

Family Guide to Respite Care



“Respite” refers to short term, temporary care provided to people with disabilities in order for their families to take a break from the daily routine of care giving.

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The Special Kids Network's regional staff in collaboration with their community partners and the Pennsylvania Department of Health's Children with Special Health Care Needs Consultants produced this guide in response to a recognized need to fill a gap in respite care services for families with children with special health care needs. This guide was developed to assist in defining respite care, highlight benefits of respite care, outline what to expect from respite providers, explain what is expected of you, and provide a list of possible local agencies that help families locate respite programs in their area. Working with state agencies and community organizations, the Family Guide to Respite Care was developed to decrease the informational gap in obtaining respite care services for children with special health care needs.

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RESPIRE CARE—AN INTRODUCTION

This informational guide was designed to assist families with making the decision to use and find respite support that fits their individual needs. Respite can be provided by a family member, a friend, a neighbor, a person from your faith community congregation, etc. It can also be activity based such as Girl Scout troops or Boy Scout troops, swimming lessons, etc. There are questions every family has when exploring the option of using respite services, including what they should expect from a provider and what is expected from the families, types of respite services available in the area and the cost of respite programs. The majority of families recognize the benefits of using respite services for the family and for the child with special needs.

“Caring for a child with special needs is a full-time job. It is easy to become overwhelmed with the care needs of a child with a disability or chronic illness. Often, families who would not hesitate to call for relief from the constant care of their typical children hesitate to call for relief from the care of their child with a disability or special health care needs. That is why respite, as the word implies, is truly an interval of rest. Respite can be your answer to renewed energies and give a new perspective to thinking and to planning ahead” (National Information Center for Children and Youth with Disabilities briefing paper, June 1996).

"Respite" refers to short term, temporary care provided to people with disabilities in order that their families can take a break from the daily routine of care giving. Respite can be based out of the family's home or out in the community. Respite services can vary from a few short hours to a week or may involve overnight care for an extended period of time.

The important purposes of respite is to give family members time and to temporarily relieve the stress they may experience while providing care for a family member and/or friend with a disability. This can also help prevent abuse and neglect, while supporting family unity. Respite care enables families to take vacations or just a few hours of time off. Respite is often referred to as a gift of time.

WHO NEEDS RESPITE CARE?

Caregivers may be reluctant to use a respite service. They may even question the “need” for this type of service. To determine if your family may need respite services ask yourself the following questions:

- Is it difficult to find temporary care for my family member?
- Does caring for my family member interfere with scheduling appointments or with personal projects?
- Is it important that my spouse and I enjoy an evening alone together, without the children?
- Do you think that you would be a better parent if you had a break now and then?
- If I had appropriate care for my family member, would I use the time for a special activity with my other family members?
- Am I concerned that in the event of a family emergency there is no one I could trust to care for my loved one?
- Would I feel comfortable having a trained, caring respite provider in my home, whether it is for an hour, an overnight stay or a vacation?

If you answered yes to several of these questions, you and your family could benefit from respite care.

BENEFITS OF RESPITE CARE

In addition to providing direct relief, respite has added benefits for families, including:

Relaxation. Respite gives families peace of mind, helps them relax, and renews their humor and their energy;

Enjoyment. Respite allows families to enjoy favorite pastimes and pursue new activities;

Stability. Respite improves the family's ability to cope with daily responsibilities and maintain stability during crisis;

Preservation. Respite helps preserve family unit and lessens the pressures that might lead to divorce, neglect and child abuse;

Involvement. Respite allows families to become involved in community activities and to feel less isolated;

Time Off. Respite allows families to take that needed vacation, spend time together and time alone;

Enrichment. Respite makes it possible for family members to establish individual identities and enrich their own growth and development.

Ref. – U.S. Department of Justice
Civil Rights Division
Disability Rights Section

National Information Center for Children and Youth with Disabilities
<http://www.nichcy.org>

HOW DO I CHOOSE A RESPITE PROGRAM OR PROVIDER?

First, decide if you are interested in caring for your family member with special needs in your home or in a community setting. Here are lists of factors to consider when deciding what options are best for your family:

Respite at home:

- Your loved one may be comfortable in your home and would be able to maintain a regular routine in familiar surroundings.
- If you feel more secure staying at home, you have the option of being in the house while the respite provider and your family member with special needs are getting to know each other.
- All of the necessary equipment, medications, food, and toys are within reach of the respite provider and do not have to be transported to a new location.

Issues to consider if in-home respite is the best option for your family:

- Will you feel comfortable having a respite provider in your home?
- Will in-home services allow you enough of a break?
- Would you like to use your respite time working on household projects that cannot be completed when attending to your family member with special needs?
- How would you find a respite provider to come to your home?

Respite in the community:

Respite care is provided outside of your home is called community-based respite. Depending on the resources in your area, the following respite options may be available to your family:

- Care can be provided in the home of another parent or caregiver who has a child(ren) with special needs.
- In the home of a neighbor or family member
- Recreational setting
- Summer camp setting
- Registered Family Day Care Homes

Questions to ask yourself if you believe community respite is the best option for your family:

- Will you be able to leave your family member with special needs in an unfamiliar place?
- Will they have trouble getting used to a new setting?
- Will you be able to arrange for transportation?
- Will transporting your loved one and all of their equipment, medications, toys and clothing require so much planning that your respite break will not be worth the effort?
- Do you feel that your family member will receive sufficient individual attention?
- Do you trust the people who will be caring for your family member?

FREQUENTLY ASKED QUESTIONS WHEN LOOKING FOR RESPITE CARE:

- How are care providers screened?
- What is the training and level of experience of the care providers?
- Will care providers need additional training to meet specific family needs?
- How, and by whom, are the care providers supervised?
- What happens during the time the clients are receiving services?
- Are there organized activities?
- How are meals handled?
- Does the program maintain current information about each client's medical and other needs? Is there a written care plan?
- Who will administer medications?
- What procedures does the program have for emergencies?
- Do these providers have training in First Aid and CPR?
- Can caregivers meet and interview the people who care for a family member?
- What kinds of services do I need? Long-term, short-term or both?
- Do I prefer services in my home, in an outside setting, or cooperative?
- Will I have to carry additional insurance to cover providers in my home?
- How far ahead of time do caregivers need to call to arrange for services?
- Are caregivers limited to a certain number of hours of services?
- Can I request a specific care provider and have the same person with my child each time?
- Will the respite care provider care for my other children too?
- Does the program provide transportation?
- What is the cost of services? How is payment arranged?
- Am I able to afford this service?
- If I can't afford the services are there funds available to assist families?

POSSIBLE PROVIDER'S RESPONSIBILITY

Anyone with the desire to provide care for someone with special needs can apply to be a respite care provider. The individual must be at least 18 years old, be literate and capable of understanding written and oral communication with families/caregivers. He/she must be able to respond appropriately to emergency situations, possess physical health, mental health, and good personal character to provide care for special needs clients.

Providers may also be responsible for:

- Obtaining necessary information about the family.
- Providing information about yourself to the family.
- Being dependable, arriving on time and ready to work.
- Providing reliable, safe and quality services to the family.
- Maintaining confidentiality about the person being cared for, and their family.
- If in your home, making sure that it is a safe and healthy environment.
- Respecting the family values, rules and home environment.
- Completing paperwork and maintaining any record keeping required by law, and the respite program.
- Knowing when to report abuse and neglect of children, adults with disabilities, and older adults.

SAMPLE RESPITE CARE FACT PACKET

Respite care providers must always have as much information as possible about the consumers with whom they work, in order to be prepared to meet each consumer's special needs. A Respite Care Fact Packet is a convenient way for parents or guardians to supply important information, and for providers to have ready access to what they need to know.

Name_____ School/Vocational Program_____

Birth date_____ Address_____

Teacher/Trainer's Name_____

Address_____ Phone_____

Parent's Home Phone_____ Work Phone_____

Case Worker's Name_____ Phone_____

Emergency

Physician's Name_____ Home Phone_____

Office Address_____ Office Phone_____

Person that can be called if parents

Can't be reached_____ Home Phone_____

Relationship_____ Work Phone _____

Preferred Hospital_____

Ambulance_____

Police_____

Fire Dept._____

Gas Co._____

Taxi Service_____

Poison Control_____

Other_____

Name of Insurance Company_____

Policy#_____

Name of Insurance Company_____

Policy#_____

Directions to our home _____

Behaviors

What rewards do you use for good behavior? _____

What methods of discipline do you use for misbehavior? _____

Describe any behavior problems (such as hitting, screaming, refusing to follow directions, etc.) _____

What are things to avoid? (ex. loud music, touch, food, etc.) _____

What safety issues are of concern to you? _____

Are there things we need to watch for and what are the best ways to handle them?

Seizures

Does the person have seizures? _____
If yes, describe in detail. _____

How long does a seizure usually last? _____

Seizures Continued

What happens before a seizure? _____

What to do during a seizure? _____

What happens after a seizure? _____

How should seizure be recorded? _____

Other: _____

Medications

1. Name of Medication: _____ Rx #: _____

Dosage: _____ Time Given _____

How Given: _____

Side Effects _____

Purpose _____

Prescribing Physician _____ Phone _____

2. Name of Medication _____ Rx #: _____

Dosage _____ Time Given _____

How Given _____

Side Effects _____

Purpose _____

Prescribing Physician _____ Phone _____

Medications Continued

3. Date of last tetanus shot: _____ Height: _____

4. Any allergies to medication? _____ Weight _____

If yes, identify

5. Check if applicable:

Autism	_____	Mental retardation	_____
Hearing Impaired	_____	Epilepsy	_____
Visually Impaired	_____	Cerebral Palsy	_____

Adaptive Equipment

1. Does the person use any special adaptive equipment? _____

If yes, please describe _____

2. Where is the equipment kept? _____

3. How is the equipment used? _____

4. For how long should equipment be used? _____

5. At what times should equipment be used? _____

6. How long has she/he been using this equipment? _____

7. Who may we contact for any necessary repairs or adjustments? _____

Allergies

Allergies/Diet

1. Does the person have any allergies? If so, please list _____

2. Is the person on any specific diet? Are there any foods that he/she shouldn't eat? _____

3. Are there any foods that the person particularly likes? _____

4. Are there any foods that the person doesn't particularly like? _____

5. Other: _____

Recreation Activities

1. List the toys (objects) the person likes to play with: _____

2. What types of things does the person like to do? _____

3. Are there certain things that frighten the person? _____

4. Does the person enjoy socializing with other people? _____

Recreation Activities Continued

5. Where are the recreational items located? _____

6. Other _____

Daily Living Skills

SPECIFY TYPE AND DEGREE OF ASSISTANCE REQUIRED IN EACH AREA.

1. Eating Right-handed _____ Left handed _____

2. Bathing Prefers tub _____ Shower _____ Other _____
Specify usual frequency and time for baths and shampoo.

3. Dressing _____

4. Toileting _____

5. Grooming (shaving, hair and teeth care) _____

6. Bedtime routine _____

Daily Living Skills Continued

- 7. Communication skill: _____

- 8. Ambulation: _____

- 9. Other _____

Daily Activities List

Please indicate how a typical day is spent:

- 6 – 7 a.m. _____
- 7 – 8 a.m. _____
- 8 – 9 a.m. _____
- 9 – 10 a.m. _____
- 10 – 11 a.m. _____
- 11 a.m.-noon _____
- Noon- 1 p.m. _____
- 1 – 2 p.m. _____
- 2 – 3 p.m. _____
- 3 – 4 p.m. _____
- 4 – 5 p.m. _____
- 5 – 6 p.m. _____
- 6 – 7 p.m. _____
- 7 – 8 p.m. _____
- 8 – 9 p.m. _____
- 9 – 10 p.m. _____
- 10 – 11 p.m. _____
- 11 p.m. – midnight _____

Emergency Information Form for Children With Special Needs



Date form completed
By Whom

Revised
Revised

Initials
Initials

Last name:

Name:		Birth date:	Nickname:
Home Address:		Home/Work Phone:	
Parent/Guardian:	Emergency Contact Names & Relationship:		
Signature/Consent*:			
Primary Language:	Phone Number(s):		
Physicians:			
Primary care physician:		Emergency Phone:	
		Fax:	
Current Specialty physician: Specialty:		Emergency Phone:	
		Fax:	
Current Specialty physician: Specialty:		Emergency Phone:	
		Fax:	
Anticipated Primary ED:		Pharmacy:	
Anticipated Tertiary Care Center:			

Diagnoses/Past Procedures/Physical Exam:	
1.	Baseline physical findings:
2.	
3.	Baseline vital signs:
4.	
Synopsis:	Baseline neurological status:

*Consent for release of this form to health care providers

TIPS FOR TAKING CARE OF MY CHILD

◆ What is special about my child _____

◆ My Child's schedule:
MORNING _____

AFTERNOON _____

EVENING _____

FEEDING

* Meal times

Breakfast _____ Lunch _____ Dinner _____

* Special Instructions _____

SLEEP HABITS AND NAP TIME _____

- ◆ Likes and dislikes_____
- _____
- ◆ Things that frighten my child_____
- _____
- ◆ Play Activities_____
 - Favorite/Special toys_____
 - Inside areas off-limits to play_____
 - Acceptable outside play areas_____
 - Acceptable visitors/playmates_____
- ◆ Special things that comfort my child:_____
- _____
- ◆ Handling
 - Special instructions for bath time_____
 - Transporting_____
- ◆ Discipline_____
- ◆ Special equipment_____
- ◆ Communication strategies_____
- ◆ Things to think about when selecting and adapting new activities_____
- _____

HOW DO WE ENFORCE FAMILY “RULES”?

In order for the respite experience to be a smooth and pleasant one for the entire family, consideration needs to be given to the establishment of “house rules” regarding the home, the child, and the parents themselves. You should communicate your ‘house rules’ to the respite care provider before an emergency occurs. You may want to keep this information in a written care plan, so that a new provider coming into the home will know what is expected. Here are some items to consider:

- | | |
|-----------------------|--|
| Respite Worker | <ul style="list-style-type: none">* Parking* Access to family home* Storage of personal belongings* Meals* Smoking* Television/radio* Telephone* Visitors |
| Child | <ul style="list-style-type: none">* Routines, nap time* Mealtime/snacks* Selection of clothing* Discipline issues* Homework* Chores of child* Areas off-limits to play* Acceptable outside play areas* Names of friends who can visit* Amount of television viewing (hours per Day and acceptable shows)* Number of telephone calls and length |
| Parents | <ul style="list-style-type: none">* Communication with respite worker* Privacy |
| Home | <ul style="list-style-type: none">* Areas off-limits to pets |

RESOURCES FOR HELP IN LOCATING RESPITE PROVIDERS

- **The Special Kids Network** 800-986-4550
<http://www.health.state.pa.us/skn>

A free statewide service that assists families of children with special needs to obtain services they need.

- **National Respite Locator Service** 919-490-5577
www.respitelocator.org

A service that helps parents, caregivers, and professionals locate respite services within their local area to match their specific needs.

- **Allegheny County Respite Care Coalition** 800-876-7607
www.acrcc.org

A non-profit organization committed to helping families access quality respite services in Allegheny County.

POSSIBLE LOCAL AGENCIES TO HELP LOCATE OR PROVIDE RESPITE SERVICES

- The Arc
- United Way
- Epilepsy Foundation
- United Cerebral Palsy (UCP)
- Spina Bifida Association
- Human Services Agency
- Mental Health/Mental Retardation Program
- Home Health Care Services
- Visiting Nurse Association
- Family Services
- Church

REFERENCES

Allegheny County Respite Care Coalition
P.O. Box 15477, Pittsburgh Pa 15237
800-876-7607 www.acrcc.org

ARCH National Respite Locator Service
www.respitelocator.org

Respite Source
<http://www.respiteresource.com/Welcome.htm>

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