and recreational opportunities as a potential for respite. Meet with the director or instructor of any program to discuss exactly what would need to happen for a specific child to successfully participate in a specific program. You may be surprised at how easy it can be. Perhaps they have never been asked before and are glad to create new opportunities. Sometimes only minor modification of a class might be necessary (raising or lowering a table, modifying equipment, etc.). Other times more extensive support such as full assistance is needed to participate. This is when you may need some creative recruitment techniques and some education of the community program about inclusion, the Americans with Disabilities Act and the value of belonging.

The following books are helpful to read before approaching people and perhaps taking along some articles to leave with them:

Arsenault, Cynda, (1990), **Let's Get Together: A Handbook in Support of Building Relationships Between Individuals with Developmental Disabilities and Their Community**, available through the Developmental Disabilities Center, 1343 Iris, Boulder, CO 80304.

Wetherow, David, Ed. (1992), **The Whole Community Catalogue: Welcoming People with Disabilities into the Heart of Community Life**, Communitas, Inc., Box 374, Manchester, CT 06040.

Programs and Activities to Consider for Potential Respite:

- City and County Recreation Programs
- Y.M.C.A./Y.W.C.A.
- Special Olympics/Unified Sports
- Youth Groups--Girl/Boy Scouts, 4H, Campfire Girls, etc.
- Team sports--hockey, soccer, baseball, etc.
- Before and After School Clubs and Activities
- Neighborhood baby-sitting co-ops
- Play groups, kids clubs
- Community schools--after-school child care and/or classes
- Churches--either participation in church sponsored events (religion classes, socials, volunteer activities) or using church members as an assistant or companion in other activities outside of church (see **Appendix III B, page 17**)

- Mall Walkers (often sponsored by local hospitals)
- Volunteer organizations--volunteering with a group (picking up highway trash, stuffing envelopes for a political candidate, going with the Optimists to visit seniors) can provide a valued activity with group support.
- Health Clubs--A good source of respite for younger children if the parent is a member. Free child care included in membership allows the parent to train, and to be close by if needed. For older children membership provides opportunities for participation in classes (aerobics, weight lifting, etc.).
- Bowling Alleys, Sport Centers--Some have child care for younger children, older children can participate on leagues, teams, etc.
- Summer camps--Specialty camps such as Lions Club, Easter Seals, American Lung Association, etc. Also consider all regular camps which may also work with the right preparation.
- Clubs--Backpackers Club, Angling Club, Folk Dance, Bird Watching. Find something the child has an interest in.
- Private classes/lessons--karate, dance, drama, horseback riding, etc.
- Being with friends--going to the park, hanging out at the mall, pinball arcades, going out to dinner, movies, friends' homes, sleep-overs.

Recruitment and Selection Ideas:

- Contact the "main office" or "central office" rather than ticket offices, when contacting agencies or organizations regarding the donation of tickets, special accommodations, etc.
- Advertise for volunteers. A program or agency may be able to offer such benefits as free registration for the class or activity when providing assistance for another student.
- Former class participants may wish to come back as a volunteer.
- Consider collaboration between the Community Centered Board, ACL or other disability agency and a recreation program. The agency or program provides the staff, recreation provides the location and activity--a Respite Day or Night and/or assisting to take general classes.
- Train the Trainers in some groups, such as Girl Scouts, train leaders on ways to include kids with disabilities. Other programs may have a designated person for ADA or other disability issues. These would be good people to enlist in discussions.
- Provide an assistant (paid by the family or a friend may volunteer).
- Encourage friends from school who may be able to take the class together.

- Work with the schools. If appropriate, recreation/leisure activity after school may be included in the IEP, school staff may train others in providing assistance, curriculum adaptation, etc.
- Form a partnership with the school for extended school year programming (school provides aides, training; recreation program provides activity, staff).
- Work with local high schools, colleges and universities for students (recreation, education, kinesiology majors, etc.) to receive credit for interning as a person's assistant/aide.
- Work carefully with the instructor of a class or program to brainstorm ways to get the necessary supports in place.
- An instructor may invite the whole class to participate in ways to provide the supports necessary to include someone new. Since many people taking recreation classes do so as a way of meeting new people, this approach can often serve to pull a group together and break down barriers. (E.g., "Susan is a new student in our pottery class but may not be able to finish her work without help. Any ideas on how we can help her?" "John is a new baseball team member but has a tendency to wander off. How can we make sure he stays on the field?")
- Use existing support people in an individual's life: an occupational therapist might be able to go with a teenager to a pottery class, introducing him/her to other class members, modeling and training the teacher and others on how to assist him/her in the class.
- Brainstorm with a child's Circle of Friends or family friends to get ideas for recreational opportunities the child might like. Who has contacts, who can go with, how to get supports? The more people thinking about resources, the more likely to find them.
- Ask family and friends to give the gift of their time and friendship (for a birthday, Christmas, graduation present) by taking a child who can go with them the next time they go on an outing (movies, swimming, shopping mall, etc.).
- Find groups of people who do things on a regular basis (jogging, walking, fishing, dinners, etc.) See if, as a group, they might be able to incorporate the inclusion of a child/teenager into their activity, e. g., a woman who walks her dog every evening at 6:00 may enjoy the company of a child who uses a wheelchair, giving the mom a chance to prepare dinner. A high school student who practices for the band every day may be able to entertain a child who likes music. This could be mutually beneficial to everyone--the child's mother gets out to the grocery store, the band student's mother gets a break from listening to practice.

- Survey all the people involved in the child's life for extracurricular activities, interests and connections: the aide at school might teach a drama class on weekends, a teacher might coach Little League, a speech therapist might be a Girl Scout leader, a nurse might take an aerobics class. Explore the possibility of that person facilitating the inclusion of the child into the group.
- Utilize Family Support Funds to pay for an assistant in class or during an activity.
- Use other traditional ways of finding volunteers (senior groups, notices, church or synagogue groups, clubs and organizations, etc.). Rather than just providing respite in the home, the volunteer can serve as an enabler, building connections to other kids/adults in the community through the activity.
- Develop a flyer that can be handed out to others or distributed around the neighborhood. Maybe an art or marketing class can help design it.
- Tap into existing networks--Employers who have volunteer pools, churches with social committees, neighborhood associations, support groups, bulletin boards, newsletters, directories, community resource centers.
- Contact clubs and associations that do things on a regular basis--Bingo (an older child might be the one to draw out the numbers, stack chairs, collect cards), Adopt a Highway, recycling collection, etc.
- Use common interests to promote connections and activities--e.g., talk to fishing clubs about the boy who loves fishing and needs someone to go with him.

STATE AND FEDERAL REQUIREMENTS:

- Community and recreational programs will have their own requirements and regulations. Request information from the director or the person in charge of the program.
- ADA (Americans with Disabilities Act) will apply to these programs (see "Resources List", page 61).
- When family members directly hire their own care provider, they act as an employer and provide payment for services. Families need to be aware of the requirements of IRS Publication 926 "Employment Taxes for Household Employers".

- Respite programs which contract with providers to care for children in their homes or the family's home, should inform them that as independent contractors they must comply with IRS code requirements for the self employed. All federal, state, and local taxes must be paid by the independent contractor.
- Families and providers may contact their local health department and fire department for information regarding requirements that may be applicable.

APPENDIX III A

WHEELCHAIR MOBILITY ACCESS GUIDE

The areas listed below have reasonable access for persons with a physical disability or for persons who use a wheelchair. However, it is advisable to have another person along for assistance if needed.

Animas River (Durango)	Located on 3rd Street in Durango. Wheelchair accessible parking and angler path.
Barbour Ponds State Park	7 miles east of Longmont on HWY 119 at I-25. Wheelchair accessible fishing pier. For information contact the state parks office at (303) 866-3437.
Big Thompson River	Access area is located 17 miles west of Loveland on HWY 34. Wheelchair accessible parking and fishing pad.
Boyd Lake State Park	Located 2 miles northeast of Loveland. Wheelchair accessible trail and fishing area. For information contact the state parks office at (303) 669-1739.
Buffalo Creek Fishing Access	US 285 to Pine Junction, then south on 126 for 10 miles. Wheelchair accessible trail and fishing along stream. For information, call (303) 236-7386.
Casey's Ponds Steamboat Springs	Chamber of Commerce Visitor Center. Wheelchair accessible asphalt trail and fishing pier.
Centennial Park Lake	Denver metro area, on South Decatur Street. Wheelchair accessible trail, parking and fishing pier.
Chatfield Reservoir	Located southwest of Denver off of C-470. Paved trail to fishing on river and accessible fishing pier on reservoir. For information, contact park office at (303) 791-7275.
Cherry Creek Reservoir	Located in Aurora at Parker Road and Quincy Avenue. Wheelchair accessible trail, accessible restroom and fishing pier. For information contact the park office at (303) 690-1166.
Chipeta Lakes State Wildlife Area	Located 3 miles south of Montrose. Wheelchair accessible parking and angler path.
Curecanti National Recreation Area	Located west of Gunnison on US 50. Wheelchair accessible restrooms and river fishing on the "Neversink Trail". For information, call (303) 641-2337.
E. B. Raines Park	Located on the Community Center Drive in Northglenn. Wheelchair accessible parking, paved trail and fishing pier. For information, call (303) 450-8720.

Eldorado Canyon State Park	Located 8 miles southeast of Boulder. Wheelchair access to picnic/fishing area near creek. For information call the state park office at (303) 866-3437.
Elevenmile State Recreation Area	Located 45 miles west of Colorado Springs on US 24. Wheelchair accessible parking, restrooms and fishing. For information, contact the park office at (719) 748-3401.
Fountain Regional Park	Located in the city of Fountain. Wheelchair accessible parking and fishing piers.
Frying Pan River	Wheelchair accessible area located 15 miles east of Basalt on the river. Paved casting areas along the stream. For current information call (303) 963-2266.
Georgetown Lake	West from Denver on I-70 at Georgetown. Wheelchair accessible for parking, ramp and fishing pier.
Golden Gate Canyon State Park	15 miles west of Golden on County Road 70. Wheelchair accessible trail and fishing on stocked trout pond. For information contact the state parks office at (303) 866-3437.
Highline State Recreation Area	Located 20 miles west of Grand Junction on I-70. Wheelchair accessible fishing. For information call (303) 866-3437.
House Creek Recreation Area	25 miles north of Dolores. Wheelchair accessible restrooms, camping and fishing near the marina on McPhee Reservoir. Information available from the US Forest Service at (303)862-7296.
Island Acres State Park	15 miles east of Grand Junction. Accessible fishing piers. For information contact the state parks office at (303) 866-3437.
Lake Estes	On US 36, 1 mile east of Estes Park. Gravel roadside turnouts for fishing. For information call 1-800-654-0949.
Lake San Isabel	West of Rye on Hwy 165. Wheelchair accessible parking and trail to lake (.25 mile).
Lathrop State Park	Located 3 miles west of Walsenburg. Accessible restrooms and fishing area by the outlet of Martin Lake.
Quincy Reservoir Aurora Parks	Southeast of Aurora on Quincy Avenue. Accessible pier and parking. For information call the Aurora Parks at (303) 699-3907.
Pueblo Lake Recreation Area	Located 6 miles west of Pueblo. Fishing pond with paved path and fishing pier. For information call the state parks office at (303) 866-3437.

Rifle Falls & Rifle Gap State Park	North of Rifle on HWY 325. Accessible stream and lake fishing. For information call the state parks office at (303) 866-3437.
Rocky Mountain National Park	Located on US 34 or 36 west of Estes Park. Accessible trails, fishing and Braille guides. For information call (303) 586-2371.
Runyon Lake	Located on Santa Fe Avenue in the city of Pueblo. Accessible parking and fishing pier.
South Platte Park Ponds	Located on south Sante Fe Drive at C-470. Accessible docks and trails.
Steamboat Lake State Park	25 miles north of Steamboat Springs. Accessible area near the marina for fishing. Contact the state parks office at (303) 866-3437.
Stillwater Reservoir	Located 15 miles southwest of the town of Yampa. Access to restrooms and fishing pier in the National Forest. For information call (303) 638-4516.
Sweitzer Lake Recreation Area	Located southeast of Delta on US 50. Accessible restrooms, camping and fishing. For information call (303) 866-3437.
Two Rivers Park	Downtown Glenwood Springs. Accessible fishing at the City Park for the Colorado and Roaring Fork Rivers. For information call (303) 945-6589.
Walden Pond	Located 4 miles northeast of Boulder. Accessible dirt trail and to fishing areas. For information call (303) 441-3950.
Washington Park	Located at Downing and South Louisiana streets in Denver. Accessible restrooms, trails and fishing areas. For information call (303) 575-2775.
Yamcola Reservoir	Located 15 miles southwest of the town of Yampa. Gravel trail which is wheelchair accessible. For information call (303) 638-4516.

APPENDIX III B

On July 13, 1993, the Robert Wood Johnson Foundation announced a massive national program that makes available up to \$23 million to start-up more than 900 new Interfaith Volunteer Caregivers Projects nationwide over the next four years. The program, FAITH IN ACTION, provides start-up grants of \$25,000 to interfaith coalitions to establish projects providing home-based volunteer services to any individuals in the community with chronic health conditions.

In addition to providing start-up funding for the Interfaith Volunteer Caregivers Projects, the Program will offer direct and intensive technical assistance to any congregation, individual, or group interested in developing and organizing a project. The staff of the National Federation of Interfaith Volunteer Caregivers, Regional Facilitators, and monthly regional technical assistance workshops will all be operating to help congregations develop strong and effective projects. The Federation will also assist groups in making application to the program.

For additional information, please contact:

National Federation of Interfaith Volunteer Caregivers, Inc.
368 Broadway, Suite 103
P.O. Box 1939
Kingston, New York 12401
(914) 331-1358

IN-HOME RESPITE CARE



For our purposes, we are defining in-home care as child care done in the home. This may be either part-time or full-time. There are many ways to create in-home respite care. This usually involves a person trained to provide respite care to children and youth with special care needs. The respite provider comes into the family home and cares for the child. When either a family member or a volunteer is used or someone is hired to work in the home, specifically to take care of the child(ren), that is called in-home care. It is an employer-employee relationship where the parent sets the hours, the responsibilities, and the rate of pay. The parent may want to ask the caregiver if s/he is willing to perform duties other than child care, such as cooking, housekeeping, or laundry. A caregiver can be hired to work part-time or full-time or to live in the family's home. In some cases, one or more families may get together to hire an in-home caregiver for a "shared-care" arrangement in one family's home, or rotated on a weekly or monthly basis from home to home.

In-home caregivers are referred to by a number of different titles: baby-sitters, nannies, au pairs, caregivers, respite providers or mother's helpers. You can look for an in-home caregiver on your own or go through agencies that specialize in placing people in these positions.

Initially, parents may feel self conscious about their home. They may be anxious about whether or not the worker will respect their property. Both parents and workers need to realize such feelings are a normal, natural part of adjusting to in-home respite care. Providing care in the home may be a very comfortable and gratifying experience for all. Having a clear understanding about expectations, routines, wishes, guidelines and information regarding the child and his/her home goes a long way in making the experience a positive and rewarding one. With experience, providers and parents will usually be less apprehensive. Once they get past these initial apprehensions, providers frequently see that many of the skills needed to provide respite care in a family's home are based on common sense.

Many families prefer this type of respite care, especially since it means the child can stay in his/her natural surroundings. There are some issues to consider. For instance, where do the parents go? The family is either occupied in other pursuits in or around the home or the family leaves while the provider and the child(ren) remain at home. Both informal and formal networking may result in the development of respite care in the home. Informally, friends, bulletin boards, church or synagogue groups, and civic organizations may be places to begin to look for ideas and sources. Formal systems exist in the form of agencies that specialize in respite care. Different types of in-home respite care typically have different characteristics to be considered. For example:

1. **Agency Provided Services:**

- Provider is an employee of an agency.
- Generic training has already been provided.
- Twenty-four hour service may be available.

2. **Sitters/Companions:**

- Special, specific training is done by parent(s).
- This is the most prevalent of respite care options.
- It is either planned or on an "as needed" basis.
- Payment varies-family or agency may pay the provider.
- Sibling care may be available.
- Specific skill development may also be provided to the child.
- The level of training and experience will vary.
- Family chooses the provider.
- Provider is paid by either the family or agency.
- Parents provide direct training to the provider.

Possible Advantages:

- Preparation for respite care is minimized in that the parent(s) do not have to "pack up" the child in preparation for being away.
- Surroundings are familiar to the child(ren) since s/he remains in their own home.
- Adaptive equipment is more readily available to the child and the provider.
- Adaptive environment is present and may provide additional comfort and safety for the child and be a convenience for the provider.
- Disruption to the child's "normal" routine is minimized.
- Sibling care is more accessible.
- Back-up systems may be easier to establish.
- Long-term relationships may develop between the family and the provider.
- Bartering for fees may be a possibility.
- Transportation for the child is not a problem or an issue.
- Parents have more decision making power in selection of the provider.
- Hours that are more unusual (i.e., very early in the day or very late at night) may be easier to accommodate.



Possible Disadvantages:

- Taxes and Workmen's Compensation issues need to be explored and clarified.
- There are no particular qualifications or licenses required for in-home caregivers, so parents must rely solely on their own judgment.
- Liability may be greater for the family and the child if the person is a stranger.
- Colorado Bureau of Investigation checks need to be initiated and completed in order to rule out additional risks (CBI phone number: **(303) 239-4230**).
- Transportation may have to be provided by the family for the provider.
- Parents must leave or be otherwise occupied.
- Arrangements may not be accessible in an emergency.
- Parents may have to "prepare" the home and "get things ready" for the provider.
- If the in-home provider is late, sick, or leaves without enough notice, the family may be inconvenienced.
- Involvement with other children may be more difficult. There may be a tendency toward isolation from others.
- Insurance such as homeowner's or renter's insurance should be maintained.

Recruitment and Selection Ideas:

- It is important that quality interviews be conducted to assure that a comfort level is reached and that both the family members and the provider have reached an acceptable level of satisfaction in the arrangement. (See **Appendix VII G, page 52**)
- Reference checks, though time consuming, need to be completed.
- Church Groups, Interfaith Coalitions (see **Appendix III B, page 17**) Civic organizations, such as Camp Fire Girls, Boy/Girl Scouts, etc., engage in service projects such as respite care.
- The local Community Centered Board (see **Appendix IV A, page 22**) or the Community Mental Health Center (see **Appendix IV B, page 23**) may know of respite resources.
- Neighbors and friends may be interested in providing care or know of others who might be interested.
- Senior Citizens' organizations often have a program of volunteers or lists of persons interested in part-time work.
- Refer to the "Information Sheet for Persons Seeking Respite Services" for additional ideas (see **Appendix VII F, page 51**).

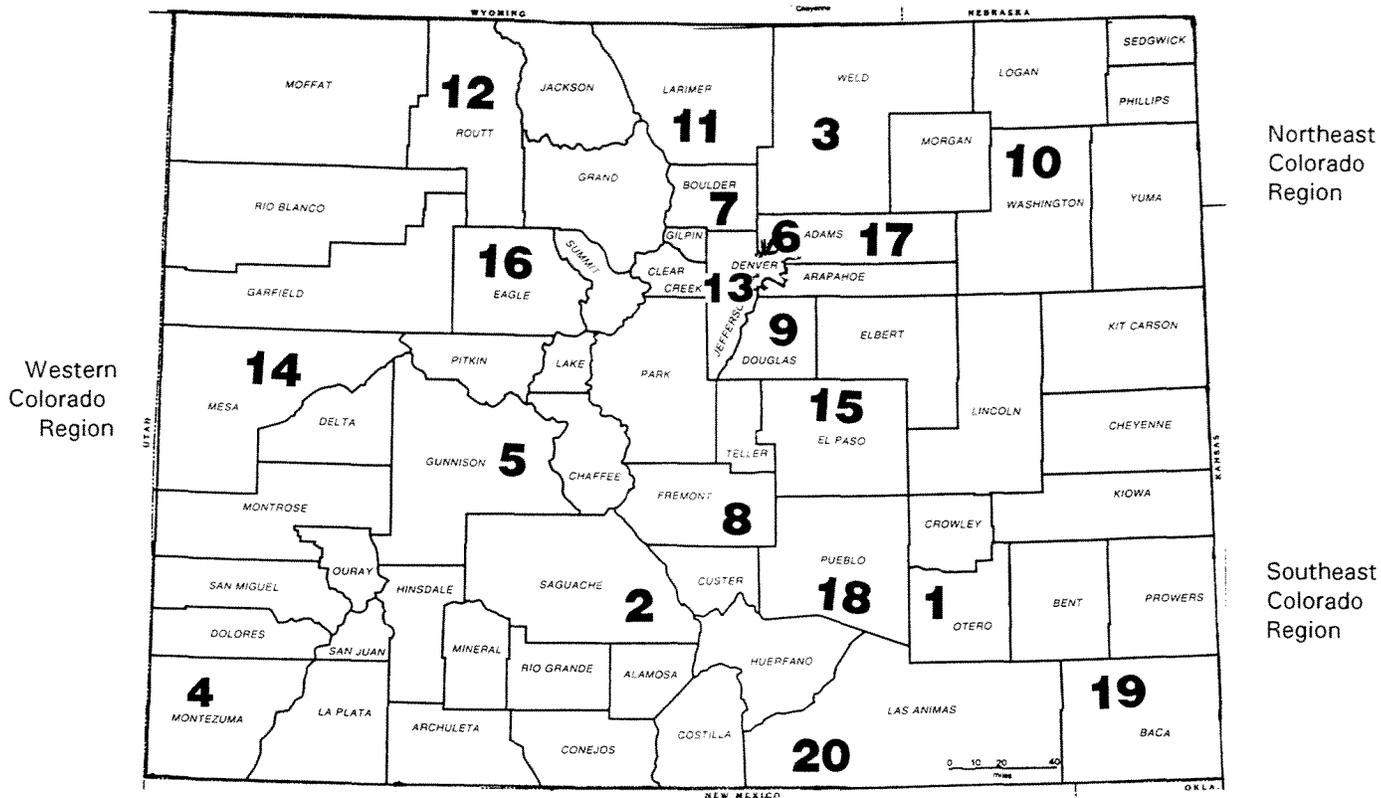
- Organizations who teach CPR and/or First Aid may have lists of certified persons.

STATE AND FEDERAL REQUIREMENTS:

- When family members directly hire their own care provider, they act as an employer and provide payment for services. Information can be obtained about these requirements by contacting your local IRS office and requesting a copy of IRS Publication 926 "Employment Taxes for Household Employers".
- Respite programs which contract with providers to care for children in their homes or the family's home, should inform them that as independent contractors they must comply with IRS code requirements for the self employed. All federal, state, and local taxes must be paid by the independent contractor.
- Families and providers may contact their local health department and fire department for information regarding requirements that may be applicable.

APPENDIX IV A

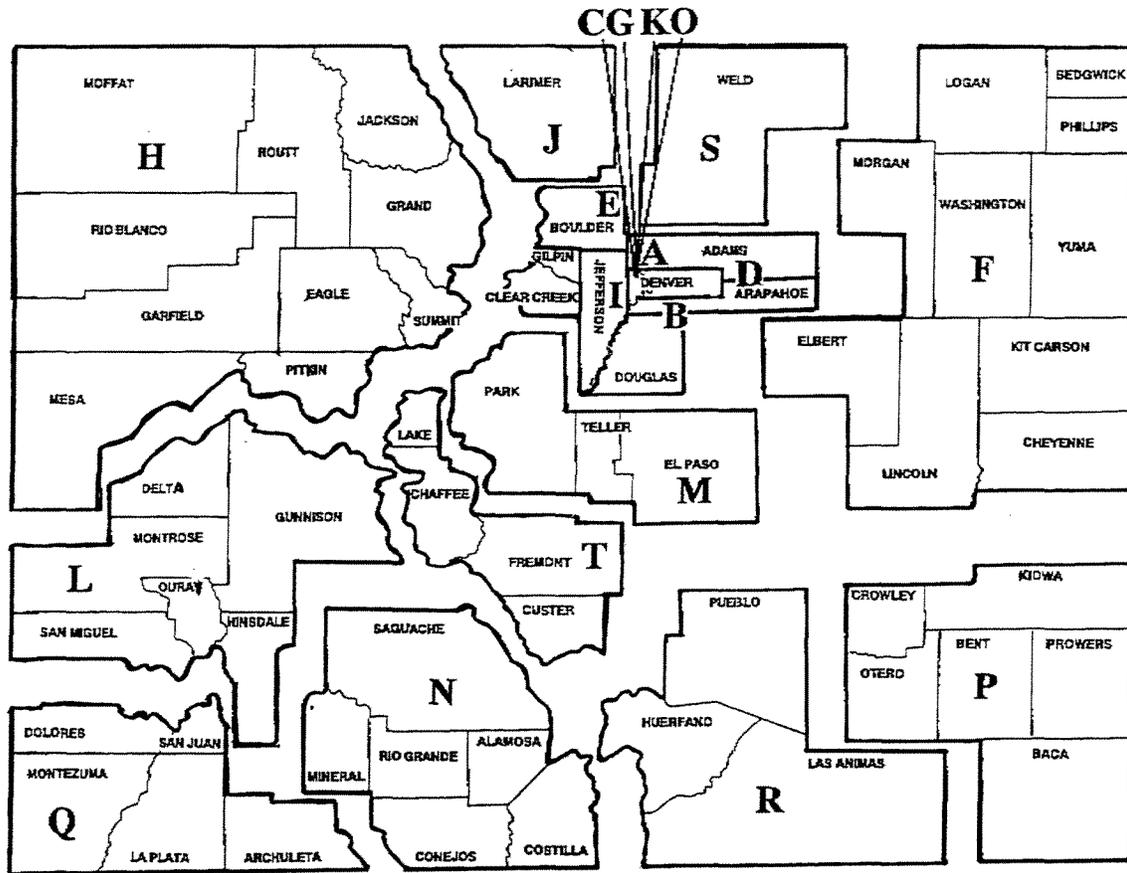
COLORADO COMMUNITY CENTERED BOARDS AND THEIR DESIGNATED SERVICE AREAS



1. Arkansas Valley Community Center, Inc. (719) 384-8741
2. Blue Peaks Developmental Services, Inc. (719) 589-5135
3. Centennial Developmental Services, Inc. (303) 339-5360
4. Community Connections, Inc. (303) 259-2464
5. Community Options, Inc. (303) 249-1412
6. Denver Options, Inc. (303) 753-6688
7. Developmental Disabilities Center, Inc. (303) 441-1090
8. Developmental Opportunities, Inc. (719) 275-1616
9. Developmental Pathways, Inc. (303) 360-6600
10. Eastern Colorado Services for the Developmentally Disabled, Inc. (303) 522-7121
11. Foothills/Gateway, Inc. (303) 226-2345
12. Horizons, Inc. (303) 879-4466
13. Jefferson County Community Center for Developmental Disabilities, Inc. (303) 233-3363
14. Mesa Developmental Services (303) 243-3702
15. Mountain Valley Developmental Services, Inc. (303) 945-2306
16. North Metro Community Services, Inc. (303) 457-1001
17. Pueblo County Board for Developmental Disabilities, Inc. (719) 546-0572
18. The Resource Exchange (719) 380-1100
19. Southeastern Developmental Services, Inc. (719) 336-3244
20. Southern Colorado Developmental Services, Inc. (719) 846-4409

APPENDIX IV B

COLORADO COMMUNITY MENTAL HEALTH CENTERS AND THEIR DESIGNATED SERVICE AREAS



- A. Adams County Mental Health Center, Inc. (303) 287-8001
- B. Arapahoe Mental Health Center, Inc. (303) 779-9676
- C. Asian/Pacific Center for Human Development (statewide) (303) 393-0304
- D. Aurora Community Mental Health Center (Adams/Arapahoe Counties) (303) 693-9500
- E. Mental Health Center of Boulder County, Inc. (303) 443-8500
- F. Centennial Mental Health Center (303) 522-4392
- G. Children's Hospital (statewide) (303) 861-6200
- H. Colorado West Regional Mental Health Center, Inc. (303) 945-2241
- I. Jefferson Center for Mental Health (303) 425-0300
- J. Larimer County Mental Health Center, Inc. (303) 498-7610
- K. Mental Health Corporation of Denver, Inc. (303) 757-7227
- L. Midwestern Colorado Mental Health Center, Inc. (303) 249-9694
- M. Pikes Peak Mental Health Center, Inc. (719) 471-8300
- N. San Luis Valley Comprehensive Community Mental Health Center (719) 589-3673
- O. Servicios de la Raza, Inc. (303) 458-5851
- P. Southeast Colorado Family Guidance and Mental Health Center, Inc. (719) 384-5446
- Q. Southwest Colorado Mental Health Center, Inc. (303) 259-2162
- R. Spanish Peaks Mental Health Center (719) 545-2746
- S. Weld Mental Health Center, Inc. (303) 353-3686
- T. West Central Mental Health Center, Inc. (719) 269-9155

APPENDIX IV C

Health and Safety Guidelines

Before using in-home respite care, you may want to refer to these guidelines and then review the results with the respite care provider during his/her first visit to your home. This will help ensure the health and safety of the family and that of the care provider during the time s/he is providing respite care in your home.

yes no comments

FIRE SAFETY:

- Windows and doors are accessible and easy to open for evacuation in case of fire
- Electric wires are in good condition (not frayed or exposed)
- Fireplace has a protective device to shield children from fire and/or sparks
- Family has a plan that all members know and have practiced for getting out in case of fire
- Fire extinguisher in the home*
- Smoke alarm in the home
- All flammable materials are securely out of reach of children (matches, gasoline, etc.)

SAFETY AND ACCIDENT PREVENTION:

- Household poisons (bleaches, detergents, paint remover, etc.) are well out of reach of children. Is Ipecac available? In case of poisoning, call 911.
- All medicines are out of reach of children or are in a locked cabinet
- All hazardous materials are securely out of reach of children (including firearms, plastic bags, sharp objects, etc.)
- Hot water pipes, steam radiators, space heaters, etc., are in safe condition and not accessible to children
- If necessary, doors, gates, or other means could be used to keep children from stairs, balconies, swimming pools, or other areas considered dangerous
- Please designate any rooms or areas that are off-limits to children and youth
- All electrical outlets have "shock guards" in them to prevent electrical hazards
- All cabinets and cupboards that contain potentially dangerous items (glassware, knives, etc.) and that are within reach of children have door guards on them or are locked in some way
- Long draw cords for window curtains are tied up out of reach of children

yes no comments

- Household and/or outdoor plants are not poisonous and are in secure areas or out of reach of children
- Pets or animals that a child might be allergic to are kept in contained rooms or outdoors to prevent allergic reactions

SANITATION AND FOOD HANDLING:

- Outside doors and windows are screened and keep out insects during summer months
- Garbage cans are tightly covered
- Garbage and refuse disposal area is reasonably clean
- Pets are not allowed on food preparation table or counters

COMFORT AND HEALTH:

- Home is well ventilated and lighted
- Rooms and furnishings are reasonably clean and orderly

SLEEPING ARRANGEMENTS FOR RESPITE CARE:

- Room for overnight care provider provides rest and privacy
- Bed for overnight care provider is clean and comfortable
- Bed and room are safe for the child with special care needs
- Sleeping quarters are close enough to each other to hear if needed during the night

PLAY AND DAYTIME LIVING SPACE:

- Home has a safe and convenient indoor play area
- There is a safe, outdoor play space
- Yard is fenced* 

*Desirable, but optional

FORMAL OUT-OF-HOME RESPITE CARE



Formal out-of-home respite refers to a variety of situations in which the person with a disability receives care away from the family home in a formal respite situation. This provides the caregivers an opportunity to relax in their own home or to go away without worrying about the home situation.

RESPITE PROVIDER'S HOME

Many respite providers open their own home to care for a child with a disability or special care needs. The child goes to the respite provider's home and may be provided meals, personal care, and recreational/social opportunities. Some respite agencies, Community Centered Boards (see **Appendix IV A, page 22**), Community Mental Health Centers (see **Appendix IV B, page 23**), Child Care Resource and Referral agencies (see **Appendix, page 40**), or the yellow pages may have a list of respite providers that provide respite in their home.

The respite provider may operate privately or through an agency. If they operate through an agency, certain regulations through the health department, fire department, and child care licensing department may need to be met. Thus, a respite provider through an agency may be more costly than an independent provider.

Possible Advantages:

- It is convenient for extended periods such as week-long vacations.
- Allows the child's family an opportunity to relax in their own home.
- Allows the child with special care needs to experience different settings and families.
- Gives the respite provider's family an opportunity to learn from the person with a disability.
- If organized through an agency, training may already be accomplished and the respite provider/family may already be experienced.
- Requires less time and energy for the family to arrange and locate respite care via this model, since it is already organized.



Possible Disadvantages:

- The child may not be familiar with the respite provider's home.
- The respite provider's home may be less predictable and controllable than another setting (such as the child's own home).
- Needed personal items, such as clothing, medication, adaptive equipment must be moved from the home to another location.
- Provision of respite care in the respite provider's home is usually more costly than if respite care takes place in the child's home
- The respite provider may care for other children/youth and it could become less individualized.

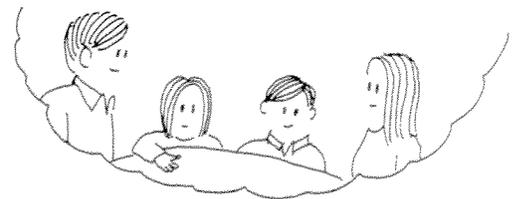
GENERIC FACILITY BASED RESPITE CARE

Some organizations such as churches, synagogues, child care centers, community centers, or schools offer respite care in their facilities for certain periods of time. This is similar to a "Mother's Day Out" program in that it provides a supervised setting by trained staff or volunteers. For example, Lakewood United Methodist Church offers respite at their church one Saturday a month. Margaret Walters school offered respite at the school one evening before the winter holidays so that families could go shopping.

Cost may vary from no fee to an hourly rate. Facilities need to observe health department, fire department and child care facility regulations.

Possible Advantages:

- Allows the family time to relax in their own home.
- Provides an opportunity for the child to get out of their home and to meet other people.
- This is an effective model in rural areas.
- Respite providers are usually trained and staff persons are experienced and trained.



Possible Disadvantages:

- There are often eligibility requirements or restrictions.
- Times for respite care are usually set or formalized and are not as flexible as some other models.
- The setting may be "segregated" in that most participants have disabilities and are grouped together rather than "integrated" with other persons who do not have a disability.
- May be 2 to 16 persons being cared for in the same setting, thus diminishing individual attention.

RESPITE HOUSE

In Colorado, there are only two known respite houses, one in Ft. Collins (Respite Inc.) and one in Colorado Springs (Martin Luther Homes). The respite houses are specifically designed for the provision of respite care by trained respite professionals on a 24 hour basis. Extended respite care up to 30 days may be available. For example, Respite Inc., in Ft. Collins, provides 24 hour respite care for up to 12 children at a time. Cost may be on an hourly or daily rate. A sliding fee scale may be available. A respite house must observe health department, fire department, and Department of Human Services' regulations.

Possible Advantages:

- Provides trained staff and adheres to safety regulations.
- Offers consistency of setting and routine to the child with special care needs and to their family.
- Allows the family time to relax in their own home or to take an extended vacation.
- May be able to handle emergencies.

Possible Disadvantages:

- Availability is currently limited to only two locations in the state.
- The setting may be "segregated" in that most participants have disabilities and are grouped together rather than "integrated" with other persons who do not have a disability.
- May be 2 to 16 persons being cared for in the same setting, thus diminishing individual attention.

HOSPITAL BASED

Some areas have a hospital that will provide respite care in their facility to persons who have extensive medical needs such as a gastrostomy tube and a tracheostomy or who are dependent on an oxygen tank. Trained medical staff such as nurses and physicians provide care to the person with a disability. For example, "Kidstreet" at Children's hospital in Denver offers care from 6:00 a.m. to 6:00 p.m. to kids with special medical needs.

To inquire if your area has a hospital based program, call the hospitals listed in the yellow pages for your community or contact the Colorado Head Injury Foundation at (303) 730-7112 for a list of facilities that accommodate persons with head injuries. Other specialized organizations may also maintain lists of facilities and resources.

Possible Advantages:

- Trained medical staff are caring for the child so parents may feel more comfortable using respite.
- Allows other family members to relax in their own home or take a vacation.
- Staff persons are experienced with and can handle emergency situations if they arise.
- Costs may be covered by Medicaid or other insurance or employers.
- Specific hospital, state and federal health and safety regulations are followed by hospitals.

Possible Disadvantages:

- This setting does not provide a "home like" environment and may be intimidating.
- Hospital stays are extremely costly, if insurance is not available.
- To qualify, the child must have medical needs requiring nursing care.
- Many children may be cared for in the same setting at the same time, thus diminishing individual attention.

SPECIALIZED RESIDENTIAL FACILITY OR FOSTER HOME

Some areas may have respite options through group homes, regional centers, nursing homes, or social service foster homes. Usually, emergency situations must exist before accessing one of these respite options. Trained staff will provide the care.

Possible Advantages:

- Trained staff are immediately available.
- Foster home provides a home-like environment.
- There is consistency in the environment and persons who provide care.
- Costs may be covered by state agencies or Medicaid. State and federal health and safety regulations will be followed.

Possible Disadvantages:

- Group homes, regional centers, and nursing homes have some degree of segregation in that most participants have disabilities and are grouped together rather than "integrated" with others without disabilities.
- Eligibility criteria are extremely limited and may eliminate some persons.
- May be 2 to 16 persons being cared for in the same setting, thus diminishing individual attention.
- The potential exists for a loss of independence or development of "institutionalization" behavior if the stay becomes prolonged.
- There is a possibility of a loss of personal involvement and spontaneity of routine and activities.

Recruitment and Selection Ideas:

- Consider asking school staff and other parents about formal out-of-home respite options they have used.
- Ask churches and civic groups to consider funding or hosting out-of-home respite options (see **Appendix III B, page 17**).
- Call the Colorado Department of Human Services, Office of Children, Youth and Families (303) 866-5942 to view the file of licensed facilities that you are considering.

- Call your local Child Care Resource and Referral agency (see **Appendix VI B, page 40**), to get a copy of the "Choosing Child Care" pamphlet that gives checklists of things to look for.
- Refer to the "Information Sheet for Persons Seeking Respite Services" (see **Appendix VII F, page 51**).
- Consider your values and prioritize what is most important to you as you decide which respite option to access. For example, community inclusion, safety, extensively trained person(s), cost, etc., may be prioritized and matched with a model that most closely satisfies your needs.

STATE AND FEDERAL REQUIREMENTS:

- When family members directly hire their own care provider, they act as an employer and provide payment for services. Families need to be aware of the requirements of IRS Publication 926 "Employment Taxes for Household Employers".
- The provider has to report the income as taxable.
- If care is provided to only one family in the home of the provider, no state or federal licensing requirements apply. If children from more than one family are cared for, state licensing requirements may apply.
- Families need to ask such questions as: What licenses do you have? Do you have homeowner's Insurance? Automobile Insurance? Other types of applicable insurance?
- Respite programs which contract with providers to care for children in their homes or the family's home, should inform them that as independent contractors they must comply with IRS code requirements for the self-employed. All federal, state, and local taxes must be paid by the independent contractor. Agencies are required to file 1099 forms for persons earning \$600.00 or more annually.
- Families and providers may contact their local health department and fire department for information regarding requirements that may be applicable.
- Licensing agencies such as the following may be contacted for further information, depending on the type of respite care selected: fire department, health department, Office of Child Care services **(303) 866-5958**.

- Respite programs should contact their state and local agencies which license family child care, center child care, residential care, emergency shelter care, home health care and/or foster care to determine if any of their program services require licensing and inspections.
- Licensing information can be obtained from the Office of Child Care Services in Denver **(303) 866-5958**.
- Home and center based programs should ascertain whether the health department and fire department need to inspect the premises on a regular basis.
- The child's family should be made aware of whether the respite service provided falls under state licensing requirements.

LICENSED AND LEGALLY-EXEMPT HOME AND CHILD CARE CENTERS



FAMILY CHILD CARE HOME-LICENSED

There are many licensed family child care providers throughout the state. For every child care center, there are approximately seven licensed family child care providers. Child care is provided in these licensed family homes, instead of in the child's home or in a child care center. Some of these homes may have provisions already in place for children with special care needs. Because these homes are required to provide training as well as activities, a child may experience appropriate and stimulating activities that also may provide new information and ideas to family members and parents. Some family child care homes are also accredited by their national association. These associations provide training and resources to the provider. Licensing requirements for these child care homes include orientation and training in the following eight areas:

- Child Growth and Development
- Early Childhood Care and Education
- Child Nutrition
- Discipline/Behavior Management
- Child Abuse and Recognition/Reporting
- Safety
- Business Management
- Health Care/Infection Control/Universal Precautions



Home providers are licensed in four different ways:

1. One type of license allows six children to be in the home. Two children may be under the age of two years and two may be described as "before/after-school" children.
2. Another license allows three children under the age of two, to stay in the home at the same time.
3. The Infant-Toddler license allows up to four children to be in the home. Two of these children may be under 12 months of age and none of the children may be over two and a half years of age.

4. This type of license occurs less often and is described as a "large family child care home" for up to 12 children. An assistant is required to be present in this home. While the large family child care home allows up to 12 children, none may be under two years of age. This is generally a multiple-age setting.

To maintain any of these licenses, providers are required to annually take continuing education classes in the eight areas listed previously. The services provided can vary from provider to provider and may range from developmentally appropriate materials being available to a formal curriculum. Field trips may also be a part of the routine.

Possible Advantages:

- This setting offers a small, multi-age group in a home environment.
- Ties between family and provider may become close, like an extension of the family.
- Location is often convenient, i.e., in the neighborhood or close to work.
- Documentation for child care tax credit for income tax purposes can be obtained.
- There is usually more flexibility and creativity when working with the home provider.
- While full-time children are on vacation, the provider may be willing to provide for short-term "drop-ins".
- Some providers will consider extending care beyond day time hours.
- Experiences out of the home are increased.
- Socialization opportunities and experiences with new and/or varied activities are expanded.
- Sliding fee scale, bartering or acceptance of families with child care subsidies are not uncommon.
- Larger settings will have an assistant to help with child care.
- Many home providers take care of the same children for years.

Possible Disadvantages:

- There may be only one adult with the group of young children and an emergency plan needs to be in place.
- Children requiring a great deal of "one-to-one" care or physical assistance may find this setting inappropriate.
- The provider does not earn a high salary and therefore may not be able to absorb costs for adaptations or specialized equipment.

FAMILY CHILD CARE HOME -- LEGALLY EXEMPT

The family home provider provides care for children from one other family plus their own children and they do so on a regular basis as a "home business". This provider is most apt to be flexible. This could possibly be a neighbor, a friend of a friend, or a church member. Once this family provider takes children from more than one family, they are required to have a license. There are no training requirements. However, some may have had previous training and provide care as a way to stay home with their own children.

Possible Advantages:

- May be flexible and easily individualized.
- The group of children may be very small.
- May begin to feel like an extended family.
- Becomes very routine and familiar over time.
- May be conveniently located close to home or to work.

Possible Disadvantages:

- Training and licensing are highly correlated to quality and are not required in these settings.
- Training or licensing oversight is not provided.
- Background checks are not required.
- Reference checks can be time consuming, but it is vital that they be completed.
- If the person is a stranger or not familiar with you and your family, reference checks are advisable as well as talking with previous families using this caregiver.
- Tax credit information may be harder to verify unless you keep your own records and have them signed by the provider. Be sure to obtain the provider's social security number before paying him/her.
- If the provider or their child is sick and there is no backup care, the parent could be stuck.
- The provider may not accept the child for care if the child is sick.
- If there are no licensing requirements or few licensed providers, the parent will be totally on their own to evaluate the safety and quality of the care provided.
- The provider may change the hours or days of care provided and these may not meet the family's need.
- The provider may not have the skills and materials necessary to offer a variety of age-appropriate activities.

CHILD CARE CENTER

Center care is group care that takes place outside a home setting. A child care center may exist on its own or be run by a larger organization, such as a church, synagogue, community center, or business. Centers can be "for profit" or "nonprofit". They can be part of a large group of centers owned and operated by a corporation. There are national accreditations available if a center wishes to apply. Most centers have single-age classrooms and a prescribed ratio of children to staff (see **Appendix VI C, page 41**). Early childhood centers, serving children from three through five years old are the most prevalent. Programs caring for infants and toddlers are increasing. Centers that care for school-age children during the late-afternoon hours are also available.

Classes must have a qualified group leader ("teacher") in charge with a class aide if the group is larger than that required for one individual. A typical class is 15 to 20 children, depending on their age. The center must have a "director qualified" person on site 60% of each day. Personnel preparation generally requires college course work, and the facility is always licensed. Some centers have more extensive curriculums and training, i.e., Montessori, British Open, Waldorf. Field trips, and visiting talent, (i.e., puppeteers, storytellers) are not uncommon to centers. It is best to talk with other parents whose children attend, observe in several classrooms, and ask quality checklist questions (see **Appendix VI A, page 39**).

Possible Advantages:

- At the end of the year, child care tax credit information is available to you.
- If a volunteer or family companion accompanies the child, some centers might be able (with advance planning) to allow the child and companion to accompany the group on a field trip on a "drop-in" basis.
- Many centers provide care for children with special care needs and are willing to learn about meeting an individual child's needs.
- With two adults in the classroom, emergencies are better handled.
- It is often easier for centers to assume some reasonable costs of special accommodations.
- If an issue arises regarding the classroom, there is often the possibility of switching classrooms without having to re-locate child care.
- The child has the opportunity for out-of-home experiences.
- Socialization opportunities exist with other children and with adults.
- Some centers have the option of half-day or partial week programs.
- Free parent education programs are sometimes offered by centers.
- Sliding scale fees or acceptance of families with child care subsidies are often acceptable.

- Some centers provide inservice training to keep their staff informed of new issues and techniques in child care.

Possible Disadvantages:

- Since centers are fewer in number than home child care, one may not be close to your home or to work.
- The larger ratio of children to caretaker may result in less individual attention for the child.
- Some classrooms may be over-stimulating for some children.
- If the center does not offer after-school care or it is out of your school district, you may not be able to have all your children in one place.
- Fees may be expensive.
- Staff turn-over may be high and a parent's task of staff orientation and training may be an ongoing process.
- Many staff members may be involved in the admission and in the ongoing "hands-on" child care process. Therefore, parents need to be in communication with a number of staff persons.

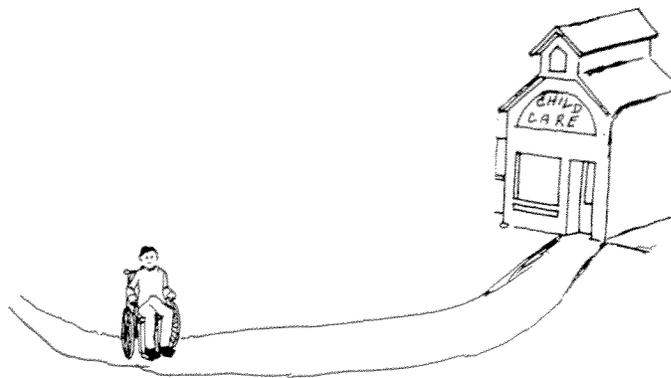
Recruitment and Selection Ideas:

All licensed home providers are listed with the County Resource and Referral Agency (see **Appendix VI B, page 40**). Upon request, they will conduct a search to match the requirements of the child and the family. This is a free public service. If an additional search is requested for those with experience in working with a child with a particular type of disability, this can also be accomplished, but should not exclude the general list. The general list may include providers who would be interested in extending their expertise and learn from parents who have a child with a disability. This service will also provide a quality checklist (see **Appendix VI A, page 39**) with suggested questions to ask a provider when conducting an interview. Phone numbers for local offices are listed by counties and can be obtained from the information located in **Appendix VI B**.

It is best to observe, speak to other parents, and to interview several providers. It is possible to review a licensed provider's file if you contact the Colorado Department of Human Services, Office of Child Care Services, in Denver. They maintain records of licensed providers, whether or not there have been any complaints and the nature of those complaints. With a one week's notice, they will provide you with the record to review in their Denver office. If you live out of the Denver area, you can call to begin the process of having this information mailed to you. Their number is: (303) 866-5958.

STATE AND FEDERAL REQUIREMENTS:

- Licensing information can be obtained from the Office of Child Care Services in Denver (303) 866-5958.
- When family members directly hire their own care provider, they act as an employer and provide payment for services. Families and providers need to be aware of these requirements as described in the IRS Publication 926 "Employment Taxes for Household Employers".
- Respite programs which contract with providers to care for children in their homes or the family's home, should inform them that as independent contractors they must comply with IRS code requirements for the self employed. All federal, state, and local taxes must be paid by the independent contractor. Agencies will be required to file 1099 forms for persons paid \$600.00 or more annually.
- Families and providers may contact their local health department and fire department for information regarding requirements that may be applicable.
- Respite programs should contact their state and local agencies which license family child care, center child care, residential care, emergency shelter care, home health care and/or foster care to determine if any of their program services require licensing.
- Home and center based programs should ascertain whether the health department and fire department need to inspect the premises on a regular basis.
- The child's family should be made aware of whether or not the respite service provided falls under state licensing requirements.



APPENDIX VI A

<p>MAKE QUALITY THE #1 PRIORITY IN YOUR CHILD CARE CHOICE!!!</p>

Use this checklist when you visit child care programs to find out if they meet some important quality standards.

YES NO BASICS

Is the program licensed or registered?
Is the group size okay for my child's age?
Is the caregiver trained and experienced?

THE PLACE

Is there enough space?
Is the outdoor play area fenced, hazard-free and completely visible to the caregiver?
Is the space bright and pleasant?
Is there an acceptable child-staff ratio?

DO THE CAREGIVERS

Genuinely like children?
Talk to children at their eye level?
Share your beliefs about discipline?
Greet your child when you arrive?
Comfort children when needed?
Keep you up-to-date on your child's activities?
Make themselves available to answer your questions?

ACTIVITIES

Are active and quiet experiences balanced?
Are activities correct for the child's age?
Are toys safe for each age, clean and available?

PARENT'S ROLE

Are unannounced visits okay?
Are there ways for you to get involved?

Checklist Source: Child Care Aware, a Dayton-Hudson Foundation project.

For more information call:

CORRA
(303) 290-9088

APPENDIX VI B

COLORADO'S RESOURCE AND REFERRAL SYSTEM
--

Adams Arapahoe Denver Douglas (303) 534-2625 Archuleta Dolores Hinsdale LaPlata Montezuma San Juan (303) 385-4747 Boulder (303) 441-3180 Chaffee Custer Fremont Huerfano Las Animas Pueblo (719) 549-3411 Clear Creek Gilpin Jefferson Park (303) 969-9500 (800) 436-3665 Delta Gunnison Montrose Ouray San Miguel (800) 530-2033	Eagle (303) 845-5999 Elbert El Paso Teller (719) 634-6765 Garfield (303) 625-5630 Grand Jackson Routt (303) 879-7330 Lake Summit (303) 668-1375 Larimer (303) 663-2288 Ft. Collins (303) 484-1902 Loveland (303) 663-1375 Alamosa Conejos Costill Mineral Rio Grande Saguache (303) 290-9088	Mesa (303) 244-3829 Moffat (303) 824-8121 Morgan (303) 867-3231 Pitkin (303) 920-5363 Rio Blanco (303) 878-4211 Washington Yuma (303) 848-3867 Weld (303) 330-7964 (800) 559-5590 Baca Bent Cheyenne Crowley Kiowa Kit Carson Lincoln Otero Prowers (303) 290-9088 Logan Phillips Sedgwick (303) 522-9411
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APPENDIX VI C

MAXIMUM GROUP SIZE FOR CHILDREN

AGES OF CHILDREN	MAXIMUM GROUP SIZE
6 weeks to 18 months	10 infants
12 months to 36 months	10 toddlers
24 months to 36 months	14 toddlers
2 1/2 years to 3 years	16 children
3 years to 4 years	20 children
4 years to 5 years	24 children
5 years and older	30 children
Mixed age group: 2 1/2 to 6 years of age	20 children

In other age combinations, the maximum group size for the younger child must be utilized if more than 20% of the group is composed of younger children.

Toddler age groups of children must be separated from each other by permanent or portable dividers or other methods as approved by the Department of Human Services, Office of Child and Family Services.

AGES OF CHILDREN	NUMBER OF STAFF
6 weeks to 18 months	1 staff member to 5 infants
12 months to 36 months	1 staff member to 5 toddlers
24 months to 36 months	1 staff member to 7 toddlers
2 1/2 years to 3 years	1 staff member to 8 children
3 years to 4 years	1 staff member to 10 children
4 years to 5 years	1 staff member to 12 children
5 years and older	1 staff member to 15 children
Mixed age group: 2 1/2 to 6 years of age	1 staff member to 10 children

In other age combinations, the staff ratio for the younger child must be utilized if more than 20% of the group is composed of younger children.

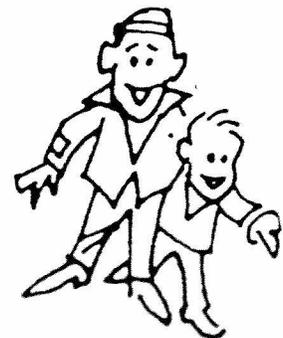
SUCCESSFULLY MATCHING FAMILIES AND RESPITE SUPPORTS

From the Parent's Viewpoint...



Families are the best individuals to determine what kind of respite supports they need and want. They are in the best position to set the times they want respite, for how long, and where. Determining what type of supports will best meet the needs of each family is the first step in being able to evaluate which model or combination of models is appropriate for each situation. Although there are many differences in needs and expectations, many families do agree on some of the basics which they want in respite care support. As a starting point in determining what is most important to the family, consider the following list of some key qualities that families have identified as most important for people who provide respite care:

- People they can trust
- Caring, positive, and supportive individuals, staff or volunteers
- Flexibility
- Reliability
- The same person(s) providing respite care each time
- Emergency care or care on short notice
- Competence
- Knowledge and resourcefulness
- Persons who are:
 - neat and clean
 - pleasant
 - on time
 - committed and dedicated
 - respectful
 - competent
- Persons who provide respite care should take care of the child's:
 - safety
 - nourishment
 - medication
 - schedules and routine
 - social, emotional and intellectual needs



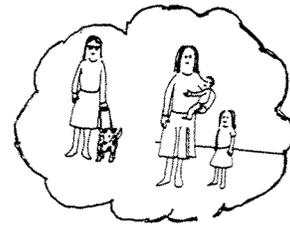
Families are the best judge of how important each quality is to them and how they would like to see each one implemented in respite care. Families are also the best ones to determine which qualities are essential for different situations. It may be that

every quality is not always available in any one option or with a particular provider. In that case, families may need to prioritize which qualities are the most important to them or have multiple options for different respite needs.

Parents and families need to actively participate in interviews with prospective providers. Families play a critical role in choosing and evaluating respite care and in determining whether the program will meet their needs. This is essential for parents to be able to make choices and decisions leading to a successful, long-term partnership with respite care providers. Once a respite care provider is chosen, families continue to play a key role in developing a positive, ongoing working relationship with the person(s) or service providing respite care. One way to assure the relationship develops in a positive direction is recognition. There are many ways of saying "Thank You" and of building good morale with the respite provider(s). For example:

- Saying "Thank You" and communicating how respite provides support and aids the individual as well as the family's well-being.
- Sending birthday cards, and special holiday greetings.
- Giving special acknowledgment to the individual and to others about the quality of care and/or the attention to detail they have provided.
- Giving small "token" awards.
- Having open communication, including positive feedback as well as correcting feedback.
- Talking about concerns openly as soon as they arise and in a neutral, non punitive manner.
- Being clear about expectations and giving the respite care provider feedback regarding how they are doing.
- Being friendly and engaging in "small talk" about events in general--both regarding the family and the provider.
- Finding out what the provider needs to do a good job, and assure that these tools are available.
- Providing sufficient information for the provider to do a good job, such as a written fact sheet or an "information sheet" (see **Appendix VII A, page 46**).
- Checking with the person(s) providing respite to see if they have what they need to do the job.
- Assuring that instructions are clearly stated and/or written and that they are understood by the person.
- Providing, on a regular basis, appreciation and respect.
- Building a friendly working relationship.
- Being on time returning home.
- Giving as much advance notice as possible that respite is needed.

From the Provider's Viewpoint...



Participation in an interview process with the parent(s) and other family members, including the child with special care needs, is an important first step to a successful "match". Providers and parents may be more comfortable with more than one interview and/or meeting before making their final decision. It is essential that all people involved feel a level of trust and confidence with one another. Providers having input and a choice in the decision or "matching" process will go a long way in assuring a successful, rewarding and long-term respite care relationship (see **Appendix VII F and G, page 51 and 52**).

All information regarding the individual should be carefully reviewed with the respite provider before care is given the first time. Behavior and medical issues should be thoroughly explained. An initial "get acquainted" visit to the home is recommended, especially before an overnight or extended stay, to allow the individual and their family members and the person providing respite to get acquainted with each other. Parents can use this opportunity to demonstrate any special techniques or adaptive equipment.

Specific information about the needs and routines of the child or youth is essential to the success of a respite experience and may be part of the interview between the family and the prospective respite care provider (see **Appendix VII A, page 46**). This information should be specific and assist the prospective provider in getting a clear picture of the individual, the routine and level of care required. The individual who provides respite care is then able to give quality care. Having parents put the necessary information in writing is the most reliable means of gathering information and will minimize the chance of miscommunication and misunderstandings. The fact sheet should be completed by the family member(s) who is the expert on the individual child.

There are a variety of creative ways of sharing information. Some examples shared by parents and providers include the use of:

- Bulletin boards in the home
- Notebooks for information and "back and forth" communication
- Video Tapes of activities, adaptive equipment in use, special care needs, etc. (contact a friend, the local high school, or camera shops for assistance in taping)
- Pictures and diagrams posted on bulletin boards or in notebooks
- Posting emergency phone numbers by the telephone
- Keeping a log book of contacts and what happened
- Placing vital authorization and release forms in a visible and easily accessible location

Some key factors to consider as necessary ingredients to doing a good job with respite care and to establishing a good three-way "partnership" between the respite care provider, the family, and the child include the following:

- Knowing who to contact in an emergency
- Behaviors to be expected from the child
- Specific behavior intervention skills and a planned back-up system if these interventions do not have the desired positive effect
- Rewards and disciplinary measures used by the parents
- Information regarding seizures
- Specific information regarding medication(s)
- Adaptive equipment--location, instructions and schedule
- Allergies, diet, and food preferences
- Recreation activities
- Self-care skills the child is able to complete independently or level of assistance s/he needs, if any
- Daily routines
- Consideration of the child's personality, their likes, dislikes, favorite activities, and the materials and supplies needed
- Knowing what is "off-limits"

There are many things the respite care provider can do to help make the experience of providing respite care successful and rewarding, including the following:

- Always maintain confidentiality. The privacy of the family must be protected and personal information regarding the family and the child with special care needs is not to be shared with others.
- Ask the parent for assistance if s/he is unsure of how to care for the individual.
- Make sure to receive complete information about the person for whom you will be caring as well as a medical treatment and liability release before the parent(s) leaves (see **Appendix VII B and C, page 48**).
- Talk about problems openly and work together to find solutions.
- Set clear limits and expectations. Be consistent and fair in discipline and behavior management techniques. Assure that these meet with the parent's approval.
- Keep the family's home as neat and orderly as it was.
- Administer and record medications carefully and according to instructions.
- Avoid temptations to attempt to change or "fix" the family's values, beliefs and/or patterns. Also, avoid "counseling" the family or listening to in-depth problems.

Appendix VII A

INFORMATION SHEET

IMPORTANT TELEPHONE NUMBERS:

- Where Mother can be reached
- Where Father can be reached
- The physician's name and telephone number
- The hospital or clinic we go to
- The pharmacy we use
- Two neighbors who can be called
- Two relatives who live near-by and who can be called

IMPORTANT INFORMATION:

- The child's name
- The name the child likes to be called, if different
- Individual information regarding the child
- Personal property
- Household rules and chores

SEIZURE INFORMATION:

- Things that may prompt a seizure
- What to do during a seizure
- Description of a "usual" seizure
- What happens before, during and after a seizure
- Frequency of seizures

MEDICATION:

- Name of all medications
- Time medication(s) is given
- Dosage of each medication
- Authorization to administer medication (if required)
- Important facts about giving medication
- Helpful cues and clues to giving medication

COMMUNICATION INFORMATION:

Assistive devices
Common gestures
Body language
Use of sign language
Words/signs/gestures with special meanings

BEHAVIORAL INFORMATION:

Rewards
What is motivating
Things that may prompt a behavioral incident
What happens before, during and after a behavioral incident
What you should do when a specific behavior occurs
What you should do following a behavioral incident
Usual discipline or intervention used

USUAL ROUTINE:

Bedtime and usual time to get up for the day, sleeping habits
Naps (if any)
Breakfast, Lunch, Dinner and snacks
Activities and other routine events
Foods that can't (or won't) be eaten

OTHER INFORMATION:

Allergies, symptoms of allergic reaction, what to do if symptoms occur
Adaptive equipment--how and when to use: wheelchair, AFOs, walkers, glasses, hearing aid, side-lyer, etc.
Favorite activities (i.e., recreational; fine/gross motor, favorite music, books, TV programs, places to go, friends to be with, etc.)
Chores which have to be done, when and by whom
Friends who frequently call/visit and when visiting is permitted
Things to know about other family members (names, ages, etc.)
Things to know about the house (temperature control, security systems, etc.)
Other things to know

APPENDIX VII B

CONSENT FOR EMERGENCY MEDICAL CARE

I, _____ father/mother of _____
(parent's name) (circle one) (child's name)

do hereby request and give consent to _____ for
(care provider's name)

above named child to receive surgical aid or emergency medical treatment as may be deemed necessary by a duly licensed or recognized physician or surgeon in case of an emergency when the parents cannot be reached.

Signature Date

Witness Date

* * * * *

APPENDIX VII C

CONSENT FOR TRANSPORTATION

I, _____ father/mother of _____
(parent's name) (circle one) (child's name)

do hereby request and give consent to _____ for
(care provider's name)

above named child to be transported to and from activities in the community.

Signature Date

Witness Date

APPENDIX VII D

MEDICAL RELEASE

In the event of an accident, injury, or illness that requires immediate medical or surgical attention, if I can not be reached to obtain my preferences and consent, I hereby give my permission to the Respite Care Provider to call 911 and/or transport my following named minor child(ren) to a doctor listed below or to admit my minor child(ren) to the hospital listed below, and to sign operative permits for such procedures as considered necessary by the physician on duty. Anesthesia may also be administered if deemed necessary. I also assume all financial responsibility for any medical care obtained for my minor child(ren) by our Care Provider. Upon signing this form, I agree to the above statement.

I prefer that the following hospital(s) and/or physician(s) treats my minor children:

Preferred hospital: (Please list in order of preference from first to last)

<u>Name</u>	<u>Address</u>	<u>Phone</u>	<u>Emergency Room Phone</u>

Preferred physician: (Please list in order of preference from first to last)

<u>Name</u>	<u>Address</u>	<u>Bus. Phone</u>	<u>After Hours Phone</u>

If one of the above physicians is not available, I authorize the Care Provider to select a physician to provide treatment.

Names of minor child(ren):

(Parent Signature)

(Date Signed)

Note: This form should be completed and signed before using Respite Care Services. It must remain with the child(ren) and the provider.

(Adapted from Loveland In-Home Respite Care Program, Fort Collins, CO)

APPENDIX VII E

PERMISSION TO GIVE MEDICATION

I, _____ father/mother of _____
 (parent's name) (circle one) (child's name)

give permission to the Respite Care Provider _____
 (provider's name)

to administer medication(s) to the above named child according to the written instructions below:

MEDICATION (Name)	DOSAGE (# of tabs, tsp., cc/ml, droppers, etc.)	DESCRIPTION (color, shape, size, liquid)	TIME (with meals, at bedtime, etc.)	SPECIAL INST (end date, through tube, in food, etc.)

COMMENTS: _____

 Signature

 Witness

 Date

 Date

APPENDIX VII F

INFORMATION SHEET FOR PERSONS SEEKING RESPITE SERVICES

It is suggested that the person seeking respite think about doing the following:

1. Interview or visit with the potential respite provider until you are comfortable with them. You may want to ask them if they have had a Colorado Bureau of Investigations check and to ask any other appropriate screening questions. For more information regarding background checks through the Colorado Bureau of Investigations, call **(303) 239-4680**.
2. Give written information about the child with special care needs i.e., medications, behavioral needs, level of assistance required, etc.
3. Make sure all medicines are properly labeled and that there is enough to last the length of service. Provide written instructions on when and how to give medication and any other medical information needed.
4. Leave the respite provider all health and insurance cards and any other information needed to get emergency medical and dental services. This should include emergency response number of 911, the name, address, and telephone number of the primary physician as well as how to get in touch with the parent(s).
5. Sign a consent agreement authorizing the provision of emergency medical treatment and stating that the family (i.e., Medicaid card, etc.) will accept the responsibility of the payment for medical costs.
6. Make sure you leave enough appropriate clothing, food for special diets, and any other needed items. Talk about arrangements for meals.
7. Discuss social/recreational activities and payment for these activities.
8. Discuss and coordinate any needed transportation. If the respite provider is providing transportation, make sure that his/her driver's license and auto insurance (Personal Injury Protection) are up to date.
9. Discuss and clarify responsibility for any damage to personal items during care.
10. Have appropriate levels of home owner's or renter's insurance or family home care insurance. You may want to ask your insurance agent about this.
11. Arrange for payment before the respite care is provided and be aware of any tax reporting requirements. You can call the IRS for more information.
12. Enjoy your respite break!!!!!!!

The above suggestions were adapted from Family Support Services; Respite/Sitter Services, Arizona Department of Economic Security, 1983, pages 3-4.

APPENDIX VII G

The following questions are suggested for use during interviews with prospective respite care providers:

- What types of experience have you had with children in the past?
- What other types of jobs have you had?
- What specific skills do you have that would assist in respite care?
- Do you have CPR training and/or First Aid Training?
- What are your interests? (Hobbies, recreational activities, etc.)
- What do you like to do?
- What is your interest in caring for my child(ren)?
- Explain how I would benefit from hiring you.
- Why are you applying for this job?
- What is your current work/school schedule?
- Is your schedule flexible?
- What are your greatest strengths?
- What are your weaknesses?
- Would you be willing to have a reference and background check done?
- What else can you tell me that would be helpful in making my decision of who to care for my child?

contributed by:

Sharmar Developmental Disabilities
Ft. Collins, Colorado

RESPITE TRAINING



Both parents and providers need to know that a certain level of competency exists in the respite provider. Training is most often identified as the vehicle necessary to secure an acceptable quality of care. Early training and initial orientation lay the groundwork for providers of respite care. Before any care is actually provided, the parent(s) is encouraged to give additional instruction that is specific to their son or daughter (see **Appendix VII A, page 46**). This is usually done immediately before respite care is actually given for the first time by a particular provider. Such specific instruction is essential as part of the initial or introductory training that follows making a “match” between the family and an individual provider. More formal training or orientation sessions cannot hope to substitute for or to include every conceivable technique, routine or method of care.

HANDS-ON TRAINING PROVIDED BY PARENTS

Practical “hands-on” training by parents and/or family members before an actual respite care situation, could arguably be the most important element of training. It is at this point that the purpose of respite care will begin to “gel” in the minds of both the providers and the families they will serve. It is this “hands-on” experience of what has already been discussed in interviews and training sessions that provides the opportunity to accomplish the following:

- Learn to understand and respect the importance of confidentiality for the family.
- Become better acquainted with the child(ren), the routine, and important information such as behavioral management, positioning and lifting, special eating techniques, etc.
- Gain a better understanding of the family’s need for respite and what would best help the situation.
- Be clear about the family’s expectations for care and what is needed to do a good job.
- Build the foundation of a good working relationship with the family.

Following the selection of a respite care provider, it is important for the parent(s) to review the provider's experience and training. This will aid the parent(s) in knowing which special care needs to focus on during the hands-on training session or sessions. The training program should focus on giving the provider practical information that s/he will need in dealing with the child with special needs. The training program needs to be evaluated by both the families and the providers who receive the training. If a training program has been evaluated by families and meets their needs, then they will be more likely to use the respite services. Likewise, if providers feel that they have received adequate training and are well prepared for working with children with special care needs, they will be more likely to initiate and continue their role as a respite care provider.

Multiple visits may be necessary before the first actual respite care situation. As part of the initial training or during a second trial visit, it is important that the parent and respite care provider consider the following:

- The goal of the practice session is for the provider to learn what s/he would need to know to provide respite care for the family and the child.
- The parent is the expert. The provider is there to learn from the parent(s).
- Be sure to figure out ways to allow the provider to spend time with the child without the parent(s) being physically present at all times during the practice session(s).
- If the provider has any problems, s/he needs to feel comfortable in asking the parent(s) for help.
- If the provider does something that is not all right with the parent, the parent needs to deal with the provider openly and honestly in working toward resolving the issue.
- Parents need to be consistent in the instructions given to the provider. If there are two parents in the home, be sure to agree on what the worker needs to do.

Basics to Include in Safety Training



Because a medical emergency can be the most harrowing event to occur during respite care, parents and providers alike recommend the following list as primary considerations to be included in training. Though these suggestions for safety training are not all inclusive, they do include fundamental considerations for training respite care providers.

- You may want to consider First Aid Training that includes training in how to administer initial treatment for the following:
 - CPR Training
 - Choking and Breathing
 - Injury to the eyes
 - Bruises, cuts and wounds
 - Bites and stings
 - Breaks, fractures and dislocations
 - Seizures
 - Poisoning
 - Burns
 - Head injuries
 - Electric shock
 - Heat stroke
- Preparation for emergencies (phone numbers, hospital, physician's name, etc.)
- Transportation safety issues
- Safety Checklist--How to develop and use one (see **Appendix IV C, page 24**)
- Environmental safety and sanitation including infection control and Universal Precautions
- Medications--administration and precautions
- Use of adaptive equipment including the scheduled routine
- Special eating needs and related techniques or requirements
- Lifting and positioning techniques

**Topics Suggested for Inclusion
in the Overall Training Curriculum**

- Confidentiality, parent's rights and the child's rights--**Staying in Charge** Video tape sponsored by The Colorado Interagency Coordinating Council (see Resource List, **page 60**)
- Positive behavioral intervention
- Behavioral Intervention Training and behavioral support (see **Appendix IV B, page 23**)
- Active listening, negotiation skills, communication styles and skills (see **Appendix VIII A, page 57**)
- Facilitating friendships and social situations
- Training in who to contact and how to use a back-up system
- Training in the importance of respite care, and the concept and philosophy of respite care (see "**Overview**" chapter, page 1)

- Suggested activities and ideas to make respite fun
- Abuse/Neglect (definitions, signs of abuse/neglect and what to do if suspected)
- Basic concepts of child development (see **Appendix VI B, page 40**)
- Physical and medical management including caring for the sick child
- An orientation to respite care which includes philosophy and values
- How to choose activities and use materials for children/youth being cared for
- How to involve the child and get the child to participate
- Sibling issues--information on how to deal with siblings
- Taxes and finances--information for families and providers
- Preparing for and becoming oriented to the child(ren) and the home
- Training in respect of differences (cultural, social, and religious diversity)
- Accepting the family "as is" and not trying to change or "fix" family members or their values
- How to use an information center, i.e., bulletin board, "back and forth" notebook, etc., for communication

SUMMARY

The training of respite providers is central to how a family thinks and feels about respite care services and experiences. The family is the best judge of whether the training which a respite provider has received is sufficient for preparing that provider for meeting the particular needs of the child. Respite providers need and deserve a training program that includes family involvement and prepares them with practical training for working with a child with special care needs. Every aspect of the training program should emphasize the equal value of all children and should prepare providers to encourage growth and development. Additional training should be provided by families each time a new care provider is introduced to the child. Families need to provide detailed, practical information about their child's medical, social, and emotional needs and strengths.

When this type of training has been provided, the provider's job is made much easier and s/he is able to be much more effective. Families who know that a provider has received appropriate training through a formal training program and from them will feel more comfortable using respite care. The chances are greatly increased that the family will be able to use respite for the reasons it was intended: to relax, to support family members, and to tend to matters for which there usually is not enough time.

APPENDIX VIII A

TIPS FOR COMMUNICATING

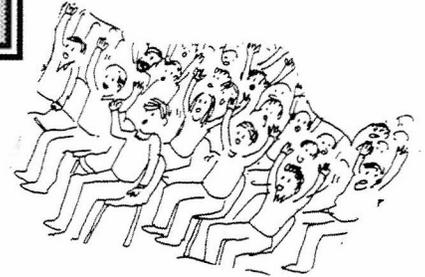
In order to feel more comfortable communicating with a child having special care needs, the following outline identifies "tips for communicating" that should be useful to a respite care provider.

- I. Pay attention to the child and what s/he is:
 - saying
 - signing
 - gesturing

- II. Encourage the child to initiate communication and expressively indicate:
 - needs
 - desires
 - thoughts

- III. Ask questions that indicate that you expect and desire a reply
 - A. Ask open end questions rather than "yes/no" questions exclusively.
 - B. Allow enough time for the child to respond.
 1. Rushing it doesn't help.
 2. "Filling in the blanks" doesn't help unless the child clearly is indicating he needs help.
 - C. Check your understanding of what someone has communicated:
 1. If you are unsure, ask for clarification.
 2. Pretending to understand doesn't help.
 - D. Accept a child's right to express his/her feelings.
 1. Even if they are not always positive.
 2. Choking off communication by only paying attention to the "good stuff" doesn't help.
 - E. Be honest in sharing your positive and negative feelings.
 - F. Use age-appropriate language.
 - G. Speak directly to an individual who communicates non-verbally.
 - H. Speak clearly.
 - I. Use specifics when asking questions, giving directions, etc.
 - J. Give positive directions when necessary.
 - K. Offer real choices or options.
 - L. Talk "to" the child, not "about" or "down to" her/him.
 - M. Use eye contact rather than staring or avoiding.
 - N. For hearing-impaired children:
 1. Let your face be seen; do not stand in front of a window or light source when speaking (keep hands away from your face--avoid chewing gum, etc.)
 2. Speak clearly, ask if signing is desired.
 3. Rephrase rather than repeat when needed.
 4. When speaking, be relatively close to the hearing-impaired child with whom you are trying to communicate.
 5. If the child wears a hearing aid, do not assume s/he can hear as well as others hear.

RESOURCE LIST



ACTION, The National Volunteer Agency
1100 Vermont Avenue N.W.
Washington, D.C. 20525
(800) 424-8666 (202) 331-2671

ARCH National Resource Center for Crisis Nurseries and Respite Care Services
Chapel Hill Training-Outreach Project
800 Eastowne Drive, Suite 105
Chapel Hill, North Carolina 27514
(800) 473-1727 (919) 460-5577 Fax: (919) 490-4905

Arnold, Mitylene, et al., Family Time Out: Mississippi Respite Care Program Training Manual, Oxford, MS: Foundation for Disability Resource, Inc.

This Manual is a reference for training respite providers. (Available through ARCH Lending Library, phone: 1-800-473-1727))

Arsenault, Cynda, (1990). Let's Get Together: A Handbook in Support of Building Relationships Between Individuals with Developmental Disabilities and Their Community. Boulder, CO. The Developmental Disabilities Center, (303) 441-1090

This handbook is written from a parent's perspective. The book assists parents in building community inclusion as a part of daily life.

Arsenault, Cynda: When Do I Get Some Time for Me? A Parent's "Make it Happen" handbook for finding and using respite care and other connections for children with special needs. 1995

A valuable resource for parents. Available through local agencies and the Division for Developmental Disabilities.

Carney, Irene, et al. Developing Respite Care Services in Your Community: A Planning Guide. Richmond, VA: The Respite Resource Project.

This guide assists agencies and communities who are attempting to make respite care available to families with children who have special care needs. It focuses on issues such as clarifying planning objectives, assessing the family's needs, and planning the course of action. (Available through ARCH lending Library, phone: 1-800-473-1727)

Cohen, S., and Warren, R.D. (1984). Respite Care: Supporting Families of Developmentally Disabled Person. Austin, Texas; Pro-Ed.

This book addresses why respite care is needed, what functions it serves, and what research has to tell us about respite care. Effective models of respite care are given.

Henson, Sarah and Bruce Larson, 1988. Risk Management: Strategies for Managing Volunteer Programs. Walla Walla, WA: Macduff/Blunt Associates.

This book identifies areas of risk, and discusses the development of policies, procedures, legal agreements and contracts, organization/ agency bylaws, tax status, and records to manage the risks.

Kempe National Center for the Prevention and Treatment of Child Abuse and Neglect
University of Colorado Health Sciences Center
1205 Oneida Street
Denver, Colorado 80220
(303) 321-3963

Lakin, K.C., and Bruininks, R.H. (1985). Strategies for Achieving Community Integration of Developmentally Disabled Citizens.

This book offers an educational approach that promotes the development of independent skills of persons with severe physical disabilities from early childhood through adulthood. Strategies for intervention, for social skill development, for vocational preparation and employment placement, and for the overall management and enhancement of integration are provided.

Lynch, Eleanor, (1992). Developing Cross-Cultural Competence: A Guide for Working with Young Children and Their Families. Baltimore, MD: Paul H. Brookes Publishing Co.

This guide examines the role that different cultures play in families' and professionals' beliefs, values, and behaviors. The guide explores the difficulties in adapting to different cultures; and provides strategies for effective Cross-Cultural interactions with families.

Kadel, Stephanie, (1992). Interagency Collaboration; Improving the Delivery of Services to Children and Families. Greensboro, NC: South Eastern Regional Vision for Education.

This guidebook provides information on the importance of collaboration, how to collaborate and implement a family service center, and state and national action to support collaboration.

National Center on Child Abuse and Neglect
Department of Health and Human Services
P.O. Box 1182
Washington, D.C. 20013
(202) 245-0586

National Information Center for Children and Youth with Disabilities (NICHCY)

NICHCY is an information clearinghouse that provides free information on disabilities and disability-related issues. NICHCY provides free information in English and Spanish to assist parents, educators, caregivers, advocates, and others in helping children and youth with disabilities participate as fully as possible in school, at home, and in the community. NICHCY can also provide personal responses to specific questions. To find out more about their full range of information and referral services, contact NICHCY and ask to speak to one of their Information Specialists. Mailing address: NICHCY, P.O. Box 1492, Washington, D.C. 20013. Phone: (800) 695-0285

Pelletier, Elaine S. (1992). How to Hire a Nanny.

A complete step by step guide for parents. This book is intended to assist families of all children who have selected to use a form of child care. Included are chapters concerning the definition of the job, cost, how to find the right person and how to manage and improve the arrangement.

Vineyard, Sue. (1989). Beyond Banquets, Plaques and Pins: Creative Ways to Recognize Volunteers. VM Systems/Heritage Arts Publishing, 1807 Prairie Ave., Downers Grove, IL. (312-964-1194).

This monograph on the subject of volunteer recognition points out creative ways to recognize volunteers and keep motivation and appreciation levels high. This guide explains several characteristics of volunteers and how to work well with different people. (Available through ARCH Lending Library, phone: 1-800-473-1727)

.....How to Manage Your Volunteer Program, Chapel Hill Training-Outreach Project, 800 Eastowne Drive, Suite 105, Chapel Hill, NC 27514.

This is a step-by-step manual for persons who wish to organize and recruit volunteers for their programs, based on the SERVE volunteer program.

.....Parent Support and Co-Op Manual, Family and Children's Services, (contact person: Ruth Newhouse) 1608 Lake Street, Kalamazoo, MI 49001, (616) 344-0202.

This manual describes the process used by a group of parents who created a parent cooperative that provides families with cost-free respite care by other families in the network in exchange for similar services.

.....Staying in Charge Video tape sponsored by The Colorado Interagency Coordinating Council, Distributed by The Colorado Department of Education, 201 East Colfax Avenue, Denver, CO 80102.

Information for families and service providers about family rights. Includes families discussing their experiences with professionals and service systems, information about the rights and procedural safeguards guaranteed by the Individuals with Disabilities Education Act (IDEA, P.L. 102-119) A toll-free phone number to 4 PARENTS HELPLINE (1-800-288-3444) to assist families in finding local support.

.....For information about The Americans with Disabilities Act, contact:

The Legal Center	Coordination and Review Section
455 Sherman	St. Civil Rights Division
Suite 130	U.S. Department of Justice
Denver, Colorado	P.O. Box 66118
(800) 288-1376 or (303) 722-0300	Washington, D.C. 20035-

.....For information about screening candidates and interviewing techniques, contact:

Big Brothers and Big Sisters of Colorado56

811 Lincoln
Denver, Colorado
(303) 831-1000