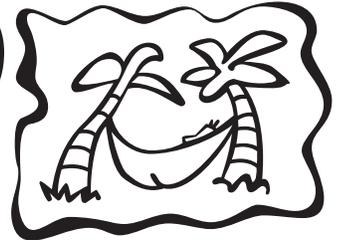


# A PRACTICAL GUIDE TO RESPITE FOR YOUR FAMILY



**By Molly Dellinger-Wray  
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Effective September 1, 2002, the Virginia Institute for Developmental Disabilities (VIDD) became the "Partnership for People with Disabilities."

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Virginia Institute for Developmental Disabilities  
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This guide represents the efforts of many dedicated individuals and was developed to assist in meeting the need for a practical resource for family members of children with disabilities and chronic or terminal illnesses. *A Practical Guide to Respite for Your Family* is designed to be used by family members and by professionals assisting families in finding and accessing respite options.

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## How to Use This Guide

This guide provides information on finding and using respite resources for your family. Information and resources include:

- ☆ Exploring respite options in your community.
- ☆ Checking out agencies and respite sites.
- ☆ Finding and hiring a respite provider.
- ☆ Getting to know your respite provider.
- ☆ Preparing your home for respite.
- ☆ Using your respite time well.
- ☆ Ensuring that your respite experience is successful  
AND MUCH MORE!!!!



There is a great deal of information and many forms and resources. You may or may not want to read through the entire book. Feel free to turn to the sections that interest you or that you are concerned about. Also, sample forms are provided. They offer suggestions for the types of information you may want to share with your respite provider. Select and use the form(s) that best meet your needs.

# Introduction To Respite!

*“I find that I’m much happier and a better parent when I’ve had some time for myself, even if it’s only for a little while.”*

## **What is respite?**

---

Respite means getting a temporary break from the caregiving responsibilities of being a parent of a child with special needs. Respite is well-deserved time off. It can range from a few hours to a week or more, and may occur in your home, another home, or a community setting. Respite typically occurs on a planned basis, however sometimes emergency care is needed. In many respects, respite is just like babysitting, only it goes beyond that to include the many other ways that families get relief from caregiving.

A respite break could free up 30 minutes a day to take a nap or enable a parent to have 2 hours to run an errand. Respite can be flexible. It could involve taking your child on a community outing while you remain at home, or having a respite provider stay with your child overnight for a week-end or week-long vacation. The most important thing about respite is that it helps families enjoy their lives more.

*“It took me awhile to get used to the idea of getting help from someone outside the family.”*

Unfortunately, many parents have forgotten what it’s like to get such breaks. In some instances, they have lost hope that anyone can be found who is willing and able to provide even occasional care for their child with special needs. Some may be worried about constantly relying on extended family members, and others have difficulty finding or affording paid respite providers.

## **Why use respite?**

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Consider this:

- ▶ As a parent of a child with special needs, you may need longer or more frequent breaks than other parents.
- ▶ Sometimes when you’re the only one who cares for your child, it’s hard to turn that responsibility over to someone else. Certainly no one can care for your child the way that you do, but to keep up your loving care and attention, you need to take good care of yourself too.

## INTRODUCTION TO RESPITE!

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- ▶ It's common to feel guilty the first time you use respite services. You may feel that you should provide a good home without help from others. Using respite services does not mean that you're an inadequate parent! On the contrary, *asking for help is a sign of strength!*
- ▶ You may be concerned about how you can afford respite services. Many organizations know that respite is a necessity and not a luxury, and some have funds available to help families pay for respite services.
- ▶ No one is healthy all of the time. You may have given some thought to who could care for your family if you became ill or hospitalized. By establishing a relationship with a respite provider, you can call upon someone to help who already has experience with your child, so that care may be provided in an emergency.

*“I realize that my child with a disability often takes up a lot of my time. I want to be able to spend some time alone with my other kids too.”*

Using quality respite services can be a benefit to you and your whole family. Respite can:

- ▶ Provide a chance for your child to meet and spend time with other children and adults outside of your family, and to develop independent leisure and social skills.
- ▶ Offer an opportunity for parents to have time with each other.
- ▶ Give you a chance to spend time with your other children and family members.
- ▶ Reduce stress on your entire family and allow an opportunity to relax together.
- ▶ Allow time for parents to participate in community life.
- ▶ Enable you to be a better parent because you have taken care of your own needs.

# Thinking About Respite Options

*“My neighbor has agreed to come over and watch my kids for an hour in the mornings so that I can take a shower. Is that considered respite?”*

## **What respite options will work for your family?**

---

Respite can occur in a variety of different ways and is not limited to licensed or specialized programs. Some of the best and most frequently used respite happens in the community through friends, neighbors, relatives, and organized groups. Respite can be arranged through agencies or arranged by you. To meet your family’s needs, respite is varied and flexible. No single type of respite service is likely to work for all families all of the time.

Before we look at the different types of respite services, consider first whether you would like care to be provided in your home or in a community setting. The setting that you choose will depend upon your child’s needs, your family’s needs, and the respite opportunities available in your community.

Then we’ll look at the pros and cons of some typical respite services and models. This information will help you consider whether you would prefer a particular setting (home or community) or type (co-op, camp, hospital) of respite program.

## **A quick look at respite provided in your home**

---

*“It was such a good feeling to get some things done because I finally had a few uninterrupted hours where nobody needed me for something!”*

You may prefer that your child be cared for in your own home because:

- ▶ Your child is comfortable in your home and would not have to adjust to a new place with a different routine.

- ▶ Your home is already “child proofed” for your child’s safety and convenience.
- ▶ You can feel secure that you can remain at home as long as you like, until you feel comfortable leaving your child with a respite provider.
- ▶ All of the necessary equipment, food, medications, and toys are within reach and do not need to be transported to another location.

If you think that in-home respite is best for you, consider the following questions:

1. Will you feel comfortable having a respite provider in your home?
2. Will you receive the break that you need with in-home respite services?
3. Would you prefer to use your respite time in your own house doing projects that aren’t possible to do with your child around?
4. Could transportation be arranged for a respite provider who doesn’t drive?

### **A quick look at respite provided in a community setting**

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*“My little girl attends a recreation program at our church on Saturday mornings. Is that considered respite?”*

Any type of respite that you arrange outside of your home is considered community respite. In your area, respite may occur in some or in a combination of several of these places:

- ✓ In the home of a neighbor, family member, or similar nonlicensed provider.
- ✓ In the home of another parent who has a child with special needs.
- ✓ In a respite center, residential program, or group home.
- ✓ In a recreational setting.
- ✓ In a summer camp setting.
- ✓ In the home of a licensed child care provider.
- ✓ In a hospital, nursing home, or hospice for children with medical needs.

You may like community respite because:

- ▶ It provides an opportunity for your child to be out with others.
- ▶ It allows you to entertain or undertake household tasks that are difficult to do when your child is present.
- ▶ It may boost your child's self-esteem because he or she was not left behind while you left home to "have fun."

If you think that community respite is best for you, consider the following questions:

1. Will it be so difficult for you to leave your child in an unfamiliar place that you will not enjoy your respite time?
2. Will your child have trouble getting used to another setting?
3. Will you be able to arrange for transportation?
4. Will packing the clothing, toys, medicine, and other equipment require so much planning that your respite break will not be worth the effort?
5. Will your child receive sufficient individual attention?

### **Respite options: Some pros and cons**

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Here is a review of some examples of respite services. For each option, the advantages and disadvantages are provided. Not all of the respite options discussed here will be available in your community, but this listing will help you clarify what resources would meet your family's needs. With some options, an agency or community group may be available to provide assistance. Often, however, families can proceed on their own to find and arrange respite. Some respite options provide respite in your home, while others use community sites. Many offer the flexibility of either setting.

In addition to the respite options listed, remember that respite can also be provided informally through family members, neighbors, and friends. Many families make use of these supports on a regular basis.

### **Respite Voucher/Stipend Programs**

---

This is the most recent trend in agency-sponsored respite. Respite voucher programs offer an option that makes it possible for families to select the respite service of their choice. Typically, the sponsoring agency uses written authorizations or "vouchers" to designate the amount of respite that can be purchased and the timeframe for use of funds. The agency providing voucher funds may make payment directly to the family, to the program or agency providing respite services, or to an individual respite provider.

### Pros:

- ▲ Respite can occur in many different settings.
- ▲ Families can choose which type of respite is best for them.
- ▲ Programs offer flexibility in assisting with cash needed for the respite desired.
- ▲ Hours of care are flexible.

### Cons:

- ▼ Families typically need to keep track of the amount of hours used per time period.
- ▼ Families may need to pay out-of-pocket first and be reimbursed, depending on the program.
- ▼ Families may need to act as the “employer” of the respite provider (hire, conduct background checks, supervise, train, pay taxes).

## Summer Camps

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Frequently, we forget that many parents have been using summer camps as respite for years! It is a nice alternative to consider because there are so many types of camps available now, from the traditional programs that emphasize outdoor experiences to camps that specialize in music or computer skills. Camps can be overnight, or just day camps. Some camps may specialize in serving campers with disabilities and chronic illnesses, and others may include all children and provide any needed supports for children with special needs.

### Pros:

- ▲ Camps are a typical activity for all children.
- ▲ There are a variety of programs to suit your child’s needs.
- ▲ Your child is exposed to structured activities with peers.
- ▲ Children are cared for by trained staff and volunteers.
- ▲ Camps offer a predictable extended period of respite.
- ▲ Financial assistance is often available.

### Cons:

- ▼ Scheduled sessions usually are not flexible.
- ▼ You may need to check on physical accessibility.
- ▼ You may need to spend time training staff on special care or techniques for your child’s needs.

## Parent Co-Op Programs

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This is a frequently used informal type of respite, in which parents arrange to provide respite for each other. Usually, parents “trade” hours of care by agreeing to provide a certain number of hours of care for a specified time period.

### Pros:

- ▲ Accessible, flexible, and easy to use.
- ▲ No cost to families.
- ▲ Can be in your home or the home of the other parent.
- ▲ Children get to know one another over time and develop friendships.
- ▲ May include care for siblings.
- ▲ Does not require agency involvement.
- ▲ May be helpful when short-notice arrangements are the norm.

### Cons:

- ▼ Requires the “right chemistry” between both parents and children.
- ▼ Involves a great amount of trust in the other parents’ care for your child.
- ▼ May involve more work for parents than they feel it’s worth.
- ▼ Involves an exchange of care, so families may not gain more time through these arrangements.

## After-School Recreation Programs

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After-school programs can be located at a school or a community recreation site. Many after-school programs integrate children with special needs along with their peers. Some programs use staff who are disability specialists to help with activities that involve all of the children. Although some programs may be available daily, often children may participate in the programs as frequently as needed for respite.

### Pros:

- ▲ Located in a school or recreational setting geared for children.
- ▲ Involves interaction with peers.
- ▲ Provides social and leisure skill-building.
- ▲ Fits into families’ work schedule.

### Cons:

- ▼ Requires a long day for the child.
- ▼ Limited to school days and schedules only.
- ▼ Can be expensive.
- ▼ Transportation may be costly or hard to arrange.

## “PARTners” Programs: Parents as Respite Trainers

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PARTners programs provide families with support in choosing and training their own respite providers. Families decide what their respite providers need to know and, with support, families train their own providers. Family members have many choices about how and where they would like respite services to be provided. Once the respite provider has been trained, the family can schedule respite as needed, and the sponsoring agency can help locate financial resources. The PARTners model was developed by Child Development Resources in Norge, Virginia.

### Pros:

- ▲ Allows the whole family to participate in finding an acceptable provider.
- ▲ Can be in the family’s home or the home of the provider.
- ▲ Easy for the family to schedule their own respite.
- ▲ Respite provider is “tailor made” in training to meet the family’s unique needs.

### Cons:

- ▼ Assistance with training requires a time commitment. Some families may feel too pressed for time to dedicate many hours of training before getting any respite.

## Hospital-Based Respite

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This type of respite occurs at a hospital where children may receive care during the day, evening, or overnight. Hospital-based programs have been designed to help families who have children with severe medical problems and health care needs. These programs provide respite services in a skilled environment with established emergency response systems for this fragile population of children whose needs may not be able to be met in the community.

### Pros:

- ▲ Allows the family to feel confident that their child can receive immediate care in case of an emergency.
- ▲ Can provide hourly and overnight care.
- ▲ Can provide “round-the-clock” medical services.
- ▲ Enables other family members to have their home to themselves.
- ▲ Employs skilled nursing staff to take care of unique medical concerns.

### Cons:

- ▼ Child or family may have negative associations with the hospital environment.
- ▼ Does not encourage interaction with peers.
- ▼ Hospital environment is more structured and restrictive than a home or community setting.

## Respitiy Programs

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This type of respite program really gives families a change of scenery and emphasizes spending time just having fun. The respite agency joins in partnership with hotels that have agreed to provide families with free rooms and meals for a specific number of nights. In addition to the luxury accommodations, a respite provider is available to provide care for the children who may either stay at home or come along for the visit.

### Pros:

- ▲ Allows parents a complete get-away, free from all routine responsibilities.
- ▲ Encourages families to have fun.

### Cons:

- ▼ Requires a great deal of organization to leave the house and family for an extended period.
- ▼ May be more time away from home than is comfortable for parents.
- ▼ May be available only on a limited basis.

## Registry Respite Programs

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Some agencies provide a list, or registry, of respite providers. Families can use the list as a resource in locating respite providers. The list includes information, such as the name, address, and phone number of the provider. Other information may be available, such as whether the provider has references, relevant experience, or transportation. Agency involvement varies considerably. Some agencies recruit, screen, train, or supervise respite providers. Others merely provide a list of people interested in providing respite, and the family must interview, orient, train, and supervise the provider.

### Pros

- ▲ Provides families with a list of respite providers.
- ▲ May provide some agency oversight of respite providers (screening, training, supervising).
- ▲ Allows families to select from many providers.
- ▲ Provides respite at the family's convenience.

### Cons

- ▼ Respite providers may not have been screened or trained.
- ▼ Agency may not provide supervision.
- ▼ Respite providers may be hard to reach or have limited availability.
- ▼ List may not be up-to-date.

## How do I decide which type of respite is good for me?

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As you can see, there are advantages and disadvantages to each type of respite. The following chapters will explore finding and checking out respite options that are best for your family. Remember, as your child grows and your family's needs change over time, you may want to explore different alternatives for respite or use multiple options during any period.



## What about the cost?

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Like any type of child care, most respite services are not free. However, many agencies can assist in easing the costs. After you have reviewed the information in this guide, you should have a good idea of what funds you would need to be put aside for your respite needs. Most families find that the freedom of having a respite break is worth the financial burden.

*“Having a respite provider come once a week does cost me money, but for my family and my own mental health, I have made it a priority. I pay for my respite before I pay my telephone bill!”*

# Finding Respite In Your Community

*“I moved to a new community away from all my family and friends, and I didn't even know where to begin to look for respite.”*

Although there may seem to be many opportunities for respite, it may be a challenge to find options that meet the needs of your family. You may prefer that respite be provided in your home or in a community setting. Respite alternatives may be available through a local agency, a generic community program, or through an individual respite provider. This chapter explores strategies for locating specific respite options in your community.

## **Respite “networking”**

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One of the best places to begin your search for respite is to talk with other parents who have a child with special needs. They can make suggestions and give you ideas based on their own experiences. Before you begin to study the established respite programs, consider the informal types of respite, such as family, friends, and neighbors. Another idea to explore is existing community offerings like “mother’s morning out” play groups, recreation programs, and after-school programs.

The next two sections offer some ideas that will help you locate respite that meets your needs. The first gets you started with community agencies that provide respite, and the second offers suggestions for finding your own provider.

## **Finding agencies and programs in the community**

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In addition to your informal contacts that may offer leads, some agencies that provide services to children with special needs also provide respite services. Even if the agency that you call doesn’t have their own respite program, they usually know who does!

Try starting with professionals or agencies that you’re already involved with, such as:

- ✓ Your child’s health care professionals and therapists.
- ✓ Your child’s public school and parent resource center.
- ✓ Your local disability services agency.
- ✓ Your local early intervention program.
- ✓ Your local department of social services.
- ✓ Your local Association for Retarded Citizens (ARC), United Cerebral Palsy (UCP) Association, or Easter Seal agency.

You may also wish to check with agencies that provide other social services. Check your Yellow Pages listings under:

- ✓ Child Day Care Centers.
- ✓ Human Services.
- ✓ Public Schools.
- ✓ Social Services.

And many community programs provide services to all children, so be sure to contact:

- ✓ Your local Department of Parks and Recreation.
- ✓ Your local YMCA and YWCA agencies.
- ✓ Your local religious programs for children.
- ✓ Your local summer camps.

### **What should you say on the telephone when you call to ask for information?**

The person who answers the telephone will have to direct your call to someone who can best answer your questions. It's a good idea to begin by identifying yourself as a parent of a child with special needs. Here are some suggestions:

*"Hello, my name is Jaime Harrison. I'm the parent of a child with special needs and I'd like to know what respite or babysitting services you can offer my child and family."*

*"Hello, I'd like to know what services you provide for children with special needs."*

*"Hello. I'm a parent caring for a child with special needs. I'm looking for a regular babysitter. Do you or your agency (program, school, organization) know of anyone who might be interested in the job?"*



[Adapted from Respite Care: A Guide for Parents, CSR, Inc., 1400 Eye Street NW, Suite 300, Washington DC 20005]

## **Finding your own respite provider**

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You may decide that you wish to find your own respite provider without contacting an agency, or that the agency-sponsored respite requires you to find your own provider. A first step in finding your own respite provider is to explore who you may know in the community.

*“There’s a waitress at a coffee shop that we visit regularly who’s always been really nice to my kids. Finally, one day I asked her, ‘Would you ever want to come over and babysit for us?’”*

Respite providers do not always need to be skilled nurses or people who have been formally trained; they could be family members or friends, as long as you feel comfortable that they can provide quality care for your child. You may know of someone who you feel would be a good respite provider, but haven’t approached them about the possibility of providing respite. Or, you may have a friend or family member who will help you out occasionally, but not on a regular basis.

If you already have a respite provider in mind, a large part of the process of finding your own provider has been completed. If you still don’t have any idea about how to find a respite provider, or would like to find an additional provider, turning to your community may be an important step.

This may seem difficult to do, because if you’re in need of respite already, you probably don’t have a lot of free time to devote to investigating respite options in your community. Thankfully, most of the search can be done on the telephone (cordless telephones have made this task a lot easier, too!). There are countless resources that all families can use to obtain child care. Some of these are listed here:

### **12 Easy Methods for Finding a Respite Provider**

1. Notify a neighborhood church, synagogue, or place of worship.
2. Place an ad on a bulletin board in a place used by many people, such as the laundromat, grocery store, or library.
3. Contact your local senior citizen center.
4. Contact high schools and teen service organizations.
5. Post an ad at the nearest university, college, or technical school.
6. Place an ad in the local newspaper.
7. Contact a “Parents without Partners” chapter.
8. Ask your child’s teacher, aide, or school personnel.
9. Ask your child’s health care worker.
10. Post an ad at a community recreation center.
11. Contact area day care centers or family home child care providers.
12. Contact your area Parent-to-Parent group.

## FINDING RESPITE IN YOUR COMMUNITY

In most cases, it will be necessary to contact the person or organization by telephone. What should you say?

*“Hello. My name is Mary Smith and I’m the parent of an 8-year old child who has a severe disability. I’m considering training and hiring someone to help care for my child on a weekly basis, and I was wondering if you knew of anyone through your organization who’d be interested”*

In the telephone call, be sure to give the organization:

- ✓ Your name.
- ✓ A brief description of your child.
- ✓ How often, when, and where you would like to get respite services.

If the person you’re speaking to isn’t able to help you find someone, ask them to take your telephone number and save it. This way, if they think of someone in the future, they can contact you. Another excellent method is to ask the organization to post an advertisement on their bulletin board. What should the advertisement say?

### **WANTED:**

*Energetic, helpful person to help care for my child in my home for 6 hours per week on Saturdays.*

*Salary up to \$6.00 per hour*

*Some food preparation and cleanup involved.*

*Must have at least two references*

*For more information contact: Maria Sanchez 555-0000*



Advertisements typically include the following information:

- ✓ Characteristics of the person you would like to hire.
- ✓ Schedule of when you would like help.
- ✓ Where you would like respite to occur (your home or another location).
- ✓ Salary information (if you want to determine it with the provider, indicate “Salary Negotiable”).
- ✓ Your name and telephone number.

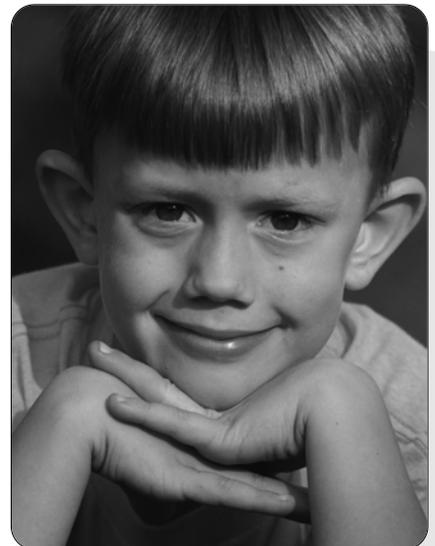
It’s also helpful to make your advertisement stand out by:

- ✓ Using a bright color paper for the background.
- ✓ Attaching a cute photo of your child or drawing by your child.
- ✓ Using neat handwriting or unusual typed lettering.

*I’m a 6-year old boy who needs to have a fun  
babysitter for me and my 2-year old sister.*

*You must like to sing songs, play games, and  
watch videos on Tuesday nights so my Mom and Dad  
can go to their computer class.*

*Mom will pay you and we can have lots of fun.  
Call my Mom, Karen Smith, at 555-0000  
with two references if you’re interested.*



If you find a respite provider on your own, and decide to interview and possibly hire them to provide respite for your child in your home, you may find chapters 6 and 7 helpful. Chapter 6 will help you learn more about your provider, and chapter 7 explores important considerations for hiring your own respite provider.

By now you should have considered what type of respite services would best meet your needs, and also have developed some strategies for locating the services or provider you would like. The next three chapters offer considerations and questions to help you look more in depth at the respite agency, site, and individual respite provider.

# Checking Out Agencies Offering Respite Assistance

*“The night before I visit a respite program, my son and I sit down and make a list of all the things we think are important to ask.”*

In some communities there may be one or more agencies that offer respite. If you decide to use an agency-sponsored respite program, you need to evaluate the service carefully. Even if the agency has a program that allows you to select your own respite provider, you will need to learn about the agency as a first step.

Agencies offer many different options for respite. Some may provide respite at a community site. Some may hire, screen, train, and supervise in-home respite providers. These agencies typically have a registry of respite providers that they match to identified family needs. Another agency may provide only financial assistance in the form of vouchers or stipends for families to independently find and hire their own providers. Another agency may provide families with a list of individuals interested in providing respite who have not been screened or trained.

Most agencies are prepared to explain their program and procedures when you make your first contact. Some agencies will begin by doing an initial interview with you and your child. Usually, you will be asked a number of questions and given some forms to complete.

Although agency personnel will ask you many questions, **this is also your opportunity to ask them questions!** Try to get as much information about the agency’s program as possible. Most agencies will have a brochure or information packet that will have the answers to many of your concerns so that you can refer to it later. If you forget to ask a question, or can’t find the information in the brochure, be sure to telephone that agency and clarify your concerns. Most agencies are used to answering all kinds of questions, so don’t feel that any questions you’d like to ask will sound foolish to them.

The following page contains some questions that may help you get started in learning about an agency. You may wish to copy the form so you can write directly on it, or use the form for more than one agency.

### Questions For Respite Agencies

Do you have written information about your program?

How do you screen your respite providers?

In your program, what training and experience have your respite providers had?

How are respite providers supervised?

May I meet the person who will be caring for my child before receiving respite?

Will I usually get the same respite provider each time that I request respite?

What is the cost of respite services? Is there an overnight flat rate?

Will care be provided for my other children also?

Is there an extra fee for more than one child? For short-notice arrangements?

How is payment arranged? Is there a cancellation fee?

Are there a minimum number of hours that I must use?

Am I limited to a certain number of hours of respite?

What hours are respite services available?

How far ahead do I need to call to arrange for services?

Will your program keep up with current information about my child's medical and other needs? Is there a written plan?

What is the procedure for medical emergencies?

Is respite available on an emergency basis, such as if I become sick?

Do you provide transportation?

What if my respite provider fails to show up at the scheduled time?

My child's questions: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Other questions: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

[Adapted from Respite Care: A Guide for Parents, CSR, Inc., 1400 Eye Street NW, Suite 300, Washington, DC 20005]

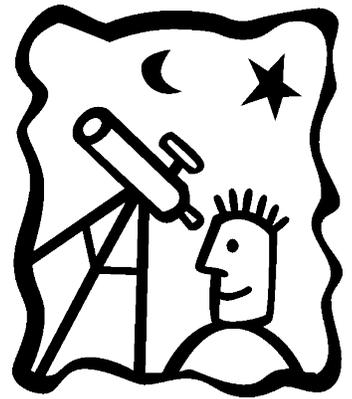
# Checking Out Community Respite Sites

## What should I look for at a respite program site?

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If you have decided that respite at a community site is best for you, you will need to check out not only the agency and the respite providers, but also the actual building or site where the respite will be provided.

Respite sites could include camp settings, recreation centers, hospitals, schools, churches, child care centers, and other community locations.



The best reference for a service will be from another family who has used it. If you do not know another family to ask, you could ask the agency to supply you with the name and telephone number of one of the families who uses their respite service to tell you about their respite experience.

It is helpful to observe the respite program while it's in action. If you have brought your child along with you, encourage him or her to assist you in observing and asking questions about the program.

The following page contains some considerations that may help you get started in checking out respite provided at a community site. Many of your questions may be answered through direct observation of the site and the program. Other questions may be more appropriate to ask staff. You may wish to copy the form so that you can write directly on it, or have an extra copy available for a different site.

### Considerations For Observing a Community Respite Site

**For Observing:**

- Is the indoor environment pleasant, clean, and friendly? Would I like to spend time here?
- Will my child be comfortable with the general noise level?
- Is the environment too warm or cold? Are there any unusual odors?
- Do the respite providers interact with the children in a manner that my child will like?
- Do the respite providers talk directly to the children in a pleasant, appropriate manner?
- What looks like something that my child will love about this place?
- Is there anything that may make my child uncomfortable?

**Questions to Ask:**

- How many respite providers will there be to care for my child? How many other children will be here?
- What happens during the program? What is the daily routine? Are there organized activities?
- How are meals handled? Who administers medication?
- Will my child have an opportunity to rest or nap if needed?
- What leisure equipment is available for my child to use?
- How much time per day will be spent outside? Will trips be made out to the community?
- How is transportation handled?
- Is there a TV? How long is it usually on per day?
- What should my child bring from home to make the stay more enjoyable?
- Is discipline administered? What types of rewards and punishment are used?
- Has the structure been inspected by health and safety officials?

My child's questions: \_\_\_\_\_

\_\_\_\_\_

Other questions: \_\_\_\_\_

\_\_\_\_\_

# Learning About Your Respite Provider

*“I was excited to finally be getting respite, but when the time came to make the final arrangements, I got a little worried. What kind of people are respite providers?”*

## **How do I find out more about the respite provider?**

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If you’ve selected an option for respite that allows you to choose a respite provider either through an agency or on your own, then you’ll need to learn more about your provider. To make your respite experience enjoyable, you need to feel completely confident with the respite provider and the type of respite that you’ve chosen. A big concern is making sure you’ve selected a good respite provider.

The respite provider may come from a variety of sources:

- ✓ From a list or registry of respite providers that an agency provides.
- ✓ From an agency that matches you with a provider; the provider may or may not have been screened and trained.
- ✓ From someone you know who has agreed to care for your child in exchange for payment from the respite agency through a voucher or stipend program.
- ✓ From a neighborhood babysitting co-op.
- ✓ From someone you already know and have chosen to hire as a respite provider.

If you’re using a respite provider who’s affiliated with an agency, often the agency will begin by visiting your home where the respite will occur. It’s helpful to have your child be a part of the process. One way to involve children is to tell them that this person is going to help find a good helper who will stay with them so that you can go out. Encourage your child to express his or her needs and the kinds of activities he or she enjoys.

Also, remember the home visit is a good opportunity for you to ask questions about the agency and the provider(s). Sometimes in a home atmosphere, you will think of additional questions. You can feel free to ask as many questions as you like to make your respite experience a positive one!

## Interviewing your respite provider

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If possible, it's best to try to interview the potential respite provider in person, but you may prefer to speak over the telephone. Before you conduct the interview, try to determine what personal qualities you are looking for in a respite provider, and have a pencil and paper handy to make notes about questions that you have. It's easier to break the ice by describing your family and your child first, and then asking questions about the respite provider. The questions you ask that mention real situations will bring forth the most revealing answers. For example, if you're interested in finding out about how the respite provider will spend time with your child, ask about specific activities that she or he has done in the past with other children. Some sample questions on the following page will help in the interview process.

## Preparing your respite provider

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Even if an agency has been involved in providing you with a respite provider, it is ultimately your responsibility to tell the respite provider about the individual needs of your child and family. This can be a very tough job, because not only do you have to inform them of what to do in case of a major emergency, but you also need to remember the small things, like when to let the dog out and where the spoons are kept.



You may want to try a “trial respite,” where you stay home and observe the respite provider’s performance during your first respite service. This would also allow you to offer assistance and suggestions, as well as provide specific training when needed. Although this may cost you some extra money, in the long run you will feel more comfortable when using future respite services.

It's best to have some written information in an organized format so that the respite provider can pull it out at a moment's notice. The forms included in this guide can be used for this purpose. **Make a copy of each form before you write on it, so that you can update the information in the future.** Complete the forms before the respite provider arrives, and then go over each one with him or her so that there is no confusion about anything. In addition, a pocket is provided at the back of this binder for storing other related items that you may want to leave for the provider (for example: insurance card, extra key, last-minute instructions.)

### **Interview Questions for In-Home Respite Providers**

Tell me about yourself.

Have you had experience working with people with a disability similar to my child's?

Why are you interested in providing respite services?

Tell me about your personality. What things do you like about yourself? What are the things that you would like to change?

What makes you the best person for this job?

Can you provide me with references from other families you've worked with?

Do you have any special training or experience (first aid, CPR, other)?

If my child has to be taken to the hospital for an emergency, what steps would you take?

How would you find out what kinds of activities my child likes to do?

Do you have any special interests or hobbies you might like to share with my child?

What would you do if you asked my child to do something and he/she refused?

What should we do if we disagree about something?

What hours are you available to work? What about during holidays and weekends?

What are your thoughts on discipline? What types of discipline have you used in the past?

What would you do if you found my child with an open bottle that you suspected was poison or medicine?

Are you comfortable taking my child out into the community?

If my child cries when I leave, how would you handle it?

Have you had a criminal background and child protective services check to determine that you have no history of child abuse? Would you be willing to have a check done?

My child's questions: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Other questions: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

[Some questions adapted from "Get Good Child Care: 30 Revealing Questions to Ask," Susan H. Kueffner, Working Mother, May 1989 in PARTners: A Manual for Family-Centered Respite Care.]

# Considerations For Hiring Your Own Respite Provider

There are a number of reasons why you may be interested in hiring your own respite provider, rather than finding one through an agency. It may allow more flexibility in your schedule and provide more control for you and your family. Also, agencies usually take awhile to go through the interview process, and it's a lot faster to find a respite provider who you like and begin the process a little earlier. However, hiring your own provider does require organization and energy!

## How much should I pay a respite provider?

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There is no single correct answer to the question of how much money a respite provider should be paid. Certainly a 15-year old student who comes over to stay while your child is sleeping for a few hours in the evening should not be paid as much as a provider who has been trained in feeding techniques for a child with special health needs. Ideally, you and the respite provider will negotiate payment together. However, to budget how much respite is affordable, it's necessary to calculate some type of hourly salary.

While considering what to pay, check the following sources:

- ✓ Current minimum wage.
- ✓ Hourly wages of workers in area day care centers.
- ✓ Hourly wages of health care support staff.
- ✓ Hourly wages of area babysitters.

Don't forget also that hourly wages are negotiable, and that you can provide financial incentive bonuses for extra efforts, such as cooking meals or caring for a child who gets sick while you're gone. Other rewards for the respite provider may include food for the provider or use of your laundry facilities while your child is receiving care.

## What about caring for siblings and performing household tasks?

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One of the biggest advantages to hiring your own respite provider is that you can decide the payment and responsibilities of the provider. Most regular sitters will charge an extra amount per child for each hour of care. For example, the respite provider could be paid \$5.00 per hour and \$1.00 for each extra child per hour. Or, you could offer to pay \$5.00 per hour and offer a \$5.00 bonus for cleaning the kitchen during the child's nap or television time.

## Obtaining information on a provider's background

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You have the option to ask potential respite providers to provide more thorough background information. Consider asking providers to supply two or three employment or volunteer references, and be sure to talk candidly with all references.

You may want to consider a local police background check, and/or a child protective services (CPS) check. Be advised that there may be a charge for background checks. Availability varies in each community, but if you call your local Police Department or Department of Social Services, they can direct you to the appropriate resources. Remember, **background checks are limited and do not always cover every area.** For example, CPS checks where you live will usually give information only about child abuse incidents from your state. Therefore, if a respite provider has recently moved from another state, it won't be helpful to have a CPS check done in your state. Obviously, if a potential provider is reluctant to have background checks done, you should take that into consideration in your hiring decision.

## Federal tax considerations – the IRS and you!

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If you choose to hire your own provider, the provider may be considered a household employee by the IRS, and you may be responsible for federal payroll taxes. The IRS considers someone a household employee if:

- ✓ They are over 18 years of age,
- ✓ They provide respite services in your home, and
- ✓ They are not employed by a respite agency.

If your provider meets the above criteria, you should consider the respite provider a household employee.

Starting in 1995, the IRS determined that if you pay a household employee \$1,000 or more in a given year, you're liable for federal social security, Medicare, and unemployment taxes. If, however, you employ several respite providers over the course of the year, and each provider averages \$200 in income from you, then you wouldn't be responsible for federal payroll taxes.

Some families employ respite providers and pay them “under the table,” without consideration of taxes. This is not recommended. Although tax requirements involve extra money and paperwork, your employee is eligible for specific benefits and may contact the IRS without consulting you first! Also, the IRS is very serious about collecting taxes that they are due!

If you employ a respite provider in your home, we strongly recommend seeking advice from a local accountant and/or lawyer to determine your status. You can also contact the IRS directly for more detailed information, and to request the IRS Publication 926: Employment Taxes for Household Employers. The IRS information telephone number is 800/829-4477.

# Taking The Plunge – Are You Ready For Respite?

*“When I walked out of my front door, I had such a feeling of freedom that I almost skipped all the way to the car!”*

## Preparing your home for your respite provider

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If you’re getting in-home respite, your home may need to be organized in advance to make things easier for the provider. Before your respite provider arrives, consider these tips:

- ✓ Prepackage individual doses of medicine in plastic storage bags.
- ✓ Prepare food/meals in advance.
- ✓ Have a first aid kit ready.
- ✓ Write down key phone numbers.
- ✓ Fill out necessary forms.
- ✓ Place valuables in a safe place.
- ✓ Have activities for your child ready for the respite provider.

You may want to use the forms in the back of this guide to assist you in providing appropriate information for your provider. Review the forms and then select and make copies of those you find helpful. Remember to always provide emergency information.

## Preparing yourself for the respite break

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It’s normal to be a little nervous or hesitant the first time you leave your child with any new respite provider. Most caring parents will have mixed feelings about sharing their child with another person. Good planning is the best way to ensure a successful respite break. It’s important to create a good working relationship from the start. According to Matthew Timm, Ph.D, of the Respite Coordination Services Project in Nashville, Tennessee, there are eight common pitfalls that can prevent respite from being successful. Let’s examine these pitfalls more thoroughly.

***Pitfall #1: Too much, too soon.*** “Easy does it” is the key phrase in planning and using respite services. Many families have discovered the benefits of scheduling the first one or two respite sessions in the home while a parent remains present. Others have arranged for the respite provider to arrive an hour or so before the family departs to permit some orientation time. You can probably think of a number of ways in which your child and a new provider can get off to a good start. The idea is to build relationships that last.

## ARE YOU READY FOR RESPITE?

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***Pitfall #2: The case of the late parent.*** There are situations when even the most responsible people get stuck in a traffic jam, have a flat tire, forget to check the time, or simply forget. However, one of the quickest ways to lose a good respite provider is to fail to arrive or return when promised. An important item for your “Things to Do” list is to be on time in dealings with your respite provider.

***Pitfall #3: The case of the lost parent.*** Emergency notification plans are essential, but are useless if you can’t be located. Any change in plans regarding your location should be communicated as quickly as possible to the respite provider. Some parents might want to wear a pager so they can be located and contacted anywhere, anytime.

***Pitfall #4: “Who ate all the ice cream?”*** It is very important to sit down with your respite provider and talk about household rules before the first respite session. Items to discuss include access to food, use of the kitchen, visitors, use of appliances, telephone, and so forth.

***Pitfall #5: “Are you sure your mother lets you take a walk by yourself every night at 10:00 p.m.?”*** The respite forms included with this guide should give a very clear picture of your child’s daily routine, but if you suspect that your child may take advantage of your absence by changing the rules a bit, be sure to alert the respite provider or discuss the rules with the provider in front of your child.

***Pitfall #6: “Now what?” Prepare for the unexpected.*** With any planned activity some complications may arise. For example, the respite provider may become locked out of the house with your child, or a car pool may forget to pick them up or take them somewhere. The respite provider may become ill. If at all possible, you and the respite provider should have a basic back-up plan in place for such circumstances. Options may include getting in touch with a neighbor or nearby relative, or going to the provider’s home to await contact. Remember to be forgiving. The respite provider is human, and unforeseen events can happen even with the best providers.

***Pitfall #7: “We knew you wouldn’t mind looking after our friend’s children while we go out to dinner together.”*** Additional children make additional responsibilities. The respite provider may have plenty to handle with one child. Never assume that an extra child or two can be tossed in without warning. You and the respite provider should establish a clear understanding from the outset regarding the number of children to be involved in respite time.

***Pitfall #8: “I wonder how things went with the respite provider and my child?”*** Not enough communication means miscommunication. It is very important to talk with the respite provider before and after each respite time. Before the session, fill in the provider on what kind of day your child has had, your child’s appetite, and fatigue level. After the respite session, ask for information on what happened during your absence. Ask the provider open-ended questions about the respite time:

*Did everything go well while we were gone?*

*What did you do?*

*What did my child eat?*

*Were there any problems? How did you handle them?*

*Did my child miss us? How did my child express this? How did you handle it?*

The purpose of these “debriefings” is to identify what information and support the respite provider might need to provide good care. Sometimes these discussions can occur on the spot, and sometimes they may need to occur later by telephone. Try to avoid sounding like a lawyer in front of a hostile witness, but be alert to the possibility of problems. You need to know if things got out of control, if the provider became angry or upset, or if the provider used questionable judgment. Further information on evaluating the experience is provided in the next chapter.

[The previous excerpt on pitfalls is adapted from The Family Respite Handbook, produced by the Respite Coordination Service Project under grant #90CN002901 to the Tennessee Department of Mental Health and Mental Retardation from the U.S. Department of Health and Human Services. This publication can be obtained from the TDMHMR at 615/532-6767.]

## **Preparing your child for the respite break**

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The best way you can prepare your child is to maintain a positive and upbeat attitude about their sharing time with the respite provider. Children are experts at interpreting their parents’ moods and will be able to detect nervousness or anxiety on your part which will, in turn, cause nervousness and anxiety in them! If your child is not used to being cared for by another adult, separation anxiety may occur.

If your child receives respite in a community setting, remember it is completely normal for a child to be apprehensive and anxious about being away from home. Involving him or her in the process may lessen some of the anxiety about what will happen when you’re gone. Also, it will enable you to emphasize the positive features of the program (“You’re going to have so much fun playing on that trampoline!”) or discuss any fears beforehand. However, you know your child the best, and if you think that a visit to a respite program may increase fears and anxiety, visit the program alone!

## **Saying good-bye**

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First and foremost, you shouldn’t feel guilty about leaving your child. Both parents and children are happier with occasional separations.

By a developmental age of 6 months, children are able to understand that separation is not permanent. So tears and anxiety are not only normal, but are good signs that a warm and close relationship has been developed. In her book, Practical Parenting Tips, author Vicki Lansky offers these tips on leave-taking without tears.

- ▶ For very young children, play “peek-a-boo” frequently to help a little one understand that you can disappear and still return.
- ▶ Leave your child at another place with a security blanket, book, or favorite toy.
- ▶ Use a good-bye ritual, including a hug and kiss and such things as waving good-bye from the doorway or window or honking the car horn as you pull away.

## ARE YOU READY FOR RESPITE?

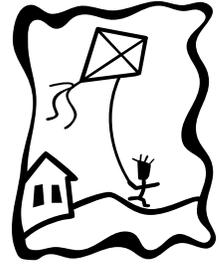
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- ▶ Get the respite provider to come a half hour or so early so that an activity can be started before you go and the child will be busy.
- ▶ Spend a few minutes with your child before you go, and try not to rush off hurriedly.
- ▶ Kiss your child's palm and close his fingers into a fist, explaining that if there's a need for a kiss, there's one in there, ready and waiting.
- ▶ Keep family pictures handy so your child can look at them for reassurance. Let your child take a picture of your family to the place where respite occurs, or place one on your refrigerator at home.
- ▶ Try to be back when you've said you will be, and remind the child that you always come back. Call if you're delayed, and explain the problem to your child in person if he or she is old enough to talk on the telephone.
- ▶ Tell a child who doesn't understand time that you'll be back "after lunch time" instead of "in 3 hours."
- ▶ If it won't make your child anxious, forewarn your child that you're going, even days ahead if possible. Talk about who will be caring for the children and what exciting things they will get to do, but be sure not to promise something that hasn't been arranged in advance with the respite provider.
- ▶ Give your child a small trinket or piece of inexpensive jewelry that belongs to you, and place it in her pocket or pin it to her clothing. Remind your child that when she sees the trinket, she should remember that you love her too much to stay away for too long.
- ▶ If you're going away overnight, give your child a sense of when you'll be coming back by filling small paper lunch bags with small treats (coloring book, crayons, and other things your child enjoys) for each day you'll be gone. When the last bag has been opened, your child will know you'll be home that day.
- ▶ Use your own common sense. If you suspect that seeing family photographs or speaking with you on the telephone will only increase your child's feelings of being lonesome, have the respite provider relay your message to him.

[©1992 by Vicki Lansky. The previous excerpt is adapted and reprinted from Practical Parenting Tips by Vicki Lansky, with permission of its publisher, Meadowbrook Press, Deephaven, MN]

## Time for RESPITE!

Families spend their respite time in many different ways. How you make use of your respite break will depend upon your schedule and your personal choices for how to use your time. However, before you consider the number of appointments, household chores, paying bills, and “things that you should be doing,” mull over some of the things that you would really like to do. For most parents, this is difficult. It’s hard to remember the things that you used to do before the responsibilities of parenthood took over.



In an article entitled, “Finding the Fun: The Importance of Play for Parents” (Exceptional Parent, July/August 1993) authors Jill Baughan, Patricia Brown, and Monica Uhl urge parents to be spontaneous. “Try to respond to the voice that’s telling you what you really want to do, with or without your child. Blow bubbles, fly a kite, go to the library and drink in the silence, buy a water pistol and use it, try juggling or a few tricks with a yo-yo.” The stress associated with being a parent of a child with special needs may seem to take away from your own sense of self, or from your relationship with your spouse. It can be very difficult to remember how to play again, and how to liberate yourself from life’s responsibilities. Authors Baughan, Brown, and Uhl offer these five pointers to help us remember how to play.

1. **Let go of time.** Don’t be afraid to block off a period of time and intentionally forget your watch. Curiously, you may actually have to plan in order to do this!
2. **Be spontaneous.** So maybe it’s been a while since you dusted under the bed. Or, your schedule may dictate that you’ve got to clean the house. Society may pronounce you “too old for that stuff” when you entertain the desire to turn cartwheels in the yard. But spontaneity, another prerequisite of play, has its own reward – liberation.
3. **Maintain a sense of humor.** This should make it easier to keep your sense of humor – a third precursor to play. If you’ve forgotten or you’re out of practice, it’s necessary to relearn how to be silly. And if you’re afraid of looking foolish when you’re acting silly, consider this: much of play’s therapeutic value comes from a childlike vulnerability that delights in the absurd. In other words, who cares if you look goofy, as long as you’re having fun.
4. **Take some risks.** Playing might well involve trying something new, so don’t be afraid to take some risks. Be a participant, not a spectator. Take up roller-blading!

5. **Keep a positive attitude.** One final requirement for a playful mind-set is an upbeat attitude. Granted, this is easier said than done. But try this: at the end of each day, in a special notebook designated for just this purpose, take 5 minutes to write down a few of the day's pleasures. Sometimes this takes some serious digging, but even the worst days have their redeeming moments: a soak in the tub, extra cheese on your pizza, an "I love you" in word or deed from someone you care about. Sharing what was your "favorite part of today" with your child and hearing his/her favorite is a good addition to the bedtime ritual to end the day on a positive note.

[The previous excerpt is adapted from Baughan, Brown, & Uhl, "Finding the fun: The importance of play for parents," Exceptional Parent, July/August 1993, 32-34. Reprinted with the expressed consent and approval of Exceptional Parent, a monthly magazine for parents and families of children with disabilities and special health care needs. Subscription cost is \$28 per year for 12 issues; call 800/247-8080; offices at 555 Kinderkamack Road, Oradell, NJ 07649-1517]

# How Did The Respite Experience Go?

*“The next time I use respite, I’m going to be sure to leave a list of activities that my child enjoys.”*

## Getting feedback from your child

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After the respite has occurred, family members can share their feelings about it with each other. If everyone feels comfortable, you can make a list of the things you liked and the things you would plan to do differently next time.

Agencies and individuals are usually responsive to suggestions that are clearly thought out and specific. Be sure to include your child’s input on the respite experience. Keep in mind that some children won’t be satisfied with any respite provider, no matter how wonderful, and would just prefer to stay with the rest of the family instead of receiving respite. In that case, you’ll just have to consider that factor as a part of your evaluation.

Some questions you could ask your child include:

- Tell me about your time with Donna. What did you do?*
- Did you like Donna? Was she nice to you?*
- Would you like Donna to come again and stay sometime?*
- What did you eat for breakfast? Did you have enough to eat?*
- What did you like best about your time with Donna?*
- What did you dislike?*

## Giving agencies feedback

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It is very important to give feedback to agencies that provide respite. They need to know about their intake process and their respite providers. Remember that because you’re their consumer, you’re an expert qualified to give them advice and feedback on your experience. If the agency does not provide you with an opportunity to offer feedback, you may have to call and remind them that you have some pointers to help out in the future.

Positive feedback is just as important as negative feedback! It is equally important to contact the agency if everything went well, and your child had a lovely respite session!

## HOW DID THE RESPITE EXPERIENCE GO?

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When you contact the agency, provide them with the following details:

- ✓ Your name.
- ✓ When you last met with them.
- ✓ When you most recently used respite services.
- ✓ Who provided respite.
- ✓ Specific information regarding the respite.

For example, you could begin by saying:

*“Hello, this is Mrs. Russo. I met with your agency last week, and I just wanted to give you some details regarding our respite provider, Donna, who came last Saturday night...”*

### Giving your respite provider feedback

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Forming a business-like relationship with a respite provider can be a challenge. Although the provider may be your paid employee, because of the nature of his or her responsibilities and close attachment to your child, you may have a hard time separating the personal relationship from the professional relationship.

Keep the following hints in mind when providing feedback to your respite provider.

***The respite provider is not a therapist.*** Because your respite provider may be the only other person with whom you trust your child, you may feel that he or she is the only person who can really understand what your day-to-day responsibilities entail. Remember though, respite providers are usually not trained marriage counselors, behavior management experts, or therapists! Certainly it’s normal to disclose some personal information in a friendly manner, but don’t burden the provider with too many of your personal problems.

***The respite provider is not working as a “favor” to you.*** One of the main advantages of hiring a respite provider and paying them is that you do not feel as though you “owe someone” a favor. Certainly, you can thank the provider for coming as part of polite conversation, but keep in mind that the provider is being paid for his or her time and that for them, this is a job. Therefore it’s not unreasonable to expect specific tasks to be done in your absence.

***The respite provider is not a mind reader.*** When caring for your own child, you’ve probably developed very specific methods of doing daily routines that have become second nature to you. For example, some children prefer the crust removed from a sandwich, and others may eat the crust first. Also, every person has different standards of what’s considered tidy or acceptable. Some parents may constantly remind their daughters to “sit like a lady;” others may consider any posture acceptable. For that reason, don’t get upset if the respite provider hasn’t done something

## HOW DID THE RESPITE EXPERIENCE GO?

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that you've forgotten to tell her. For your next respite session, you can mention to the respite provider that you neglected to mention something the last time he or she was there ("Amy, I forgot to mention two things the last time you were here. One is that little Jimmy prefers to have a light on at bedtime, and the other is that I usually don't turn on the dishwasher until after everyone is in bed so that it doesn't use up all of the hot water for my shower.")

***Respite providers need some feedback, both positive and negative!*** It's important to give anyone who's performing a job for you some feedback as to how they're doing. This may be uncomfortable at first if you've never supervised anyone. The most important factor to remember is to begin and end the conversation on a positive note. Most people aren't used to praising others and become self-conscious when telling someone what they like about them. You may have to think about how to put your thoughts into words, or try writing them down first. Here are some examples of how to provide someone with positive feedback:

*"Amy, I really like the way you relate to Mark. He seems to really like you."*



*"Amy, I really appreciate the way you cleaned up the bathroom after you gave Mark a bath. That makes things a lot easier for me."*

*"I think that it's great the way you made up the game using the letters of Mark's name. You're very creative!"*

After you've established the positive points of your respite provider's visit, you can mention the ones that need some improvement. Although you won't want to intimidate your respite provider, you can stress important things that were neglected. Be specific. Tell your respite provider about concerns that you need to review with him/her before the next session. In most cases, the respite provider will be processing so much information that you can safely treat any mistakes as something that will need to be reviewed again. Be patient! It takes a long time to learn someone's routine! Here are some examples of how to provide someone with critical feedback.

*"Amy, I don't think I was clear about how Mark prefers his leg braces put on."*

*"The last time you were here, I noticed that Mark didn't have a bath. Are you having trouble getting him into the tub?"*

*"I made a list of a few things that I need to review with you before the next time you stay with Mark."*

As we mentioned, begin and end the conversation on a positive note.

### **Some safety concerns**

---

If a respite provider does not seem competent to you, or has been unable or unwilling to follow your directions for your child's safe care, by all means find another provider. The process of finding and training a respite provider will usually weed out the individuals who are not able to perform the job tasks, but occasionally there can be a bad match.

If your child isn't verbal or is unable to tell you what happened during the respite stay, it's particularly important that you trust the respite provider completely. If you have any doubts regarding your child's happiness or well being, end the relationship with this respite provider, but don't give up on finding a good match for your family!

### **Will you try this again?**

---

*“In many ways, organizing respite is just one more thing to organize. For me the break is worth it!”*

For many families, the stress of organizing and obtaining a respite provider may seem overwhelming. But as with all new routines, it takes some practice to make things work smoothly. When you become comfortable with one respite provider, your departures and preparation will be much less complicated. You may think that no other respite provider can become as close to your family, and may be surprised that there may be several providers who meet your needs!

As we mentioned in the previous chapter, it is vital that families take a break from the constant responsibility of caring for a child with special needs. Unfortunately, for most families, the first time requires a huge amount of energy and time toward the ultimate goal of having some time to yourself. However, once a routine is developed, the separations and preparations will become familiar. Then respite won't seem like another task that needs to be undertaken, and the break will be worth it!

## References

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- Baughan, J., Brown, P.J., & Uhl, M. (1993). "Finding the fun: The importance of play for parents." Exceptional Parent, 32-34.
- Karp, N. (1992). Time out for families: Epilepsy and respite care. Landover, MD: Epilepsy Foundation of America.
- Kniest, B.A., & Garland, C.W. (1991). PARTners: A manual for family-centered respite care. Lightfoot, VA: Child Development Resources.
- Kueffner, S.H. (1989, May). "Get good child care: 30 revealing questions to ask." Working Mother, 90-95.
- Lanksy, V. (1992). Practical parenting tips. Deephaven, MN: Meadowbrook Press.
- Purdy, J. (1991). Respite care: A guide for parents. Washington, DC: CSR, Incorporated and The Association for the Care of Children's Health.
- Respite care: A guide for parents (1992). Easter Seal Society of South Dakota, Inc.
- Timm, M. (1992). The family respite handbook. Nashville, TN: Respite Coordination Services Project, Tennessee Department of Mental Health and Mental Retardation.

# QUICK NOTES



I can be reached at \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

My child's doctor's name and number is \_\_\_\_\_

\_\_\_\_\_

If I can't be reached by phone and you have an emergency, call \_\_\_\_\_

\_\_\_\_\_

Health insurance information is located \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Food available for meals and snacks \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Don't forget \_\_\_\_\_

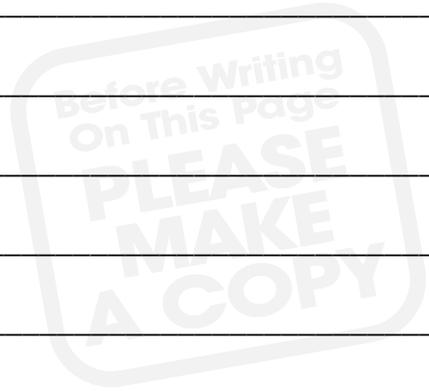
\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



# EMERGENCY INFORMATION



**Physician's Name** \_\_\_\_\_

Address \_\_\_\_\_

Telephone \_\_\_\_\_

**Nearest Hospital** \_\_\_\_\_

Address \_\_\_\_\_

Telephone \_\_\_\_\_

**Preferred Hospital** \_\_\_\_\_

Address \_\_\_\_\_

Telephone \_\_\_\_\_

**Person to phone if parent or legal guardian can't be reached:**

#1 Name \_\_\_\_\_ #2 Name \_\_\_\_\_

Relationship \_\_\_\_\_ Relationship \_\_\_\_\_

Telephone \_\_\_\_\_ Telephone \_\_\_\_\_

**Name of closest neighbor** \_\_\_\_\_

Telephone \_\_\_\_\_

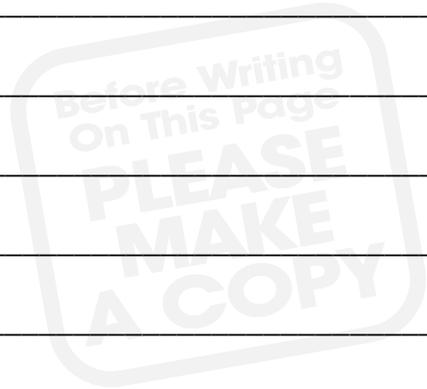
**Health Insurance Company** \_\_\_\_\_

Policy Number \_\_\_\_\_

Location of Health Insurance card \_\_\_\_\_

**Poison Control** \_\_\_\_\_ **Police** \_\_\_\_\_

**Fire Department** \_\_\_\_\_



# MEDICAL PERMISSION



I, \_\_\_\_\_, am the parent or legal guardian of \_\_\_\_\_, who is unable to give informed consent for medical treatment because he/she is a minor and has special needs. In the event of a medical emergency, I hereby authorize the provision of emergency medical treatments and any transportation required for such treatment for the above-mentioned individual. I agree to accept full responsibility for all costs of any emergency medical treatment rendered.

\_\_\_\_\_  
Parent or Legal Guardian

\_\_\_\_\_  
Date

\_\_\_\_\_  
Address

\_\_\_\_\_  
Telephone

State of Virginia, City of \_\_\_\_\_, to wit:

I, \_\_\_\_\_, a Notary Public in and for the afore  
said City and State, hereby certify that the parent/legal guardian of  
\_\_\_\_\_ acknowledges the foregoing  
instrument before me this day of \_\_\_\_\_, 199\_\_\_\_\_.

\_\_\_\_\_  
Notary Public

# MEDICATION



Does your child have any known allergies to medications? \_\_\_\_\_

\_\_\_\_\_

Any other allergies? \_\_\_\_\_

\_\_\_\_\_

Does your child willingly take regular medication? \_\_\_\_\_

If no, what methods do you use to ensure that the entire dose has been consumed? \_\_\_\_\_

\_\_\_\_\_

List the medications that your child currently takes on a regular basis. Complete this form in pencil, so that it may be updated as medications and dosages change.

<b>Medication Name</b>	Times given
------------------------	-------------

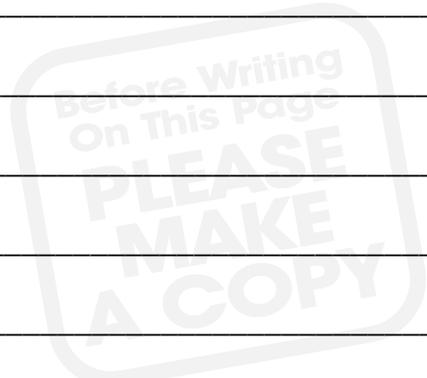
Dosage	How taken?
--------	------------

Medication prescribed for	Prescribing Physician
---------------------------	-----------------------

<b>Medication Name</b>	Times given
------------------------	-------------

Dosage	How taken?
--------	------------

Medication prescribed for	Prescribing Physician
---------------------------	-----------------------



Medication (continued)



<b>Medication Name</b>	Times given
Dosage	How taken?
Medication prescribed for	Prescribing Physician

*Before Writing  
On This Page  
PLEASE  
MAKE  
A COPY*

<b>Medication Name</b>	Times given
Dosage	How taken?
Medication prescribed for	Prescribing Physician

Describe any medication side effects: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Special Instructions:**

# SEIZURES



Does your child have seizures? \_\_\_\_\_

Is it likely that your child will have a seizure while the respite provider is there?

\_\_\_\_\_yes \_\_\_\_\_no \_\_\_\_\_maybe

What usually happens before a seizure? \_\_\_\_\_

\_\_\_\_\_

Describe seizures in detail \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

How long do seizures usually last? \_\_\_\_\_

\_\_\_\_\_

What should the respite provider do during the seizure? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

What should the respite provider do after the seizure? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Should the respite provider contact you if a seizure occurs? \_\_\_\_\_

\_\_\_\_\_

Should the seizure be recorded by the respite provider? \_\_\_\_\_yes \_\_\_\_\_no

**Special Instructions** (use back if necessary):

# **ADAPTIVE EQUIPMENT**

---



Does your child use adaptive equipment? \_\_\_\_\_yes \_\_\_\_\_no \_\_\_\_\_sometimes

Describe the adaptive equipment \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Where is the equipment kept? \_\_\_\_\_

\_\_\_\_\_

When should the equipment be used? \_\_\_\_\_

\_\_\_\_\_

How long should the equipment be used? \_\_\_\_\_

\_\_\_\_\_

What should the respite provider do if the equipment needs repairs or adjustments? \_\_\_\_\_

\_\_\_\_\_

How much supervision is required while using the equipment? \_\_\_\_\_

\_\_\_\_\_

**Special Instructions** (use back if necessary):

# HOUSEHOLD RULES

---



## Indoor Play

In what rooms does your child play? \_\_\_\_\_

\_\_\_\_\_

Are any rooms "off limits?" \_\_\_\_\_

\_\_\_\_\_

What are each child's favorite toys, games, or activities?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Where are old clothes for messy projects like painting and pasting? \_\_\_\_\_

\_\_\_\_\_

May the child assist in cooking or baking? \_\_\_\_\_

\_\_\_\_\_

## Television

May we watch television? \_\_\_\_yes \_\_\_\_no \_\_\_\_sometimes

When? \_\_\_\_\_

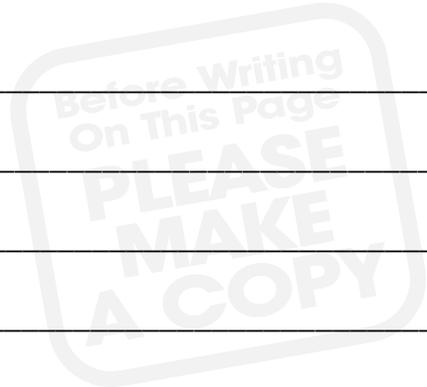
Where? \_\_\_\_\_

What programs or tapes may your child watch? \_\_\_\_\_

\_\_\_\_\_

Are any programs forbidden? \_\_\_\_\_

\_\_\_\_\_



Household Rules (continued)



May your child turn on the television without help? \_\_\_\_\_

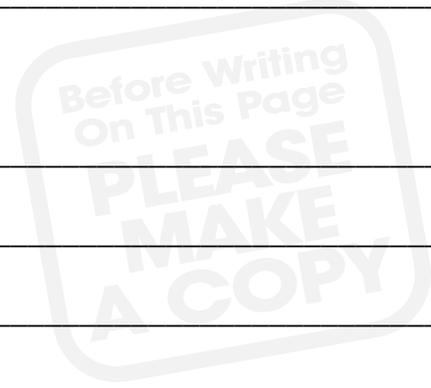
**Siblings and Friends**

Are friends allowed inside? \_\_\_\_\_

How many? \_\_\_\_\_

Who? \_\_\_\_\_

May your child go to a friend's house? \_\_\_\_\_



Friends' Names

Addresses

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

How are arguments over toys usually handled? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Are children allowed to run and roughhouse inside? \_\_\_\_\_

\_\_\_\_\_

**Outdoor Play**

Where does your child play: front yard, back yard, park? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Household Rules** (continued)



What are your child's favorite outdoor toys, games, activities? \_\_\_\_\_

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---

Are there any special rules for outside? \_\_\_\_\_

---

---

Are friends allowed in the yard? \_\_\_\_\_

How many? \_\_\_\_\_

Are insect bites a problem for any of the children? How should bites be treated? \_\_\_\_\_

---

---

Should all yard toys (bikes, wagons, strollers, etc.) be put away at the end of the day? If so, where?

---

---

Outdoor play concerns: \_\_\_\_\_

---

---

**Special Instructions** (use back if necessary):

# **ADDITIONAL HOUSEHOLD INFORMATION**



## **Pets**

What pets do you currently keep in your house? \_\_\_\_\_

\_\_\_\_\_

Are these pets permitted outside? \_\_\_\_\_

What should the respite provider do if a pet escapes? \_\_\_\_\_

\_\_\_\_\_

Will the respite provider need to feed the pets in your absence? \_\_\_\_\_

\_\_\_\_\_

Are the pets permitted to have table scraps? \_\_\_\_\_

Are the children permitted to play with the pets? \_\_\_\_\_

Should your child be supervised closely when with the pets? Describe any concerns...

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## **Security and Emergency Information**

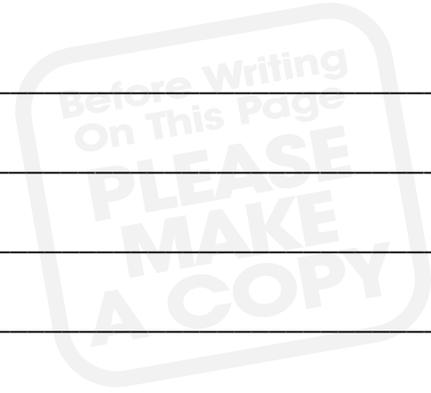
Where is an extra key located in case the respite provider is locked out? \_\_\_\_\_

\_\_\_\_\_

Should all doors and windows remain closed while the respite provider is in the house? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



**Additional Household Information** (continued)



Should your respite provider be wary about opening your front door to answer the door bell?

\_\_\_\_\_

Does your home have a security system? \_\_\_\_\_

Should your respite provider be instructed on its use? \_\_\_\_\_

What should your respite provider do if the system alarms in your absence? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Is there an emergency supply of cash if the respite provider needs it during long-term respite?

\_\_\_\_\_

**Telephone**

Where are telephones located in the house? \_\_\_\_\_

\_\_\_\_\_

Should the respite provider take messages for you? \_\_\_\_\_

\_\_\_\_\_

Do you have a telephone answering system? If yes, should the respite provider instruct callers to repeat their call and allow the system to take a message?

\_\_\_\_\_

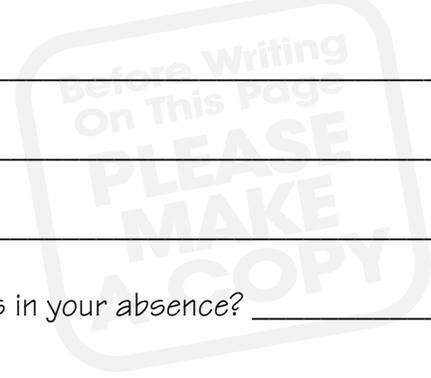
**Energy Conservation**

Should lights and electronic equipment (stereo, VCR) be turned off when not in use? \_\_\_\_\_

\_\_\_\_\_

Which lights should remain on during evening hours? \_\_\_\_\_

\_\_\_\_\_



**Additional Household Information** (continued)



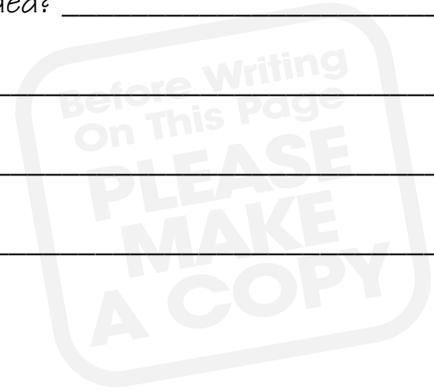
Should the respite provider adjust the thermostat if needed? \_\_\_\_\_

Where is the thermostat located? \_\_\_\_\_

What is the usual range of settings for your thermostat? \_\_\_\_\_

\_\_\_\_\_

**Special Instructions:**



# DISCIPLINE



What activities or daily routines are difficult for your child? \_\_\_\_\_

\_\_\_\_\_

How does your child typically express dislike or resistance to a situation? \_\_\_\_\_

\_\_\_\_\_

What do you do to help your child through difficult situations? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Which of these would you like a respite provider to do to help activities go well?

- \_\_\_\_\_ set limits consistently
- \_\_\_\_\_ ignore poor behaviors
- \_\_\_\_\_ be specific about what is expected
- \_\_\_\_\_ verbal praise of good behaviors
- \_\_\_\_\_ hugs and smiles for good behavior
- \_\_\_\_\_ have specific start and stop times

What signals will your child give that a problem behavior is about to occur? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

What would you like a respite provider to do if a problem behavior occurs? Be specific! \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Discipline** (continued)



What do certain behaviors mean? \_\_\_\_\_

\_\_\_\_\_

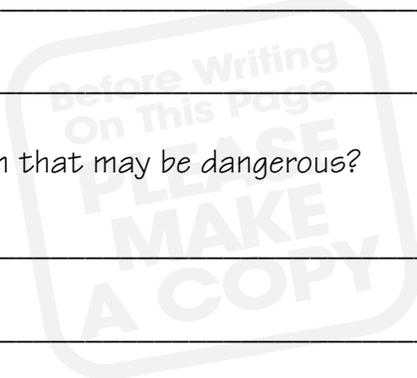
What behaviors do you worry that your child may engage in that may be dangerous?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



**Special Instructions:**

# MEALS



How does your child indicate hunger? \_\_\_\_\_

\_\_\_\_\_

Where are meals usually eaten? \_\_\_\_\_

Is your child on a special diet? \_\_\_\_\_yes \_\_\_\_\_no

If yes, what reactions should be watched for? \_\_\_\_\_

\_\_\_\_\_

What steps should be taken if a reaction occurs? \_\_\_\_\_

\_\_\_\_\_

What foods are off limits? \_\_\_\_\_

\_\_\_\_\_

What foods does your child particularly like? \_\_\_\_\_

\_\_\_\_\_

What foods does your child dislike? \_\_\_\_\_

What time is mealtime?

Breakfast \_\_\_\_\_

Lunch \_\_\_\_\_

Dinner \_\_\_\_\_

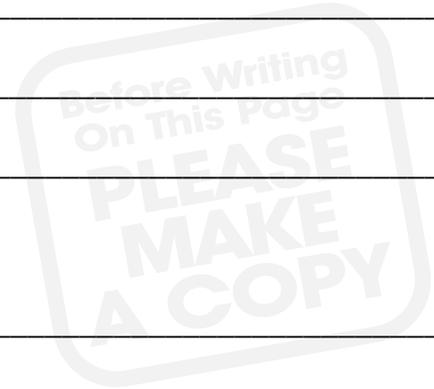
Does your child use special dishes, spoons, bibs, or adaptive equipment? \_\_\_\_\_

\_\_\_\_\_

Should any special food preparation methods be used (thickener, puree, chop in small pieces, serve hot/cold):

\_\_\_\_\_

\_\_\_\_\_



**Meals** (continued)



Does your child feed himself/herself? \_\_\_\_\_

\_\_\_\_\_

Does your child need to be reminded to chew food or to swallow? \_\_\_\_\_

\_\_\_\_\_

Does your child need to be reminded to use a napkin? \_\_\_\_\_

What should your child eat?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

How do the following appliances work?

Stove \_\_\_\_\_

Microwave \_\_\_\_\_

Toaster \_\_\_\_\_

High Chair \_\_\_\_\_

Blender \_\_\_\_\_

Other \_\_\_\_\_

Does your child help prepare or clean up after meals? \_\_\_\_\_

Does your child have any favorite snacks? \_\_\_\_\_

\_\_\_\_\_

At what time may your child have a snack? \_\_\_\_\_

Is there anything that should not be eaten for a snack? \_\_\_\_\_

\_\_\_\_\_

Where may snacks be eaten? \_\_\_\_\_

**Meals** (continued)



**Bottle Feeding and Infant Foods**

How does your baby indicate hunger? \_\_\_\_\_

\_\_\_\_\_

What does your baby take in his/her bottle? \_\_\_\_\_milk \_\_\_\_\_juice \_\_\_\_\_formula

Should the bottle be heated, room temperature, or straight from the refrigerator? \_\_\_\_\_

\_\_\_\_\_

If heated, how do you heat the bottle? \_\_\_\_\_

\_\_\_\_\_

How often does your baby take a bottle or eat? (On a regular schedule? Anytime baby feels hungry?)

\_\_\_\_\_

\_\_\_\_\_

Does your baby eat any solid foods yet? \_\_\_\_\_

\_\_\_\_\_

Are there any other special instructions for feeding your baby? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Special Instructions** (use back if necessary):

# **BATHING AND TOILETING**



## **Bathing**

Is a bath needed? When? \_\_\_\_\_

Is your child fearful in the tub? \_\_\_\_\_

Do your children bathe together? \_\_\_\_\_

Where are the towels kept? \_\_\_\_\_

Is your child able to sit unassisted in the tub for short periods of time? \_\_\_\_\_

\_\_\_\_\_

Should the respite provider stay in the bathroom with older children? \_\_\_\_\_

\_\_\_\_\_

What type of assistance is needed in bathing? \_\_\_\_\_

Should hair be shampooed? \_\_\_\_\_

What toys are allowed in the tub? \_\_\_\_\_

How long does bath time typically last? \_\_\_\_\_

Does your bathroom door lock? Is your child allowed to lock the bathroom door? \_\_\_\_\_

\_\_\_\_\_

Can the door be unlocked from the outside? \_\_\_\_\_

**Special Instructions** (use back if necessary):

**Bathing and Toileting** (continued)



**Toileting**

Does your child use the toilet on a regular basis? Is he/she in the process of learning?

---

---

Where are the diapers? \_\_\_\_\_

Will your child indicate that his/her diaper is wet or soiled? \_\_\_\_\_

Will your child resist diaper changing? What techniques do you use to get the diaper changed without stress?

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Where are training pants kept? \_\_\_\_\_

Should powder or lotion be used? \_\_\_\_\_

How does your child indicate a need to use the bathroom (gestures, special word)? \_\_\_\_\_

---

---

Will your child use the bathroom alone? \_\_\_\_\_

How often should your child be taken to the bathroom? \_\_\_\_\_

Does your child need an adult to assist with buttons, snaps, or elastic-waist pants? \_\_\_\_\_

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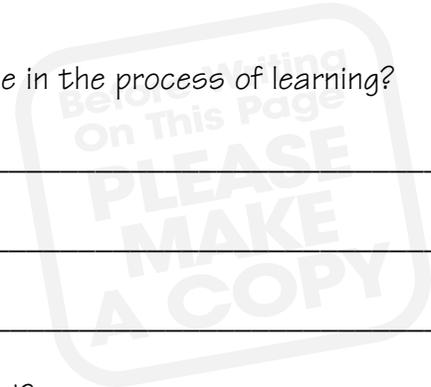
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Does your child need assistance with wiping after using the toilet? \_\_\_\_\_

Does your child wash his/her hands after using the toilet? \_\_\_\_\_

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**Bathing and Toileting** (continued)



Should the respite provider discourage water play in the sink? \_\_\_\_\_

If you have a girl, have her menstrual periods begun? \_\_\_\_\_

What kind of assistance is needed in changing menstrual pads and tampons? \_\_\_\_\_

**Dressing**

Does your child dress him/herself? \_\_\_\_\_

Is your child able to pick out appropriate clothing? \_\_\_\_\_

Is your child able to:

Button? \_\_\_\_\_

Snap? \_\_\_\_\_

Lace? \_\_\_\_\_

Tie? \_\_\_\_\_

**Dental Care**

How often are teeth usually brushed? \_\_\_\_\_

How much assistance does your child need to brush his or her teeth? \_\_\_\_\_

Does your child use a particular toothpaste? \_\_\_\_\_

**Special Instructions** (use back if necessary):

# **NAPS AND BEDTIME**



## **Naps**

Does your child take a nap? If so, what time does your child nap? \_\_\_\_\_

\_\_\_\_\_

How long does your child nap? \_\_\_\_\_

Does your child have a special doll, toy, or blanket for naps/bedtime? \_\_\_\_\_

\_\_\_\_\_

Does your child use a pacifier? Are there any special routines that you do before naps?

\_\_\_\_\_

What should the respite provider do if your child won't sleep? May your child lie quietly or read a book or play in his/her room? Should the respite provider lie down with your child?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Does your child sleep on his/her back or stomach? \_\_\_\_\_

Should the door be open or shut? \_\_\_\_\_

Does your child nap with the lights on or off? \_\_\_\_\_

## **Bedtime**

What time is bedtime for each child? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Where are the pajamas? \_\_\_\_\_

**Naps and Bedtime** (continued)



Is there a bedtime snack? \_\_\_\_\_

Is your child afraid of the dark, monsters, thunder, or other things at night? \_\_\_\_\_

\_\_\_\_\_

How are fears consoled? \_\_\_\_\_

\_\_\_\_\_

Does the respite provider need to awaken your child to take him/her to the bathroom?

\_\_\_\_\_

Are there any usual prayers, songs, books or other bedtime routines? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Does your child usually awaken during the night? \_\_\_\_\_

What should the respite provider do if your child awakens during the night? \_\_\_\_\_

Does your child sleepwalk or prowl at night? \_\_\_\_\_

How should the respite provider handle sleepwalking or prowling? \_\_\_\_\_

\_\_\_\_\_

**Special Instructions** (use back if necessary):

