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## **FOREWORD**

Family Connection of South Carolina, Inc. is a network of parents working with community professionals to provide parent-to-parent support and assurance, which strengthens families with children of all ages, which have special needs. Programs and services are based on the principle of parent-to-parent networking. Through sensitivity to the special needs of the child and the cultural background of the family, parents are matched to help one another meet the needs of their families.

Family Connection also seeks to increase awareness among the general public and specific groups about persons with disabilities and their families, and to foster connections between family members and professionals. In order to provide this help, Support Parents are trained to offer emotional support and understanding; information about support and advocacy organizations, services, and educational programs; and, introductions and access to individuals and groups who share their concerns and who can help the family meet their needs.

The mission of Family Connection, Inc. is to strengthen families that have children with developmental delays, disabilities, or chronic illnesses through a parent-to-parent network of family-focused support to provide assurance, information, community awareness, and enhanced parent/professional relationships.

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We are also very grateful to the Governor's Office Developmental Disabilities Council for the funding for the initial development of this project.



## PREFACE

The tree from which these respite cooperatives blossomed was our own personal need for a break from caring for our son. We wanted to share this personal testimony of its roots.

These respite cooperatives are the outgrowth of a lesson learned by this author years ago. My wife and I learned the value of respite care after we had our first son six years ago. He has Down syndrome. Though we are fortunate that he has no need for intensive medical care, we learned that we still needed a regular break from the demands of caring for him. As a pastor in Columbia, South Carolina, I received a gift from my church—one thousand dollars—with the stipulation that I use twenty dollars each week for my wife and I to go out to dinner. These dinners became “lifelines” for my wife and me, and they continue to be that five years later with two more children, a four-year-old and one-year-old. It’s “our time” for reviewing, regrouping, re-plotting, and romancing.

My wife and I began pondering the respite needs of other families like ours. Some hadn’t gotten a break from caring for their child since she was born. We approached Family Connection of South Carolina, a statewide parent-to-parent organization, whose volunteer support parent had given us support from the day Karl was born. With help from the Governor’s Developmental Disabilities Council, Family Connection birthed Special Connection. After our first year of partnering with parents to find respite options that work, our site-based respite cooperatives were engineered with the help of the faith community. Special Connection now has faith communities all over the state, which are supporting the respite needs of families that have children with special needs by hosting respite cooperatives. Volunteers from the congregation and local community assist the parents in caring for the children.

The fruit of our labor and that of parents and churches all over the state has been:

- ❑ parents who are refreshed by getting a regular break from caring for their child with special needs;
- ❑ children who are getting to know other caregivers and children;
- ❑ siblings who are enjoying the friendship of other siblings and their siblings with special needs;
- ❑ faith communities which, for the first time, are not afraid to minister more broadly to these families having children with special needs;
- ❑ volunteers who have awakened to a new love for these children with special needs and their families.

This and more make the process of respite cooperatives a blessing for us and for families and churches across the state. We are grateful to be a part of Special Connection, thankful to Family Connection for its support with us, and indebted to the families who have children with special needs and the faith communities who are supporting them.

W.C. Hoecke

## INTRODUCTION

We are assuming that you, the reader, are familiar with respite and the very real need of families who care for children with special needs to have a break from this care. We assume that you also know the frequent lack in availability of respite options for families, the reasons why respite is so important and the benefits of respite. However, in this introduction, we have very briefly outlined these points. For more in-depth information, we turn your attention to Appendix A – Respite Care for Children and Families in South Carolina.

Appendix A is a report of the Committee for Children with Special Health Care Needs of the South Carolina Maternal, Infant, Child Health Council (MICH). It is a good resource for more specific information related to the aforementioned points. Completed on March 22, 2000, it is specific to the state of South Carolina, but would be helpful for any state. Its contents will also assist in drafting any grant proposal for respite. Feel free to cut and paste, but please acknowledge the MICH Council as your source.

### ***Respite Defined***

Very simply put, respite is temporary relief of care giving responsibilities. Every parent, at some point, feels the need for a break from the demands of child rearing. For those who have children with special needs, these demands are much more complicated and often involve serious medical care. As a result their need for a break is heightened.

### ***The Need for Respite***

In both research and practice, nationally and in South Carolina, respite care has been the need most frequently identified by families of children with special health care needs (see Appendix A). Two regional Children's Councils within South Carolina independently identified respite care as one of two primary prevention efforts needed to prevent abuse and neglect of children with disabilities. One county found respite care to be the primary barrier to parent participation in parent support groups.

Though state disability and special needs boards supply vouchers for respite, the families of only three percent of the 187,000 children in South Carolina who have special needs have received vouchers in these programs. Finding a qualified provider and meeting necessary criteria set by these agencies are two primary deterrents to families getting the respite needs met by these agencies. Overall, the lack of qualified providers was cited by survey as the primary barrier to respite care; lack of eligibility was the second.

### ***Why Respite Care?***

The weight of finding proper doctors, teachers, and financial resources for the child's care can take a tremendous toll on the family of a child with special needs. Multiple responsibilities, as well as the unrelenting demands for daily care of the child, prove to be very stressful for parents. Parent-reported mental health treatments for stress is 2 to 3 times higher for parents of children with special health care needs versus that reported by parents of well children (see Appendix A). Families exhibit isolation, depression, loneliness and fatigue, which contribute to possible abuse and neglect situations and which may lead to institutional care for the child. Additionally, many marriages end in divorce.

These parental impacts are detrimental in and of themselves, and it is important to note that the parents' response to stress also affects the child. Regular respite is one remedy for this stress, for both the child and the parent.

### ***Benefits of Respite***

The benefits of high quality respite care for the family who has a child with special needs are numerous. This intervention directly impacts the family, the child with special needs, her/his siblings and those providing the care. Refer to Appendix A and to the Table of Contents for specific benefits.

### ***RESPITE COOPERATIVES – A History***

Respite cooperatives are not a new concept. The idea has existed for years. Yet, there doesn't seem to be much longevity to these programs. One reason for this lack of staying power to maintain a program over a period of time is a lack of consistency and staffing needed to sustain the program. A parent who has the vision and is willing to coordinate the program usually propels these programs. However, often the schedules of parents of children with a disability change with their child's needs. Therefore, one crisis in a parent coordinator's life, and the whole program can come tumbling down.

It is our experience that by partnering with a civic organization or the faith community, the coordination can be maintained. Furthermore, because there are multiple parents involved, the quality of care is kept at the highest level while meeting the families' need for respite.

### ***Family Connection Cooperatives***

In July of 1998 Family Connection of South Carolina, Inc. was awarded a grant from the Developmental Disabilities Council in the Governors Office to establish parent-to-parent cooperatives. It began by hiring co-coordinators W.C. and Catherine Hoecke. Preliminary research and information searches were done to find what had already been implemented in our state and elsewhere. Family Connection had a resource of over 9,000 families in its database, most of whom were parents of children with disabilities. The organizational goal, established by Family Connection's Family Council, was to encourage parents to trade the caring for each other's children.

It was our belief that with mutual input, parents—who know their children best—are the most qualified providers of childcare. Parents, for the most part, are the most qualified to care for a child with special needs whether it be their own or other children, like theirs, with special needs. Our first priority was to find and relieve any of the fears that parents might have, such as liability and providing a safe and secure environment, issues that might hinder families from participating in this respite opportunity.

Therefore, the first major project was the establishment of our *Family Notebook for Respite*. This tool was developed so that a parent could clearly share any pertinent information about their child and family in a uniform and consistent manner. When first developed, we worried that in our attempt to make it comprehensive, we had made it too long (19 pages). So we asked the Family Council to critique it and cut out anything they felt unnecessary. We were surprised when they returned it with a few pages added. They thought all the information was necessary with the option of each family filling out only what they felt necessary.

So in its current form, *The Family Notebook for Respite* includes emergency information, likes and dislikes of the child, the regular routine of caring for their child, information about

siblings, etc. It also allows for parents to find answers to some of the questions that are hard to ask in person (for example: “Do you have any fire arms in your home?” or “Is there a fire extinguisher in your home, and where is it?”). This tool did much to help create a safe environment to care for our children.

Even with this notebook, parents in our metropolitan areas still showed concern in leaving their child “behind someone’s closed door”. The suggestion was made that we try our program at a site where parents would find comfort in numbers. Thus, site-based cooperatives were born.

Our first model looked something like this: a group of eight families agreed that they needed respite and would like to cooperate together in a cooperative. They had a total of 12 children—children with special needs and siblings. Additional volunteers were recruited to keep provider-to-child ratios appropriate. A church agreed to provide a facility for them. The group chose the first and third Saturday of every month from 5-8 p.m. for their co-op.

The parents completed the *Family Notebook for Respite*. For the first meeting, the local disability and special needs (DSN) board provided volunteers so that all the parents and volunteers could meet together. Families and church volunteers met at a church that had agreed to house the co-op in two of its children’s educational classrooms with access to an outside playground and restrooms.

After children were settled with the DSN volunteers, each parent and church volunteer sat together and one parent from each family shared information from their *Family Notebook for Respite*. The parents also went over simple initial guidelines including a schedule of who would provide respite for the next four co-op times. The families familiarized themselves with the facilities (two large rooms). All the parents and non-parent volunteers also signed an agreement to be “Family Connection volunteers” for this respite site, allowing all parents and volunteers to be covered by Family Connections liability insurance.

On Saturday, two of the parents and church volunteers assigned to provide respite that day arrived 15 minutes early with their children, providing some time for preparation. The other families arrived at 5 p.m. with their children (siblings too), their *Family Notebook for Respite*, and a snack for their child(ren). Children had a meal before they came. After signing the appropriate portions of the *Respite Agreement* (Appendix E), those parents or couples (six) were able to get a break for three hours.

At 8 p.m., the parents returned for their children and took a few minutes to de-brief, evaluate, and the appointed facilitator made note of needed changes. For the first two to four times the cooperative operated, there was an effort by all families to update the guidelines to suit their co-op. These were accomplished in collaboration with the facility manager who has responsibility of the site. By the fifth co-op date, a simple one-page guide described the co-op and defined procedure. The group then was easily able to evolve together, with the possibility of growth.

Parents invested their time and energy into making the co-op work. Special Connection provided all the materials necessary for respite information. The church provided volunteers, the facility and maintenance. This family co-op used families to provide maximum quality respite care by “people who are trained”—parents. This is just a grassroots effort to meet the essential needs of South Carolina families.

Since this first respite cooperative was instituted, more have begun. With each group, some fine-tuning was necessary as the group evolved. Within a few months of the start of the cooperative mentioned above, three more sites were secured and four more co-ops were founded, each meeting one or two Saturdays of the month.

Our goal is to strengthen families through parent-to-parent networking, by providing a break from the ongoing responsibility of caring for a child with special needs.

Our outcome was simple-- parents get a break to do the activities they want to do. We had no idea of all the other outcomes cooperatives would foster.

### **Advantages for Parents\caregivers**

- ❑ As parents serve with another parent they learn from each other how to better care for their children.
- ❑ They also encourage each other in the importance of taking a break; therefore, they give each other “permission” to take care of themselves.
- ❑ Cooperatives create a comfort level that allows a parent to take a break without guilt. For many this was a first time for someone outside of the family to care for their loved one.
- ❑ Often parents go out together socially, further connecting their relationship and encouraging greater networking among families.
- ❑ As comfort levels rose, parents began providing respite for each other in their homes as well.

### **Advantages for Children**

- ❑ Many of the children in respite cooperatives have few if any extracurricular activities. Co-op has become their “T-ball”. This is a fun place to go. Our children go to therapy, school, and doctors’ appointments; few of them have an activity they can really call their own. Co-op has become their special activity.
- ❑ They have developed deep friendships with each other. For example, two from one co-op now participate in sleepovers at each other’s homes.
- ❑ The co-ops have no IEP or IFSP goals; rather we just have FUN goals. Our objective is for the children to have safe and memorable fun and to want to come again.

### **Advantages for Siblings**

- ❑ Siblings have bonded with each other. These children learn that they are “not alone”. They now have other children to play and talk with who know what it’s like to have a sibling with special needs.
- ❑ They are also validated for their knowledge and experience. Very often siblings help in the care of their brother or sister with special needs. At the co-op site, it is our opinion that families are the experts.
- ❑ They see others accepting their brother or sister. Others see their sister or brother as a joy, not a burden.

### **Advantages for Volunteers, the Faith Community or Other Hosting Organizations**

- ❑ The co-op is a safe and non-threatening way for a church or organization to open its doors to inclusion within their congregation or membership.
- ❑ When their staffs have been trained in caring for the families at the cooperatives, they no longer carry the fears that so many have about true inclusion. When fear is replaced with love by these individuals, many churches have made programming shifts, using volunteer shadows to include children in typical Sunday school classes and activities, thus breaking down fears in the other students and the teachers involved.

- This has helped to put faces and relationships on the American Disabilities Act. A church now wants to comply with ADA because they honestly want to help families, not to just comply with a federal mandate.

Within a short time our Special Connection coordinator (W.C. Hoecke) who participated in each cooperative had wonderfully working models. The new cooperatives were genuinely meeting the respite needs of the families. There was one problem: there are only so many places the coordinator could be at one time. We soon realized we needed to do something better than just start and oversee co-ops. We needed to create co-ops in such a way that, after initiation, the church or organization would coordinate and be equipped for the respite group at their site. We wanted to empower such organizations to create their own cooperatives, resulting in the need for this Start-Up Manual.

Our hope is that you understand the philosophy and vision of respite cooperatives and have the motivation and tools to start a co-op with the help of this manual. We hope the reading of this manual encourages respite in the lives of many families who need it so desperately, and we encourage you, the reader, in your ability to see this born out of your time and effort.

## GETTING STARTED

Knowing that respite is a need and that respite cooperatives are a viable answer for the respite needs of families with children with special needs, a site where a cooperative might be held must be identified. Often a family who has a child with special needs can introduce the idea to and with their own church leadership and family or to their own daycare facility. Other times a representative of the special needs community might approach a church or daycare facility in their area. Either way, the leadership within the church organization or daycare facility must catch a vision for how they can meet the need of the families in their community through hosting a respite cooperative.

### ***Suggested Time Line***

Below is a timeline for how the cooperative might be started is as follows. A church is used as the location in this timeline.

- Recruit and find a location. The process of securing the location may take some time depending on the protocol that the church requires for approving participation. For example, when the cooperative is the idea of leaders already within the church, respite cooperatives can start within weeks. When members of a church (those who have family or friends with children with special needs) approach their church, it can take weeks or months. When approaching a whole organization of cooperating churches or denomination with the idea of respite co-ops, the process of approving and securing a site usually takes months. Refer to the Appendix D --Family Respite Cooperative Proposal, for more information.
- Identify a program coordinator and program assistant. The overall coordination of the respite cooperative is best when done by a representative chosen from the church. The best choice is for a church leader or member to take this responsibility as knowledge of the church, its schedule and how it works is critical. Cooperatives led by such a person have a better relationship with the church as well and are able to recruit volunteers within the church more effectively. It also relieves the pressure of the parent of a child with special needs from being responsible for one more thing. A Parent Coordinator may also be recruited as a liaison to the church. Often a parent can recruit and help coordinate the parents schedule more easily because of their standing relationship with each other.
- Recruit volunteers from the church. Volunteers from the local church or surrounding churches are recruited to serve as shadows for the children. These volunteers participate alongside the parent volunteers in caring for the children. They participate in activities with the whole group while parents lead.
- Recruit Families for the co-op (see page 44 and see Appendix J)
- Training of Volunteers
  - the signs and symptoms of illness and seizures
  - fire safety and disaster preparedness
  - disability awareness
  - confidentiality issue
  - First Aid
  - Reporting of Child Abuse and Neglect (see Appendix M and N)
- Training of Volunteers and Parents
  - agreement upon policies and procedures
  - determination time and frequency of cooperatives (ex: 1<sup>st</sup> Saturday of month from 3 p.m. to 7 p.m.)
  - review of each Family Respite Notebook

- review of emergency information and procedure for each child
  - review of emergency preparedness
  - review of the signs and symptoms of illness and seizures (as necessary)
  - review of confidentiality issue
  - training of on specific equipment
  - review reporting of Child Abuse and Neglect (see Appendix M)
- First Cooperative
 

During the first cooperative everyone stays and works together while the kids, parents and volunteers familiarize themselves with one another. This might be a shorter period of time than the regular cooperative; however, a similar schedule of activities should be used.
- Second Cooperative
 

The second co-op will be the first that looks like the ones that follow. The volunteers assigned to this co-op and the two parents serving as volunteers should get to the location 30 minutes early. The same schedule of activities is used. A 15-minute debriefs and clean-up time is required for those volunteers and parents serving.
- Third Cooperative and following
 

Rotation of parents and volunteers in effect, the cooperative functions as is described in Chapter 2.
- Review
 

Every 6 months or year, a review should be done reassessing the needs of the families participating in the cooperative and adjusting the procedures or schedule of the cooperative to better meet these needs if necessary.
- Evaluation tool
 

For grant purposes you may be required to have an evaluation tool. Contact Family Connection for a sample.

### ***Proposal to Organizations***

A Family Respite Cooperative Proposal (see Appendix D) is sent out to prospective churches and organizations. After the initial contact, this proposal is the first formal step in the process of beginning a respite cooperative at that organization's site. This process will probably take some time, depending on the church structure. Often a proposal to a church will have to pass through several committees before a decision can be rendered. It is also suggested that the preliminary policies and procedures (see Appendix H) be sent out in this proposal, for this will reduce many of the policymaking questions that will arise.

After a proposal is accepted, a cooperative coordinator is identified within the church or organizational structure to serve as a liaison.

### ***Facility Suggestions***

The factors that must be considered in the cooperative site are safety, number of children, size of the site, developmental appropriateness of toys and activities and parent comfort levels.

## **Safety Issues**

Consideration should be made regarding the safety of the building itself. Most childcare facilities have an emergency exit plan, electrical outlet covers and general safety measures in place already. The following should be addressed:

- Fire and Building Safety
  - ❑ Two exits from each room (2 doors or door and 1<sup>st</sup> story window. See Building Codes for child care facilities)
  - ❑ Extinguishers
  - ❑ Emergency plan and number(s)
  - ❑ Severe weather plan
- First Aid
  - ❑ Staff who have first aid training
  - ❑ Well-equipped first aid box
  - ❑ Medical emergency plan

## **Facility**

The size of the facility may restrict the number of children that can be served. A minimum of two rooms—a playroom and a quiet room—is suggested. A fenced-in outdoor play area is a plus. Developmentally-appropriateness of the toys and activities can be discussed among parents in the co-op.

## ***Consent—The Respite Agreement***

An agreement must be signed when a parent leaves a child or children at a cooperative. A sample consent form that Family Connection used is included in Appendix E. **We recommend that you consult your own legal advisor for issues that may be pertinent to you or local or state statutes.**

## ***Liability***

When no funds are being exchanged for childcare and there is no direct service being paid for, the issues of liability are shifted to a volunteer situation.

Serving others out of the goodness of your heart (whether an organization or a volunteer) does not exempt you from a lawsuit. The greatest likelihood of a lawsuit comes as the result of an injury caused by an accident. Our goal is to document that we have made every effort to create a safe environment. We do so by documenting our process of:

### *Screening*

- The physical ability of volunteers to perform tasks
- Skills necessary to provide childcare
- Maturity of those providing
- Safety of work site

### *Supervision*

- What are the procedures for an emergency
- Accountability to make sure policies are followed

- A clear chain of command ( especially in case of an emergency)

### *Training*

- In the use of any equipment
- Develop, maintain, and dissemination of co-op procedures
- Need to follow well defined procedures

Our goal is to have a document-able and clear plan to reduce any form of risk. This process is typically called Risk Management. We have included ARCH's Factsheet on this subject. (See Appendix B—ARCH *Factsheet Number 17, Sept. 1992*). We have also include an article by Pamela DeFanti Robinson on the Volunteer Protection Act of 1997 (See Appendix C for *Pamela DeFanti Robinson on the Volunteer Protection Act of 1997*).

A great resource for applying risk management to volunteer administration can be found in chapter 14 of Volunteer Management , by Steve McCurley and Rick Lynch, c. 1996 Heritage Arts Publishing, Downers Grove, IL. They recommend a process that is extremely helpful in developing a risk management plan.

## **Volunteer Recruiting**

Those who typically participate in the faith community's programs do so for the purpose of bettering themselves and their communities. They also have built long-standing relationships with others of like-minded vision. There is also a strong base structure that has stood the test of time. This structure is usually community based and their contacts and sphere of influence go far beyond the facility within which they meet.

For most faith communities, the majority of their programs or ministries are volunteer-based and volunteer conducted. In many cases these volunteers have worked together before on various activities that can help maintain a community-based focus. Although youth have proven open and enthusiastic volunteers in respite programs, other mission groups or members with a health or human service background are a tremendous resource as well.

Once volunteers are trained and serving individuals, they often build lasting relationships. It is not uncommon for a volunteer to offer respite outside of the scheduled respite program. Because the family develops a relationship with these volunteers, they often feel much more comfortable using these volunteers as providers in other settings, and some have relied on these providers in emergency situations in particular.

## **Increasing Awareness**

Although the faith community may easily enlist volunteers through polling its congregation, the most effective strategy we have found is to schedule a workshop on disability awareness for the Sunday school class or group, which would most likely help with the cooperative. Some faith communities have scheduled an evening service or Sunday (church) school to conduct such a workshop. Having a parent tell their story is a real advantage. An outline of what these type of presentations usually include is:

- Parent outlines personal need for respite
- Discovering disabilities

- A role play (a brief, hands-on demonstration where participants get a feel for what having a disability is like)
- Blind Snack (spreading peanut butter on cracker while blind-folded)
- Mirror Star (while looking at a mirror showing you a paper in front of you, draw a star)—gives a likeness to the feeling of dyslexia
- Arthritis—picking up paper clips and tying shoes while wearing heavy work gloves
- Painting with mouth—using a Q-tip in your mouth, dip in paint and write your name.  
Ask: How does it make you feel to have a disability? What do you think the feelings and emotions are for a person who has an ongoing disability?
- Recognizing the fear that we often have associated with including people with disabilities
  - How do you feel about being around someone with special needs?
  - What is it that keeps us separated from those with disabilities?
  - Identifying the problem: fear.
  - Discuss the definition of fear.
  - Fear causes times of worship and work to be the most segregated times of the week.
- Recognize how our fear affects our relationship with those with disabilities?
  - If you had to be blind or deaf, which would you choose? Eighty percent of you want to be deaf.
  - However, when the same question is asked to the blind and deaf community, 90% say blind. Why?
  - Blindness (not being able to see) separates you from things. Deafness (not being able to hearing what people say) separates you from people.
  - Imagine everyone who wants to communicate with you has to learn your language. How isolated would you feel?
  - This is the same way every disable person feels.
  - Whether it is deafness or a wheelchair, we must move past the disability and see the people who happen to have a disability.
- Fear and love (“Perfect love casts out fear”—St. John). It is better to be controlled by love, concern and care for people than the fears we may have of those people.
- Recognize how we can be acting out of love and not fear toward those with disabilities. It is better to be misunderstood doing something good than not to try at all.

## **POLICIES and PROCEDURES**

### ***Training***

Training for the volunteers who serve at the cooperative is very important. However, unlike respite sites where the parents of the children are not present during respite, the presence of parents at each of the cooperatives lessens considerably the hours of training both the volunteers and parents feel comfortable with. Much of the training required for volunteers to actually care for the children is learned from the parents as they serve together once the cooperative is underway.

The parents, faith community (or people that give site for cooperative) and volunteers should both be involved in making the decision of what training is necessary, as both have a vested interest in the activity of the cooperative. Part of the beauty of a cooperative is that it is designed cooperatively meaning everyone works together to make its policies and procedures suitable to all.

In most of the cooperatives we have launched in South Carolina, there has been a consensus that certain training for the volunteers is necessary for parents to feel comfortable. The training has included all of the following with at least one strategic individual (volunteer) being trained in the last (CPR):

- Confidentiality training
- Training in understanding the disability or disabilities represented at the cooperative
- Signs and symptoms of illness
- Fire Safety procedures for the site
- Disaster preparedness protocol for the site
- Training in Cardiopulmonary Resuscitation (CPR)

### ***Volunteer Enrollment and Agreement***

As you can see in Appendix F, each volunteer must fill out an enrollment form. A blank copy of the form Family Connection uses may be found in this appendix. As you can see background information and references are requested. This is assist in really avoiding the type of volunteer that would not be suitable for the job. However, remember: the beauty of a cooperative is that no worker is alone with a child. One of the policies that all cooperatives agreed upon is that no child be alone with an individual. This avoids any doubt of impropriety.

A Volunteer Childcare Job Description is also important. A list of qualifications, a list of responsibilities and volunteer philosophy is outlined. A signature is then required from each volunteer who participates. A sample of this is in Appendix G.

### ***Guidelines for Participants***

A copy of policies and procedures is drawn up early on by the cooperative members—within the first two meetings. A sample of such a document is in Appendix H. The parents involved in a cooperative or the faith community may want to add additional items.

If an accident occurs or a child becomes ill or out of control, it is important that a report be immediately filled out to document it. Both the parent and the coordinator must sign the form and give a copy to the parent of the child. A sample of such an Incident Report is included in Appendix I.

# THE COOPERATIVE SITE

## ***Cooperative Routine***

As you plan to begin your cooperative, it is important to remember that children in general have a much more pleasant experience if there is routine to their day. Such is the reason for a routine in school each day. Children with disabilities have been found to really need a routine in their day for optimal development. Therefore, it is prudent for the respite cooperative coordinator, a team of volunteers or a group of the participating parents to develop a routine for the cooperative. This schedule would, of course, be affected by the following variables:

- time of day
- length of time of the cooperative
- facility
- ages and disabilities of children

A typical routine for a cooperative held beginning at 4 p.m. would include, but not be limited to, the following:

- Circle Time- welcome, getting to know each other, songs.
- Outside Play- best if the facility has a fenced-in area.
- Snack Time or Meal time- according to what has been agreed upon. The parent(s) should bring this snack or meal to co-op for the children they have participating and mark clearly each container with the respective child's name.
- Story Time- story telling, reading books or lesson, and songs
- Activity- planned game, such as balloon volleyball, duck-duck-goose, etc...
- Arts and Crafts- painting and Play-doh have been favorites
- Movie time- watching a child-oriented video (Be sensitive to what may be objectionable to some parents yet not to others. For example, Power Rangers is too scary for some kids.)

## ***Suggestions***

- We have found that it works best if certain volunteers have specific responsibilities, such as telling a story, doing a craft, leading an activity, shadowing a certain child or being in charge of a certain area of room or playground. If their responsibility for one of these is completed, they would then pitch in and help where needed for the balance of the time at the cooperative.
- Some co-ops have separated older children with a separate volunteer to lead their activities. This has worked well since some of the younger and/or children with certain special needs prefer a quieter, more structured environment and routine.
- When planning arts and crafts, simple is best. More involved crafts such as t-shirts, gifts for parents, etc. are great for special occasions, but remember to schedule more help to assist with these activities.
- Some co-ops have assigned parent volunteers to bring the video for each co-op.
- At snack time or mealtime it works best to assign volunteers to specific children that require assistance and be sure to double check the names on food and drink containers. This avoids germs being spread from child to child and meets appropriate diet concerns.

## THE PARENTS

### ***Letter to the Parents***

Some parents are truly unaware of their need and their family's need for respite. We created a flyer that gives personal testimonies from families about their need for and benefit from respite that appeals even to the parent who may be hesitant to admit need for respite. A draft of the flyer, which we mailed out, is in the Appendices (see Appendix J—Flyer for Mail out to Parents).

We have also included a bulletin insert (Appendix K) for any of the faith communities to use within their worship service bulletins so that parents who may be interested or volunteers who are needed might learn of the cooperatives.

### ***Need for Respite***

A tool used by early interventionists or service coordinators, this insert flyer found in Appendix L—MICH Brochure—can quickly introduce families to their need for respite and to the opportunities or resource options. It is essential to remember that some families often see respite as a luxury—an opportunity for only the well to do. Other parents don't recognize their need for respite nor the help that respite can be to their own state of mind and emotion and that of their family's. This is very important for everyone, service coordinators included, to awaken parents to their need and opportunities.

### ***Parent Responsibilities***

Parent(s) as the leader(s) of their families—those who are served through the respite cooperative—have a responsibility to the cooperative. The following outlines what parents should be expected to do in order to benefit from the respite care the cooperative provides:

- To fill out the *Family Notebook for Respite* and keep it updated.
- To bring the notebook with you to every co-op.
- To attend initial training or serve the first one to two times until trained.
- To learn as much as you can about caring for the other children in co-op, as well as sharing as much as you can about your child with the other parents and volunteers.
- To serve at appointed times in caring for the children or as parent coordinator.
- To be sure that any changes in care or medication have been shared with coordinator before you leave your child.
- Be prompt at picking up your children at the time appointed.
- Find out if there were any questions or problems with or about your child, and follow up.
- Encourage and thank volunteers every time you see them. They need to know how much this means to you and your family.

## FAMILY RESPITE NOTEBOOK

The *Family Notebook for Respite*—the tool that keeps the respite cooperative an informed and safe opportunity—has proved to be most valuable. At one cooperative, a child began crying and the parents serving that day just couldn't calm her, so the volunteers and parents at the co-op read her family's notebook and found the exact trigger for her tears and the plan for calming her.

We used similar resources, used by permission from other states and programs, to come up with our first draft of this notebook. It is designed so that parents may pick and choose from the pages that are applicable to their family and respite situation. Our first draft was 19 or so pages. We thought this to be too long, so we went to the experts--other parents within a local committee. They returned it to us saying they liked it and adding a few pages of their own, especially some request for information that applies to an autistic child. The final product is a very thorough resource of which parents fill out only those pages which apply to their child.

In each respite cooperative, the parent(s) from each family completes this and brings it with their child to each cooperative. It is a vital tool in the training of the volunteers. Volunteers can read and learn more and more about the children. The more they know, the better care they can provide.

Because of it is essential for safety and quality of care for each child, no family is allowed to leave their child at a cooperative without his/her accompanying *Family Notebook for Respite*. A copy of the *Family Notebook for Respite*, which we give each family to fill out, is included here in Appendix M. A Spanish version of the same is available upon request. Just call Family Connection of South Carolina, 1-800-578-8750.

## GLOSSARY

Even within the respite movement in the United States, different terms refer to different individuals. A good example of this is caregiver and provider. For the purposes of this document, a caregiver and a provider will be defined as follows. Find other definitions as well.

**Caregiver** – the parent or individual providing care for the child all the time.

**Provider** – the person who provides respite care so the caregiver can receive a break.

Again, although other organizations may use the following terms differently, we will define the following important terms as follows:

**Cooperative Site** – location where respite is provided (could be a church, synagogue, mosque, childcare center)

**Faith Community** – location of respite site and/or the people who make up the “body” of that church, synagogue, mosque or other.

**Parent** – participant in cooperative that is leaving children in your care.

**Parent coordinator** - the parent who schedules dates for parents to serve, calls parents to remind them of co-op, and to get numbers of children coming to report to the program coordinator.

**Parent volunteer** - the parent who is serving as a volunteer on their date to serve.

**Program coordinator** - the person who has the overall coordination of the respite program and is the liaison to the local faith community or civic organization. This person can include the responsibility of the parent coordinator in his/her job where appropriate.

**Volunteer** - those who volunteer to do childcare during a coop.

**Team Leaders** - volunteers who coordinate activities during the co-op. (art, music, games, etc.)

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## **APPENDICES**

### ***Appendix A – Respite Care for Children and Families in South Carolina***

#### **RESPITE CARE FOR CHILDREN AND FAMILIES IN SOUTH CAROLINA**

#### **A REPORT OF THE COMMITTEE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS OF THE SOUTH CAROLINA MATERNAL, INFANT, CHILD HEALTH COUNCIL March 22, 2000**

The need for respite care for families of children with special health care needs in South Carolina is reported by parents and professionals to be a pressing concern. It is the purpose of this report to present an overview of the current state of respite care for these families, including need for respite care, availability of respite care, benefits of respite care and recommendations for future direction in this area.

#### **DEFINITION OF RESPITE CARE**

At the outset it is important to define respite care. In its simplest form, respite is the temporary relief of care giving responsibilities. Every parent at some point feels the need for respite from the daily demands of child rearing. Respite care for families of children with special health care needs, however, is a much different matter. These families provide care, which is often extraordinarily complex and time consuming, on a 24-hour, 7-day-a-week basis for children with developmental disabilities, physical disabilities, chronic illnesses and emotional and behavioral disorders. In such situations, the provision of respite care simply means that someone else steps in to care for the child for some number of hours allowing the primary caregiver, and perhaps other family members the opportunity to step back from the overwhelming demands of care. Respite of this kind enhances the primary caregiver's ability to continue to provide appropriate care for the child over many months and years. It also helps to preserve the family unit and reduces the risk of abuse and neglect. Ideally, respite care should be flexible. It might be provided in the home, community or residential settings, by paid staff, volunteers, family or friends, all of whom should have received appropriate training and should be appropriately supervised.

#### **NEEDS ASSESSMENT AND AVAILABILITY**

In both research and practice, nationally and in South Carolina, respite care has been the need most frequently identified by families of children with special health care needs (Family Connection of SC, 1997; Congressman George Miller, 1994; Cohen & Warren,

1985). In a February 1997 survey of its Family Partners who are parents of children who have life long disabilities, Family Connection of SC, Inc. identified respite services as a critical need, especially in rural areas. The SC Developmental Disabilities Council, in its 1996 state plan, identified respite services as one of the six major service priorities. In a 1996 survey of parents, the Kershaw County Disabilities Board found that respite care was the major barrier to parent participation in a parent support group. In 1996, two regional Children's Councils of the BabyNet early intervention system independently identified respite care as one of two primary prevention efforts needed to prevent abuse and neglect of children with disabilities.

The most current assessment of children with special health care needs in South Carolina was completed in 1995 by the University Affiliated Programs of the University of South Carolina (Lopez-De Fede et al, 1995). This assessment identified 187,000 children in our state with one or more diagnosed special needs. Some of these children and their families receive a range of services through state agencies including the Department of Disabilities and Special Needs, the BabyNet Program—early intervention for children, birth to age three—and the Children's Rehabilitative Services Division of the Department of Health and Environmental Control, the Department of Social Services and the Department of Mental Health. Many of these services are funded through Medicaid.

During the calendar year 1998-1999, respite care was provided by two agencies. DDSN reported that 5,539 families received respite care through the MRRD waiver, the HASCI waiver or Family Support. For this same period, DSS reported that 106 families received respite care. In total, respite care was provided for 5,645 families who qualify to receive services from these agencies. *This figure represents three percent of the 187,000 children with special health care needs in South Carolina.*

Parents have described many problems with currently available respite resources. First, there are too few resources/options. Some agencies, such as DDSN and DSS, provide vouchers to pay for respite that is identified by the family. While the voucher system is helpful, families often have difficulty finding someone to provide the respite. Because of the level of care that is often required, teenage sitters are not an option. Family members and friends may also feel uncomfortable providing the necessary level of care. In a 1999 Respite Survey conducted by Family Connection of South Carolina, 99% of parents responding cited "lack of qualified providers" as the greatest barrier to respite care. South Carolina averages fewer than two respite providers per county with Edgefield County having no providers. Additionally, there is a severe shortage of childcare centers both willing and trained to work with children with special health care needs. Of the 4,340 registered childcare centers in South Carolina, only 184 (4.3%) serve children with special needs (SC DHHS, June, 1996).

Another key problem is that all of the above respite services are limited to only those families meeting specific agency eligibility criteria. Despite the numerous agencies offering services, many families fall into the cracks based on type of disability, age, complexity of care, location, income, lack of transportation and any number of other criteria. It is difficult to determine the true extent of unmet need for respite care in South Carolina because most providers document only the respite provided by their agency, not the requests they are unable to serve.

## **WHY RESPITE CARE?**

Although special health care needs in childhood cover a wide range of physical and psychological challenges, they all share two important characteristics. They are long-term, being measured in months to years, and they are universally stressful for both children and families. Very often, they involve complex routines of physical care as well.

Over the past decade, the home has increasingly become a “mini-hospital” in which complicated schedules of medication administration; IV’s and complex therapies need to be integrated with routine family activities. Parents of children with both physical and psychological diagnoses have increasingly become responsible for implementing their child’s treatment and prevention services and serving as their child’s case manager. At the same time, these parents must work and meet all the normal demands of family life. Although children with special health care needs require frequent visits to clinics, therapies and physicians, parents receive no special consideration from employers in regard to parental leave and work schedules. It is estimated that currently fewer than half of all workers receive paid sick leave and fewer receive personal leave days to attend to sick children (Stipek & McCroskey, 1989). Additionally, lack of adequate insurance or funding sources to cover the medical needs of the child often cause overwhelming financial stress.

These multiple responsibilities, as well as the unrelenting demands for daily care of the child, prove to be very stressful for parents. Parent-reported mental health treatment for stress is 2 to 3 times higher for parents of children with special health care needs versus that reported by parents of well children (The Ontario Child Health Study. Cadman, Rosenbaum, Boyle & Offord, 1991). Families exhibit isolation, depression, loneliness and fatigue, which contribute to possible abuse and neglect situations and which may lead to institutional care for the child. Additionally, many marriages end in divorce. These parental impacts are detrimental in and of themselves, and it is important to note that the parents’ response to stress also affects the child. Positive adaptation of the parent and family to the stress of the special health need is a very significant factor in the positive adaptation of the child. Disruption in parenting and family functioning has been found to be one of the primary mechanisms causing further dysfunction in the child (J.M. Perrin & MacLean, 1988b). It is estimated that up to 30% of the children who experience a chronic illness by the age of 15 years may also be expected to be impaired by secondary psychological maladjustment (Pless & Roghmann, 1971).

In truth, it is impossible to separate the well being of the child from the well being of the parents and family. The family not only provides the day-to-day care of the child, but it is also the primary influence on a child’s cognitive and social development. The importance of families in facilitating the development of young children with special needs was emphasized through the passage in 1986 of Public Law 99-457, the Education of the Handicapped Act Amendments. The passage of this law was seen to represent a philosophical shift from child-centered to family-centered intervention (Baryk, 1989, pg. 724). It recognized that the family is the constant in a child’s life and that the needs of the family must be recognized and addressed. As stated by Robert Thompson, “Policy objectives should include meeting the special needs in a way that will maintain a normal developmental course and make parenting less difficult. More specifically, policy initiatives could be directed toward reducing stress and increasing support as ways of

maintaining normal development and fostering family functioning” (Adaptation to Chronic Childhood Illness, pg.295). Public Law 99-457 and the philosophy it embodies remain in effect today under current authorization as the Individuals with Disabilities Education Act, (I.D.E.A.-97).

### **BENEFITS**

The availability of high quality respite care is perhaps the intervention that most directly impacts the well-being of the caregiver and family. The benefits of respite care for families are many and well documented. Results of the 1991 and 1992 ARCH National Resource Centers’ annual evaluation surveys of families receiving respite services documented the benefits in maintaining family stability and prevention of abuse (Huntington & Langmeyer, 1993). Families report benefits including: receiving a needed break from care giving; being able to spend more time with other family members; allowing the family to engage in daily activities; decreasing feelings of isolation; providing needed rest and relaxation; improving ability to cope with daily responsibilities; helping preserve the family unit by decreasing pressures that might lead to divorce, institutionalization, abuse and neglect; and making it possible for people with disabilities to establish individual identities and enrich their own growth and development (Cernock, 1992).

The benefits of respite care are not limited to the parents or family as a whole. Benefits have been documented for both siblings and the child with the special need, as well. Benefits for siblings include the opportunity for time with the parents; the opportunity to meet and talk with other siblings; an enhanced relationship with the child with special needs; and simply having a break. Benefits for the child with a special need include the opportunity to develop relationships with other children and adults; the opportunities to develop new skills and show new talents; and a break from constant interaction with parents and siblings. The ultimate benefit of these activities is to enhance the quality of life of children with special health care needs and their families.

## **Appendix B – Risk Management - ARCH Factsheet Number 17, Sept. 1992**

### **RISK MANAGEMENT**

#### **INTRODUCTION**

Temporary childcare programs are built on a trust relationship between the agencies and the families they serve. To maintain a high level of trust, and to protect the people touched by the delivery of service, it is important to have a plan for any difficulties that might be encountered.

To understand risk management and put it in its proper context, one first needs to understand the concept of liability. Liability in a specific situation depends upon whether an individual behaved inappropriately towards another, and, as a result, that person was injured. The inappropriate behavior may be through one's negligence, i.e., failure to behave according to a recognized standard of conduct, or through one's intentional actions, as in the case of assault or breach of confidentiality. If you fail to meet these standards, and your failure causes harm, you become liable for the harm.

In crisis nursery or respite care programs, harm could be caused by a variety of actions done by a volunteer and/or paid staff. Providing direct care services to children who have disabilities, or who are experiencing crises in their lives, and to their families, can be risky. To ensure proper risk management, programs need to develop and implement a risk management program.

Risk management is a structured process for

- minimizing potential liability
- avoiding harm to your clients
- stabilizing your insurance costs
- protecting your agency from ruinous financial losses.

#### **RISK MANAGEMENT POLICY STATEMENT**

Prior to developing a risk management program, develop a policy statement on risk management. This sends a message to staff about the importance of a risk management program. Obtain assistance from your insurance agent or an experienced risk manager. (Check your local United Way, Community Hospital, or your insurance agent; all of them can provide technical assistance in risk management.) The policy statement should include:

- The mission of the risk management program (i.e., to reduce risks for children, families, and the agency)
- The linkage between the risk management mission and the overall agency mission
- The actions staff and volunteers can/should take to manage risks
- The identification of the person in the agency responsible for ongoing risk management efforts (usually the director)

#### **STEPS OF RISK MANAGEMENT**

The steps of risk management are simple and straightforward:

- identify the risk

- analyze and evaluate the risk
- control or eliminate the risk
- protect the agency and the consumers of its services
- manage any failures

***The first step is to identify the risk.*** Take inventory of all the tasks agency staff performs. Identify those tasks that have the potential to cause harm to your clients. Some examples include:

- A child involved in a car accident while being transported by a volunteer
- A child tripping over a loose rug and breaking a bone
- Failure to recognize a child developing a life-threatening illness
- Failure to seek medical care in a timely manner
- A child being treated roughly or abused by a caretaker
- A child being released to a parent or guardian who appears to be incapacitated by drugs or alcohol

The everyday, mundane kinds of activities may be where programs are the most liable. Remember, legally, volunteers are defined as “gratuitous employees,” and should be included in the staff inventory. Programs are liable for the activities volunteers perform while volunteering.

Assess the safety of the program and the facility. Review the agency’s program structure and services, and identify factors that could prevent you from performing these functions in a less risky manner. Some areas to examine include:

- physical plant soundness
- staffing patterns
- supervisor to staff ratios
- education and competence level of staff
- job assignments
- level of training provided

Utilize both internal staff and external consultants to assist in identifying both the areas of risk and the causes of the risk.

***The second step of risk management is to analyze and evaluate the risk.*** There are two questions to ask:

***Is the potential injury significant?***

- If the *risk is significant*, i.e., if it has the potential of causing severe harm to even a few individuals, then actions must be taken to eliminate or reduce the risk.

***How frequent is the risk?***

- Consider how frequently the risk taking activity occurs. The more often an activity occurs, the greater the chance of an injury resulting.

Once you have evaluated the risks, you must prioritize them. Not all risks are equal. For example, an activity may take place frequently, but when mistakes occur they produce insignificant harm. Such activities may require less attention than those that, though they seldom occur, can lead to substantial harm.

***The third step of risk management is to control or eliminate the risk.***

- Educate agency staff about the problems of potential liability risks.
- Develop policies and procedures which will reduce the risk. For example, to reduce the risk of releasing a child to a parent who appears to be incapacitated by drugs or alcohol, develop a discharge policy which is explained to parents when they enter their child in the program.
- Develop an attitude of accountability. All staff has a role to play in keeping clients safe and reducing the liability of the agency.
- Utilize staff and parents to develop the agency structure (policies and procedures) designed to reduce or control the risks.

***The fourth step of risk management is to protect the agency.*** Most agencies do this through liability insurance. The purpose of liability insurance is twofold: 1) to protect the agency and staff from financial loss, and 2) to provide injured parties with funds to cover losses the agency caused. In choosing insurance and obtaining adequate coverage, use the assistance of an insurance consultant or experienced risk manager. There are several publications (listed at the end of this factsheet) that are available to help temporary childcare agencies identify insurance needs. Know what is reasonable coverage for your agency, and shop accordingly. The United Way or similar human service agencies may be able to provide assistance in determining what is reasonable coverage.

Some items to explore regarding insurance coverage for an agency are:

- Whether volunteers and members of the board of directors are included in the policy
- Whether certain events, such as sexual molestation, are excluded from the policy
- Whether professional staff are covered by malpractice insurance
- Whether financial limits on coverage adequately safeguard the agency
- Whether the policy will protect the agency twenty years from now, when an infant client is an adult and brings a law suit
- Whether an employee's or volunteer's vehicle is covered in the policy

***The fifth, and last, step of risk management is to manage any failures.*** Be realistic about the fact that mistakes happen. A staff member may give a child a food item to which he or she is allergic and the child may suffer a reaction. A toddler may fall down and split his/her lip open and need stitches. Whatever the incident, be honest and open about it. Do not try to hide it. Acknowledge the agency's role. By dealing with the situation honestly, the agency will earn respect rather than anger. The way such situations are handled initially may determine the family and community's reaction to the agency.

#### **AGENCY STRUCTURE AS A RISK MANAGEMENT TOOL**

How an agency is structured and staffed can increase or decrease its overall risk. Agency policies and procedures were previously mentioned as a means of controlling or eliminating risk. Agency policies and procedures should exist before providing services, and should reflect the standard of care for the services provided. In addition, the policies and procedures should include the parameters of activities and behaviors for all staff, including volunteers. Examples of such

parameters are policies against child abuse and sexual harassment, and procedures for reporting such incidents. Because these standards of care and parameters of activities and behavior can change, the person designated as the agency's risk manager should continually review and revise the policies and procedures.

Another aspect of the agency structure is the staffing pattern. If the program is licensed by a state agency, staffing ratios will be identified. However, the standard of practice may be to staff above the ratios identified by licensing regulations simply because of the needs of the children served by the program (e.g., children who are medically fragile need a higher adult-child ratio). Licensing regulations may not include supervisor to staff ratios. The type of supervision provided can increase or decrease the agency's risk.

In addition, the job responsibilities of staff can increase or decrease the risk. For example, if a staff person is responsible for monitoring 50 homes, but can only adequately monitor and ensure quality care in 40, the agency lends itself to a higher level of risk.

Agencies that provide in-home services may have special liability concerns. Staff and volunteers are not working in the more controlled and supervised facility-based setting, and parents may assume an added role in overseeing and shaping the service. Nonetheless, through appropriate policies, procedures, and staff/volunteer training, these circumstances may be accounted for by instituting meaningful risk management practices.

An overlooked strategy for increasing the agency's competence in managing risk is the training of staff and volunteers. As part of the initial risk identification process, identify knowledge and skills staff members require to do their jobs. Are training opportunities provided to ensure that staff has the knowledge and skills they need to do their jobs? Does staff have access to ongoing training opportunities to increase their skills? Are they aware of the current best practices?

## **ADDRESSING PARENT CONCERNS AND CONFIDENTIALITY**

Another important area of risk management is the development of policies and procedures to address parent concerns, especially concerns over the care of their child. Good practice dictates involving parents in the decisions concerning their children. Parents should always be apprised of exactly what services the agency does provide. Agencies need to be responsive to the concerns and issues raised by parents. Agencies should have a "grievance" policy which is explained to parents when they apply for services. In addition, parents should be informed of any appeal processes, especially if they are denied services by a public agency.

Agencies should pay special attention to privacy concerns of families. For the most part, confidentiality requirements differ by state. Because many different state and even federal laws control confidentiality, agencies should review their policies with counsel. Parents should be informed of these policies, including the obligation to report suspected child abuse or neglect.

## **SUMMARY**

Temporary childcare agencies need to develop and implement a risk management plan before providing crisis nursery or respite care services, and revise it on a regular basis. Identify the potential areas of risk, analyze and evaluate the risk, control or eliminate the potential risk, protect the agency with insurance, and, if an incident occurs, manage it. The development of thoughtful policies and procedures now will help to prevent serious difficulties in the future.

## **RESOURCES**

*Planning It Safe: How to Control Liability and Risk in Volunteer Programs*, 1992. Available from: Minnesota Office on Volunteer Services, MN Department of Administration, 500 Rice Street, St. Paul, MN 55155.

*Liability in Child Welfare and Protection Work: Risk Management Strategies*, 1991. Available from: ABA Center on Children and the Law, 1800 M Street N.W., Washington, DC 20036.

*Managing Risks While Protecting Children*, 1986. Available from: National Association of Counsel for Children, 1205 Oneida Street, Denver, Colorado 80220, or, American Association for Protecting Children, 9725 East Hampden Ave., Denver, Colorado 80231.

“Nonprofits’ Risk Management and Insurance Sampler” and “Reconsidering Legal Liability and Insurance for Nonprofit Organizations” by C. Tremper. Available from: Nonprofits’ Risk Management and Insurance Institute, 1731 Connecticut Ave. N.W., Suite 300, Washington, DC 20009.

*Risk Management Guide for Nonprofits*, 1987. Available from: United Way of America, Alexandria, VA.

“Am I Covered For..?” *A Comprehensive Guide to Insuring Your Non-Profit Organization*, 2<sup>nd</sup> ed., 1992. Available from: Consortium for Human Services, Inc., P.O. Box 1183, San Jose, CA 95108.

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A special “thank you” to Robert Horowitz, Director of the National Legal Resource Center for Child Welfare, and other members of the ARCH National Advisory Committee’s Liability/Risk Management Subcommittee who reviewed and provided input for the development of this fact sheet.

This fact sheet was produced by the ARCH National Resource Center for Crisis Nurseries and Respite Care Services funded by the U.S. Department of Health and Human Services, Administration for Children and Families, Administration on Children, Youth and Families, Children’s Bureau Cooperative Agreement No. 90-CN-0121 under contract with the North Carolina Department of Human Resources, Mental Health/Developmental Disabilities/Substance Abuse Services, Child and Family Services Branch of Mental Health Services, Raleigh, North Carolina. The contents of this publication do not necessarily reflect the views or policies of the funders, nor does mention of trade names, commercial products or organizations imply endorsement by the U.S. Department of Health and Human Services. This information is in the public domain. Readers are encouraged to copy and share it, but please credit the ARCH National Resource Center.

**Appendix C—On the Volunteer Act of 1997**

**PAMELA DEFANTI ROBINSON, PROFESSOR AT THE  
UNIVERSITY OF SOUTH CAROLINA SCHOOL OF LAW,  
ON THE VOLUNTEER PROTECTION ACT OF 1997  
*PUBLIC LAW 105-19***

**SYNOPSIS AND ANALYSIS**

This synopsis and analysis is offered as an aid to the volunteer administrator in S. C. An attempt has been made to summarize each section of Public Law 105-19 and to follow with an analysis where indicated. The analysis is based on SC law and is only the interpretation of the author; it is not intended nor will it be considered legal advice. Many issues raised by the analysis are yet to be determined by either the legislature or by case law. It is incumbent upon all volunteer administrators to keep up to date on changes and developments in this area. It would be advisable to consider options such as changes in insurance, review the organization's risk management policy and discuss the issues raised by Public Law 105-19 with the policy makers for your organization.

The format for this paper is as follows:

Synopsis (plain text) The author's summary of each section language in the Act.

analysis (***bold italics***) The author's interpretation of the Act with suggestions and questions for volunteer managers.

Another feature of this paper is the extra wide margin on the right. This area is for the reader to make notations regarding follow-up activities, suggestions, or questions.

This paper has been prepared for distribution by Pamela DeFanti Robinson, Director, University of South Carolina School of Law Pro Bono Program, for members of the S. C. Association for Volunteer Administration (SCAVA). SCAVA is the professional organization of volunteer administrators in South Carolina. Reproduction is permitted if credit is given to SCAVA and the author.

The Volunteer Protection Act of 1997  
Public Law 105-9

Purpose: To provide certain protections to volunteers, non-profit organizations, and governmental entities in lawsuits based on the activities of volunteers.

***No real pitfalls in interpretation in this section;***

**SECTION 1. TITLE**

This Act is titled "the Volunteer Protection Act of 1997"

## SECTION 2. FINDINGS

Congress finds that volunteers are willing to serve but are deterred by the potential of lawsuits against them. As a result of the deterrence many volunteer based organizations, non-profits and governmental entities have been adversely affected. They note that volunteers have withdrawn from boards of directors and other types of service. Congress finds a link between the adverse affect of fewer volunteers and the diminishment of services to the communities. Fewer and more expensive programs are a result.

Congress also finds that the deterrence to volunteering based on a fear of lawsuits will affect programs that use Federal funds and which are very successful public-private partnerships. The national scope of such programs was also noted. This section also makes a direct link between the goods and services provided by volunteers, especially in private entities that operate in interstate commerce and the appropriateness of Congress passing a law to protect volunteers. This is a necessary legal connection to preserve the constitutionality of the Act. (article 1, section 8, clause 3) Congress also makes the link to interstate commerce based on the finding that higher liability costs and unwarranted litigation cost will require volunteers and non-profits to face higher costs in purchasing insurance through interstate insurance carriers.

The Act concludes this section with the reasons that Federal legislation is appropriate. They include: national scope of the problem, legitimate fears of volunteers, the expenditure of Federal Government funds and provision of federal tax exemptions for organizations that depend on volunteers. Liability reform will promote the free flow of goods and services, and uphold constitutionally protected rights. Of great interest is the finding that clarifying liability risk is in the interest of the Federal Government, as it is to it's benefit to encourage the continued operation of volunteer services because the Federal Government lacks the capacity to carry out all of the services provided by such organizations and individuals.

***There is a slight chance that someone might challenge the finding linking this legislation to the Commerce Clause of the US Constitution.***

## SECTION 3: PREEMPTION AND STATE NON-APPLICABILITY

This technical section states that the Act is the law of the land unless a state has a law that is inconsistent with the Act. State law that provides greater protection shall prevail.

For this Act to be nonapplicable in state court the legislature of a state must proactively pass legislation whereby this Act would not apply to actions in that state.

***It is unlikely that the SC legislature will pass a law whereby this Act would be declared nonapplicable to the citizens of South Carolina. This means that if a volunteer is sued in State or Federal court this Act will apply. There may be some areas in SC where specific groups of volunteers have special laws that cover their liability. If that law is inconsistent with this Act the state law will apply not this Act. For example, volunteer Guardians ad Litem that operate within the statewide program have a statute that provides them with protection. Both this Act and the state statute have similar language as to the standard to apply, i.e, if the harm is not willful misconduct or gross negligence the volunteer will be protected.***

***It is unknown how a court will deal with the application of this statute and a state law. One theory is that a court would start with the applicable state statute and then***

*pick and choose the sections of the statute that would be best for the plaintiff. The Federal law would be applied only if needed to protect the plaintiff.*

**SECTION 4: LIMITATION ON LIABILITY**

(a) This is the heart of the Act. With exceptions (noted below; see Section 4(d)) no volunteer in a non-profit or governmental entity shall be liable for harm caused by an act or omission of the volunteer on behalf of the organization. The volunteer must be acting within the scope of the volunteer’s responsibilities at the time of the act or the omission; if appropriate or required the volunteer must be properly licensed, certified or authorized by the proper authorities; and the harm was not caused by willful or criminal misconduct, gross negligence, reckless misconduct, or a conscious, flagrant indifference to the rights or safety of the individual harmed by the acts of the volunteer. Of special note is the portion of this section that removes the liability protection if the harm was committed by the volunteer while operating a motor vehicle, vessel, aircraft, or other vehicle for which the State requires a license or insurance.

*The words “on behalf” and “in the scope of” are significant to the analysis of this section. They bring to bear the doctrine of “respondent superior”. This phrase indicates that the master is liable in certain cases for the wrongful acts of his servant. In the world of volunteers the master would be the volunteer administrator or the organization; the servant is the volunteer. All volunteers should be informed about this doctrine and its potential for liability .*

*Below is a diagram explaining the theories of negligence with an example of each in italics:*

<i>Types of Negligence</i>	<i>Example</i>
<i>Simple</i>	<i>Sneeze while driving</i>
<i>Gross, reckless flagrant indifference</i>	<i>Reading the NY Times while driving</i>
<i>Intentional, willful criminal misconduct intent to harm</i>	<i>Aiming your car at a person with the</i>

*As with all tort law there are always the possibilities that other circumstances will affect the outcome. For example, if a person knew that they had a disease that caused them to sneeze hundreds of times a day and still drove this could move the negligence from simple to the gross category.*

(b) Other parts of this section include:  
Non-profit and governmental entities can still bring a civil action against one of their volunteers.

***For example, if a volunteer was working in the kitchen and broke the organization's prize Waterford punch bowl, the organization could still sue the volunteer to recover the loss.***

(c) Non-profit and governmental entities can still be sued for harm caused to any person.

***This brings up the serious and often convoluted issues of vicarious liability, indemnification, and subrogation. First the simple definitions. Vicarious liability is indirect legal responsibility; for example, the liability of an employer for the acts of an employee. Indemnification is the process of restoring a victim of a loss, in whole or in part, by payment, repair, or replacement. Some states provide for special funds to compensate crime victims. Insurance is often a method of indemnifying an organization or person from the cost of a loss. For the purposes of this analysis subrogation is the lawful substitution of the insurance carrier for the insurers. Of extreme interest is the fact that often there will be a clause in the insurance policy that because the insurance company has the right of subrogation the insurance company, not the organization makes the decision of whether or not to sue. For example, in court an organization is determined to be liable for the act of one of its volunteers. The organization is held liable for \$25,000. For public relations reasons the organization decides not to try to recover this amount from the volunteer and just let their insurance cover it. The insurance carrier may invoke the subrogation clause and sue the volunteer to recover the \$25,000. The key for volunteer administrators is to determine whether your insurance process has a subrogation clause and if so work to have it removed.***

(d) Exceptions to volunteer liability protection

State laws that limit liability protection subject to one or more of the following conditions will not be considered inconsistent with the Act. The conditions include:

- State laws that require adherence to risk management procedures including mandatory training for volunteers
- State law that applies the same liability standard for volunteers as it does for employees
- State law which allows an officer of the State or local government to sue a volunteer unless State law prohibits it
- State law which limits liability only if the organization or entity provides a financially secure source of recovery for those harmed by the acts or omissions of a volunteer.

***This is an area that should be watched carefully as state legislative response might be to pass laws to require one or more of the above conditions.***

(e) Limitation on punitive damages based on the actions of volunteers.

The only way a claimant can recover punitive damages for the actions of a volunteer operating within the scope of their duties is to establish by clear and convincing evidence that the harm was proximately caused by the volunteer acting in manner that was willful

or criminal misconduct, or a conscious, flagrant indifference to the rights or safety of the individual harmed. There are exceptions to this limitation. They are:

- ❑ if the misconduct constitutes a crime of violence (defined in USC Title 8 (sect)16) or of international terrorism and the defendant is convicted in any court
- ❑ the misconduct constitutes a hate crime, involves a sexual offense (as defined by State law), or involves misconduct whereby the defendant is found to have violated at Federal or State civil rights law
- ❑ where the defendant was under the influence of alcohol or drugs (as defined by State law).

***Recovery of punitive damages requires a direct link between the actions or omissions of the volunteers and the harm caused. The evidence must meet the evidentiary standard of clear and convincing proof. This means the proof should leave the trier of facts with a firm belief or conviction that the allegations are true. This is not the high standard to be met in criminal cases that require proof beyond a reasonable doubt but is more than a mere preponderance of the evidence. Section 4(e) moves us into the area of damages and away from liability protection. In this section the harm must go beyond simple negligence into the area of gross negligence to arrive at the issue of punitive damages. To recover punitive damages you must face a high standard of proof. For example if while volunteering for your organization a volunteer was found negligent while driving a car, the or she would not have immunity protection; but the limitations on punitive damages may come to the volunteer's aid. The volunteer would still be liable for actual damages.***

***Here is another example of the right hand taking away what the left hand had given; another limitation on liability protection.***

***Another interesting point is that under state law it is unclear what is the definition of a sex offense.***

## **SECTION 5. GENERAL RULES - LIABILITY**

Volunteers will be liable for certain amounts of non-economic loss. The amount of noneconomic loss allocated to that volunteer is in direct proportion to the percentage of responsibility for the harm caused, as determined by the trier of fact. There shall be separate judgements against each defendant declaring the percentage of liability.

***This section should be read in conjunction with Sec.4(a) Liability protection for volunteers. For definitions please look at Section 6. This Federal law applies a pure form of comparative negligence for determining the amount of noneconomic loss a plaintiff would recover. For example in the pure form, if a volunteer was responsible for only 10% of the harm that resulted in non-economic loss, then the volunteer would only be required to pay 10% of that loss. SC uses a not-greater - than version of doctrine of comparative negligence. Plaintiff can recover only if his negligence is not as great as the defendant's negligence.***

***The end result is that in some cases the volunteer could be better off with the application of the Federal law rather than the SC version.***

## **SECTION 6. DEFINITIONS**

Economic loss- any pecuniary loss resulting from harm. This includes loss of earnings and benefits related to employment, medical expenses, replacement services, loss due to death, burial costs, and loss of business or employment opportunities. The losses are to the extent recovery is allowed under state law.

Harm- physical, nonphysical, economic, and noneconomic losses

Noneconomic loss- losses for physical and emotional pain, suffering, inconvenience, physical impairment, mental anguish, disfigurement, loss of enjoyment of life, loss of society and companionship, loss of consortium (but not domestic services) hedonic damages, injury to reputation and all other nonpecuniary losses of any kind or nature.

Nonprofit organization- IRS 501© 3 organizations; and any not for profit organization which is organized and conducted for public benefit and operated primarily for charitable, civic, educational, religious, welfare, or health purposes. Neither type of organization can practice actions that constitute a hate crime.

*This last sentence was placed in the Act to deny protection for members of such groups as the KKK.*

State- means the individual states and a group of territories or districts such as D.C. and Puerto Rico. It also includes the political subdivisions of the states and territories.

Volunteer- an individual who performs services for a nonprofit or governmental entity who does not receive compensation (except reasonable reimbursement for expenses incurred) or any other thing of value in lieu of compensation, in excess of \$500 a year. The term also applies to directors, officers, trustees or direct service volunteers.

*Carefully determine if by providing extra benefits and services for your volunteers you have not removed them by definition from coverage by this Act. Community service programs that provide reimbursement and scholarships at the conclusion of their service are probably not covered. Other service learners, especially mandatory programs should also evaluate the cost of a required course to determine if these students fall under the definition of volunteer. Ironically people who are court mandated to perform community service may be covered. Another interesting point is that the intent to serve is not an issue in defining volunteer but could become an important fact in the minds of any jury.*

## **SECTION 7- EFFECTIVE DATE**

The Act becomes effective 90 days after enactment. The harm must have occurred after the effective date of the Act.

*President Clinton signed this bill into law (P. L. 105-19) on June 18, 1997. The effective date is September 16, 1997*

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Main and Green Street, Columbia, SC 29208

**“Celebrating 10 Years of Making A Difference”**

## **Appendix D - Family Respite Cooperative Proposal**

### **FAMILY RESPITE COOPERATIVE PROPOSAL IN COLLABORATION WITH (CHURCH NAME)**

#### **MISSION**

To provide respite care for families with children with special needs through cooperation among a group of families.

#### **SITE**

(CHURCH NAME) will provide facilities for the group's respite program including appropriate room(s), maintenance and janitorial service. A volunteer coordinator and volunteers may also be recruited.

#### **ORGANIZATION**

The group of families who agree to cooperate will set up simple procedures/guidelines within the first four respite co-op occasions. These guidelines would include:

- the frequency and duration of respite co-op (once or twice a month for 3-4 hours possibly).
- the frequency with which each parent would provide and receive respite break.
- the training of parents in how to provide care—including emergency procedure—for each child using *Our Family Notebook for Respite* as a tool.
- the guidelines for operation—including changes in the roster of providers for a particular co-op time.
- the appointment of one parent as the facilitator—calling parents involved in respite co-op, coordinating volunteers who are mentored in this process (if parents choose to use such), etc. This would be their “co-op service”.

#### **A MODEL—THE WAY IT MIGHT LOOK**

A group of eight families agree that they need respite and would like to co-op. They have a total of 12 children—children with special needs and siblings. Additional volunteers would be recruited to keep provider child ratios appropriate. (CHURCH NAME) agrees to provide a facility for them. The group chooses the first and third Saturday of every month from 5-8 p.m. for their co-op.

The parents complete *Our Family Notebook for Respite*. For the first meeting, the local disability and special needs board may be recruited to provide volunteers so that all the parents and volunteers can meet together. Each family would share information from their *Family Notebook for Respite*. The parents would also go over simple initial

guidelines (see attached)—including a schedule of who will provide respite for the next 4 co-op times. All the parents and volunteers agree to be “volunteers of (CHURCH NAME)” for this respite site. This allows all parents to be covered by their liability insurance. The families familiarize themselves with the facilities (two large rooms).

On Saturday two of the parents and volunteers assigned to provide respite that day would arrive 15 minutes early with their children, providing some time for preparation. The other families would arrive with their children (siblings too), their *Family Notebook for Respite*, and a snack for their child(ren) at 5 p.m. (children would have had dinner before coming.) After signing the appropriate portions of the *Respite Agreement* (found in back of notebook), those parents (six) would be able to get a break for three hours.

At 8 p.m., the parents would return for their children and take a few minutes to debrief, evaluate and have the appointed facilitator make note of needed change for the next time. This process may be best accomplished through use of a *Respite Co-op Follow-up Questionnaire* (a copy is included in notebook).

For the first two to four times the group cooperates, there would be an effort by all families to update the guidelines to suit their co-op, in collaboration with the facility that provides the respite site. Hopefully, by the fifth co-op date, a simple one-page guide could describe the co-op and define procedure. The group would then easily be able to evolve together, with the possibility of growth. Special Connection will always be available for informational support as needed (1-800-578-8750).

## **COST**

Parents would invest their time and energy into making the co-op work. Special Connection would provide all the materials necessary for *Respite* information. (CHURCH NAME) would provide facility, maintenance and volunteers.

## **BENEFIT**

The group family co-op uses families to provide maximum quality respite care by “people who are trained”—parents. No cost to tax payers—just a grass-roots effort to meet an essential need among families.

**Appendix E - RESPITE AGREEMENT**

**RESPITE AGREEMENT**

**CONSENT OF SERVICE**

I, \_\_\_\_\_, hereby give \_\_\_\_\_  
(parent or guardian) (respite provider)  
permission to provide respite service to my child or children: \_\_\_\_\_  
\_\_\_\_\_(list children by name).

By my initials after each point and consent signature at the end of this document, I give my consent to these stated points.

**LIABILITY AND INDEMNITY RELEASE**

I hereby release, indemnify, and hold harmless the above named respite provider from any and all loss or damage to clothes or other personal articles belonging to my child or children named above.

I hereby release, indemnify, and hold harmless the above named respite provider from any and all claims, damages or other liability for injuries to or damage by my child or children named above which are not the result of gross negligence by the respite provider in the provision of respite services.

I hereby give the permission to discipline the above named child or children in a firm and consistent manner, utilizing individual talks, removal of privileges or any other nonphysical punishment appropriate for his/her developmental level. Spanking, emotional maltreatment, or any other form of physical punishment are not allowed at any time.

**MEDICAL CONSENT**

I hereby grant permission in an emergency for necessary and required transportation and medical care, including admission to a local hospital, anesthesia when it is indicated and when it is deemed necessary by a duly licensed or recognized physician or surgeon. I hereby give consent to surgical aid as deemed necessary by the above mentioned physicians. It is understood that a conscientious effort will be made to locate and contact me or the designated emergency contact before any action will be taken.

I hereby authorize the above mentioned respite provider to administer prescriptions and nonprescription medications to \_\_\_\_\_(child's or children's names) as medically indicated. I also give my permission to the provider to consult a doctor for medical care for the above-mentioned child or children.

**CONSENT TO TRANSPORT**

\_\_\_\_\_ I hereby release the above mentioned respite provider to transport my child or children in their personal vehicle which is registered and insured for liability at the minimum level required by South Carolina law. The respite provider shall be the sole driver of this vehicle. Provider's valid driver's license number is \_\_\_\_\_ as registered in the state of \_\_\_\_\_.

Signed, \_\_\_\_\_ Date \_\_\_\_\_  
(parent or guardian)

I, \_\_\_\_\_, the above mentioned respite provider have read and  
(respite provider) seen the initialed and above signed agreement.

Signed, \_\_\_\_\_ Date \_\_\_\_\_

**Appendix F - Volunteer Enrollment Form**

**VOLUNTEER ENROLLMENT FORM**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone: (Day) \_\_\_\_\_ (Evening) \_\_\_\_\_

In Case of an emergency contact: \_\_\_\_\_

Relationship: \_\_\_\_\_ Phone Number: \_\_\_\_\_

**I. Skills and Interest**

1. Education background: \_\_\_\_\_
2. Current occupation: \_\_\_\_\_
3. Employer Name and Address: \_\_\_\_\_
4. Hobbies, skills, interests: \_\_\_\_\_
5. Previous volunteer experience: \_\_\_\_\_

**II. Availability**

1. At what times are you interested in volunteering?  
 Am flexible       Prefer weekdays       Prefer evenings  
 Prefer weekends       Prefer days       Other: \_\_\_\_\_
2. Do you have a means of transportation?     Yes     No

**III. Background Verification**

1. Have you ever been convicted of a felony criminal offense?  
 Yes       No
2. Have you ever been charged with neglect, abuse or assault?  
 Yes       No
3. Have you ever been convicted of neglect, abuse or assault?  
 Yes       No
4. Has your driver's license ever been suspended or revoked in any state?  
 Yes       No
5. Do you use illegal drugs?  
 Yes       No
6. Do you have any physical limitations or are you under any course of treatment, which might limit your ability to perform certain types of work?  
 Yes       No

If you answered yes to any of the above, please explain \_\_\_\_\_

---

Please list two non-family references whom we might contact:

- a. \_\_\_\_\_ Phone: \_\_\_\_\_
- b. \_\_\_\_\_ Phone: \_\_\_\_\_

**Appendix G - Volunteer Childcare Job Description**

**VOLUNTEER CHILDCARE JOB DESCRIPTION**

**QUALIFICATIONS**

Childcare providers will work under the supervision of the program Coordinator or parent providers.

**RESPONSIBILITIES**

*Volunteers will work collaboratively with program Coordinator to carry out the following responsibilities:*

- Provide direct child care;
- Follow all policies and procedures.
- Conduct group and individual play activities; prepare children’s snacks as necessary. The child care areas must be returned to the condition in which they were found;
  - ❑ Volunteers may be asked to change diapers, dress or undress children, prepare food for snacks, help feed younger children and assist in clean up.
- In the event of any injury or illness the Program Coordinator will be notified immediately and an incident report must be completed. {see attached }
- Maintain Confidentiality regarding family information or incidents that may occur during a respite coop. This means that any conversations I have with the families will be kept private.
- Monitor and notify the Program Coordinator of the need for supplies;
- Performs related tasks as assigned.
- Log all volunteer hours on log sheet provided

**VOLUNTEER PHILOSOPHY**

*Offering caring support to children during respite in an established childcare setting is essential to a successful Co-op.. Without the support of a dedicated group of committed volunteers respite would not be possible. Offering childcare, in many cases, is the only way that parents are able to get a break. **Thank You!***

**I have read and fully understand this job description as it relates to my responsibilities working in coordination with \_\_\_\_\_ to provide childcare at their respite sites.**

**Signature of Volunteer:**

\_\_\_\_\_

**Date:** \_\_\_\_\_

**Signature of Program Coordinator:**

\_\_\_\_\_

**Date:** \_\_\_\_\_

## **Appendix H - Policies and Procedures**

### **POLICIES AND PROCEDURES PARENT VOLUNTEERS / VOLUNTEERS**

Policies and Procedures to follow when providing childcare on behalf of Family Connection of South Carolina, Inc. are as follows:

1. Only the Respite Program Coordinator is allowed to sign children in or out. Only parents are allowed to drop off and pick up their children.
2. Parents must leave the number where they can be reached, preferably of their cell phone or pagers at time of leaving child.
3. Parents must sign a respite agreement each time they drop off their child.
4. Respite notebooks must be left with the child/children at the time of drop off. **No Exceptions.**
5. Each family is responsible for bringing a change of clothes, wipes, diapers or extra underwear and snacks for each child.
6. One provider must be CPR and First-Aid trained.
7. A First Aid Kit will be on site at all respite locations. In the event of an injury or illness the Respite Program Coordinator must be notified immediately.
8. Please no smoking.
9. The ratio of caregiver to child should be 1 to 3 plus program coordinator. All siblings are welcome.
10. To promote proper care, each child must be in the presence of at least two caregivers at all times.
11. If you notice any unsafe behavior, or if a child seems sick or hurt, please report this to the program coordinator.
12. If your child shows **any** sign of contagious sickness, please do not attend the cooperative.
13. Diaper changes: Gloves must be worn during each diaper change and when assisting with toileting. Soiled diapers or clothing must be placed in a plastic bag.
14. No physical punishment will be administered.
15. The respite site must be kept neat and tidy. Please be sure to leave the area as it was found. All trash cans must be emptied, especially diaper receptacles.
16. Log all volunteer hours at the completion of each cooperative.
17. Volunteers should arrive 15 minutes prior to the co-op to assist with any set-up necessary.
18. In the case that you cannot serve on your scheduled day, please try to find someone who can trade days with you. If a replacement cannot be found, contact the Respite Program Coordinator immediately. In case of tardiness or absence, please notify the Respite Program Coordinator immediately or the designated parent provider for the cooperative.

**Appendix I - Accident Report**

**INCIDENT REPORT**

\_\_\_\_\_ **ACCIDENT REPORT**

\_\_\_\_\_ **ILLNESS REPORT**

Name of child: \_\_\_\_\_

Date and time of accident/illness: \_\_\_\_\_

Place of accident: \_\_\_\_\_

Nature of injury: \_\_\_\_\_

---

What happened? (use back of page if needed) \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Caregiver(s) at time of accident or illness: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Action taken: \_\_\_\_\_

Administered by: \_\_\_\_\_

Was the child taken to the hospital? If so, where and by whom? \_\_\_\_\_

---

Respite Coordinator Signature: \_\_\_\_\_

Parent Provider: \_\_\_\_\_

Parent/Guardian Signature: \_\_\_\_\_

## ***Need a Break?***

### ***How about three hours of time to yourself or spouse or friend?***

We all need to be sure that we are taking the necessary breaks from caring for our children, so as research shows, we can better care for them.

#### **Have We Got a Deal for You!**

With Special Connection of Family Connection of SC, Smith Presbyterian Church has opened its doors to a Family Respite Cooperative. Parent-initiated, parent-designed and parent-run, this co-op is designed to meet the needs of the cooperating families the [third Saturday of every month]. Parents take turns serving as lead volunteers along with other volunteers to provide quality care for our children (including siblings). One parent from each family has to serve every third or fourth co-op.

#### **It works!**

#### **Here is what parents involved in a respite co-op have to say!**

The parents who give respite know the children and we have become a close-knit group. By us providing respite, we get to know what the routine is like when we are not there. It also makes me feel good to have a member of Family Connection there.

Cindy Lacy

With seven kids, it has definitely helped. My oldest child is mentally retarded and for one hour with a sitter, it cost \$10.00. It is a wonderful break. My wife and I can date again!

Gary Gagliostro

There is at least one person there every time that knows my child.

Sherry Larson

- if you would like a break every month on the 3<sup>rd</sup> Saturday, and
- if one adult in your family is willing to volunteer when it's his/her turn,

**WE WANT YOU TO JOIN US!!**

**The Family Respite CO-OP**

**Contact: W.C. Hoecke 252-0914**

**Hope to have you take part in this wonderful opportunity!**

***Appendix K – Bulletin Insert for Faith Communities***





## Appendix L – MICH Brochure

### Leave my child?

**But she's my responsibility!**

**How can I take a break?**

**Why should I use Respite services?**

That's what each of us said after our children with special needs were born. It was our primary concern to get them whatever they needed to develop as typically as possible. How could that happen if we weren't with them every moment?

Is this the way you feel or think? Another parent shared these insights with us; we found them very helpful in our thought process:

- Your child, no matter how severe the disability, **can enjoy a break from home and family.**
- You will be a **more patient parent** when you are with your child, if you take some time for yourself.
- Your **marriage** and significant relationships can really benefit from you taking a break together.
- Your **other children** will appreciate it when you take a break.
- Your **child's abilities and gifts** can be appreciated, and often discovered, by someone other than those with whom he lives.
- Many families in our state are eligible or have respite options available but are not aware of them.

Try taking a break from parenting and caregiving.

**You deserve it!  
Your family deserves it!**



### Where do I begin?

Start building relationships with those who can learn to care for your child so that you can get away. There are respite services that your child may be eligible for. Talk with your Service Coordinator, Early Interventionist, Caseworker, or Family Connection Family Partner or Support Parent.

Remember these things:

- It requires a leap of faith on your part to break away and trust someone else to care for your child.
- Start small! (Stay with the care provider the first time, then take one or two hour breaks to begin with.)
- Start when your child is young. It's easier to find a provider.
- See it as an investment in relationships: the more we build these, the more opportunities we will have. Caregiving providers make an investment in your whole family.
- Cooperate with other families to trade off care. There are even sites in South Carolina where parents have created respite cooperatives that they "own".
- We will be better people to relate to, to live with and to work with when we take time to take a break.

Take it from us, parents who used to feel that we could never take a break from caring for our child,

**Taking a Break  
IS OK!**

A message from parents who wish that they had heard this advice earlier.

## **Appendix M – Training for Reporting of Child Abuse and Neglect**

Most of us do not abuse or neglect children. Still, every parent or caregiver needs to know something about abuse and neglect. This is **especially true** for families of young children with disabilities.

The fact that young children with disabilities are **twice as likely** as other children to be abused or neglected shows how serious the problem is. There are other reasons to be aware. If it occurs, abuse or neglect can **add to** the challenges the child already experiences. Abuse or neglect may cause a child to **lose** skills he or she has already learned.

No matter who you are parent or caregiver, knowing more about abuse and neglect will help to protect your young child. If you ever suspect a child is not being treated properly, knowing more will help you decide what to do.

What are signs of possible abuse and neglect in infants and young children?

If a young child with a disability were to be mistreated, the child **probably would not be able to tell someone what happened**. This is why parents and other caregivers need to **know the signs** of possible abuse and neglect. Some signs may be subtle, like a change in your child's behavior that can't be explained. **Know your child and know your child's disability**. If he or she has difficulty with balance, bruises may not be signs of possible abuse. **Parents are the best judge of whether your child's appearance or behavior has changed**.

Some of the signs of possible abuse and neglect are listed on the next two pages. Signs for infants are shown first, in two groups: physical signs that can be seen, and other signs that have to do with how a baby acts.

The signs for young children are grouped by three types of abuse and neglect. If you think your child may have been abused or neglected and **any combination of these signs** are present, call your county office of the Department of Social Services or the South Carolina Cares for Children number listed on the next page. **If you have any other reason to believe abuse or neglect has occurred, call for your peace of mind**. Help will be provided.

Remember as you read the lists that these are signs of **possible** abuse or neglect. Some signs are usually easy to see, such as physical injuries. Others, like odd behavior, may be less visible.

\*It is possible for a child to show one or more of the signs and no abuse or neglect has occurred.

## **Possible Signs of Abuse or Neglect in Infants**

- Unexplained breathing difficulties
- Unexplained bruises or marks
- Blood in diapers
- Unexplained bruises, marks, or wounds around the genital areas or by the mouth
- Contact or immersion (placed in hot water) burns
- Bulging or other change in the soft part of the scalp known as the “soft spot”

## **Other Possible Signs**

- A sudden dramatic change in alertness or attentiveness
- Unexplained extreme agitation toward self or others, places, or objects
- Unexplained loss of cooing or attempts at language
- Less or little smiling, eye contact, or exploring

## **Physical Abuse (Does the child....)**

- Have unexplained burns, bites, broken bones, or black eyes?
- Have unexplained fading bruises or other marks?
- Seem frightened of the caregiver and protests or cries when it is time to go home from school, church, etc.?
- Shrink at the approach of adults?
- Talk about injury by a parent or another adult caregiver?

## **Physical Neglect (Does the child....)**

- Have unexplained school absences?
- Beg or steal food or money from friends or classmates?
- Lack needed medical or dental care, immunizations, or glasses?
- Appear consistently dirty or have severe body odor?
- Say that there is no one at home to provide care?

## **Sexual Abuse (Does the child....)**

- Have unexplained difficulty walking or sitting?
- Have unexplained difficulty with urination?
- Demonstrate bizarre, sophisticated, or unusual sexual knowledge or behavior?
- Have a venereal disease?
- Have unexplained new fears which need reassurance (such as a sudden fear of males or females, of being touched, or of going to a particular place)?  
Talk about possible sexual abuse?

## **Reporting of child abuse and neglect**

Any time that child abuse or neglect is suspected, the caregiver should contact the respite coordinator, church staff or a child protection agency. Agencies are required to respond in a timely fashion and determine the child's safety. The parent or provider may worry that the report will endanger their relationship. They also may question their ability to determine whether or not abuse actually has occurred.

Reporting allows **someone else trained** in this area to make this determination. The "goal" of child protection agencies is not to remove children - unless they are in clear danger - but to make sure that children live in a safe environment. Sometimes, that may require that parents attend parenting classes, or a volunteer is dismissed. It may mean that basic resources must be provided to the family. Removing the children from the home or coop is a **last resort**.

Ideally, child abuse should be prevented rather than be treated after it has occurred. Frequently, parents benefit from having another adult to talk to in order to maintain a sense of balance and break the isolation. Respite providers can be an appropriate outlet. **Respite care** is another important intervention for all families. All parents/caregivers need a break at some point, especially when responsibilities increase during times of crisis. Support and educational groups allow parents to problem-solve alternative methods of discipline and punishment and provide adult conversation with others in a similar situation.

Although making a report to child protective services is serious, it is important to remember that a referral is in the **child's best interest**. It also is important for the caregiver to make the report in a way that reduces the risk that the relationship between the Family and the caregiver will be jeopardized.

If you feel a report is warranted, talk to the respite coordinator or church staff and allow them to fill the report. If a volunteer of the coop is suspected parents will always be informed. If a parent is suspected the faith community will chose whether they will tell the family about filling a report. For example, they suspect that a young child is being left unattended or is being hit too hard and too frequently, the faith community may chose to share there concern and the fact that they are filling a report with the family. Be as honest and straightforward as possible. Explain that you are legally required to report based on possible harm to child, not as an accusation against the parents. Your relationship with the Family may be strained for a while, but the foundation of trust will remain. When you do make a report, tell the intake worker what you have observed and relate your concerns. There is no need to share other personal and private matters not pertaining to the suspected abuse shared by the Family with you in confidence.

Try to remember that the vast majority of families love their children and want to make a good family. They may be under tremendous strain or not have the skills to parent effectively at this time. Your support as a respite provider and the help of child protective services may allow them to better express their love for their children. This is one of the best times to practice being non-judgmental and balances the protection of the child with compassion for the family.

# Reporting of Suspected Child Abuse or Neglect

*A Summary of South Carolina Statutes  
S.C. Code Ann. ( Supp. 2001)*

## **Mandatory Reporters** §20-7-510(A)

The law requires certain professionals to report suspected cases of child abuse or neglect. These Professionals are:

- Physicians, nurses, dentists, optometrists
- Medical examiners and coroners, and their employees
- Any other medical, emergency medical services, mental health, or allied health professionals
- Christian Science practitioners, religious healers
- School teachers, counselors, principals, assistant principals
- Social or public assistance workers
- Substance abuse treatment staff
- Child care workers in day care centers and foster care facilities
- Police or law enforcement officers
- Undertakers, funeral home directors and employees
- Persons responsible for processing of films
- Judges

## **When to Report** §20-7-510

Mandated professionals must report when, in their professional capacity, they have received information giving them the reason to believe that a child's physical or mental health or welfare has been or may be adversely affected by abuse or neglect.

## **Where to Report** §20-7-510 (B) and (C)

- When a child is suspected of being abused by a parent, guardian, or other person responsible for the child's welfare, reports must be made to the county department of social services (or law enforcement).
- Mandated reporters are required to report to law enforcement if they have reason to believe that a child is being abused or neglected by someone other than their parent, guardian, or other person responsible for the child's welfare.

## **Failure to Report** §20-7-560

A person who is required to report and fails to do so is guilty of a misdemeanor. Upon conviction, he/she must be fined up to \$500 or imprisoned up to 6 months, or both.

## **Confidentiality of Report** §20-7-510(E) and §20-7-690(E) and §20-7-695

- The name of a person making a report to either DSS or law enforcement must be kept confidential
- DSS and law enforcement must disclose the name of the reporter to one another.
- If the testimony of the reporter is necessary in family court or a criminal trial, it cannot be disclosed that the person was the reporter.
- The name of a reporter can only be released if the court finds that the reporter acted maliciously or in bad faith. The subject of an unfounded case may file an action in family court for a determination that the reporter acted maliciously or in bad faith. The court makes a determination based on review of the case file, oral or written arguments, or both. If the court finds probable cause that the reporter acted in bad faith or maliciously, the identity of the reporter must be disclosed.

## **Immunity** §20-7-540

- Persons who report, participate in the investigation resulting from a report, or participate in court hearings, acting in good faith, are immune from civil and criminal liability.
- Immunity covers full disclosure of all the facts that led the person to reasonably believe that a child was or might be abused or neglected.
- Good faith is rebuttably presumed.

**Photographs and Medical Examinations** §20-7-530

- Persons required to report may take color photos of the areas of trauma visible on a child who is the subject of a report.
- Physicians may order X-rays or other medical examinations or tests if medically indicated, without the consent of the child's parents or guardians.
- Copies of all photographs, negatives, and medical reports must be sent to DSS at the time of the report, or as soon as possible

**Privilege Abrogated** §20-7-550

The statutes expressly abrogates (voids) privileged communication between husband/ wife and professional/ patient or client for purposes of reporting child maltreatment. The only exception is privileged communication between attorney/ client and priest/ penitent.

***Appendix N - Guidelines for Mandatory Reporters***

## **Responding to Child**

- Listen attentively while the child is talking to you.
- Do not probe for details, particularly concerning sexual abuse. (Proving sexual abuse in court often depends heavily on the child's statement. Discussing details of the abuse with the child is essentially the handling of evidence, and should only be done by trained investigators.)
- Do not indicate doubt or disbelief.
- Do not express shock or anger at the possible perpetrator. Children often love the person who mistreats them.
- Tell the child what you will do, e.g. that you will contact DSS and a caseworker will come and talk with the child.
- Do not give the child false assurance.

## **Making the Report**

- Make the report as soon as possible after receiving the information which causes you to suspect abuse or neglect.
- Do not wait for proof. The law requires you to report when you have "reason to believe."
- Do not try to investigate yourself or excessively question the child. Leave the investigation for caseworkers or law enforcement officers who have been specially trained.
- Follow your employer's procedures regarding notification of supervisors or others. However, remember that you are required by law to report and agency policy cannot disallow this.
- Collect as much of the following information as possible to convey to the investigating agency: child's name, age, date of birth, and address; child's present location; names and ages of siblings; parent's names and addresses.
- Although reports can be made anonymously, it is often helpful to provide your name and address in the event that further information is needed.
- At the time the report is made, you can request to be notified as to the outcome of an investigation.

## **Documentation**

- Document the basis of your concerns, including physical and behavioral signs.

- Document the child's statements to you, as closely as possible to exact words.
- Document the child's demeanor while talking with you. Note any signs of fear or distress.
- If you make the report orally, record the date, time, and the person and agency you contacted. If you make the report in writing, save a copy of the correspondence.

### **Contact with Parents**

- Consider whether you should inform the parents of the report depending on the type and extent of maltreatment, who the perpetrator may be, and your organizational setting. For example, if the child reports physical abuse and the parent is volatile, informing the parent before appropriate intervention can be made may set the child up for additional abuse. On the other hand, if the child is chronically neglected and your organization provides services to parents, informing them of the report may preserve a relationship with them and set the stage for future help.
- Never accuse a parent of abuse or neglect. Explain that you are legally required to report based on possible harm to child, not as an accusation against the parents.

### **Follow-Up**

Your continued help may be necessary. All professionals and agencies must work together to improve outcomes for children. Be willing to meet with multidisciplinary teams and/or testify in court if requested.

## ***Appendix O – Family Respite Notebook***