

Relax. Take a Break:

A Family Guide to Respite for Children in Michigan



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What is respite?

Respite is a type of support available to families of children with developmental disabilities (DD) or serious emotional disturbance (SED)¹. The word *respite* means “break” or “relief.” Respite care services are designed to offer families the opportunity for a break from care giving responsibilities.

Respite allows parents time to engage in activities that they find relaxing, entertaining, or restful while a trained respite provider cares for your child.

A respite break can mean an hour to take a walk while a respite provider stays in your home to care for your child. It may be a weekend away while your child is cared for outside of your home. It can also mean time to take a nap or chat with a friend while the respite provider takes your child on a community outing.

How is respite different from daycare?

Daycare or traditional childcare is needed by parents in order to go to work or school and it

¹ Serious emotional disturbance (SED) is a diagnosable mental, behavioral, or emotional disorder that interferes with or limits a child's ability to interact with others in his/her family, school, or community.

is provided on a daily or regular basis. Respite, on the other hand, is provided on an intermittent or short-term basis to provide the parent with a break from caring for their child with a disability.

How can respite help my family?

Parenting is a difficult job and every parent can benefit from time away from the responsibilities of caring for a child. Being the best parent possible requires getting the rest and relaxation that you need. Caring for a child with special needs presents additional challenges that go beyond the everyday stresses of being a parent. As a result, you may need longer rest periods or more down time. In addition, it may also be more difficult to find a qualified person to care for your child. Respite can help offset these challenges.

Respite can help strengthen your whole family and lead to a decrease in stress and an increase in your family's health and well being. In addition to giving parents and caregivers a chance to rest, it may provide opportunities to spend more time with other members of your family improving relationships with children, spouses/partners, or other family members.

The overall goal of respite is to support parents or primary caregivers, so that families can

avoid an out of home placement and keep their child living with them in their home.

Is respite care right for my family?

Ask yourself the following questions.² If your answer is “yes” to several of these questions, respite care may be right for your family.

- ❖ Is finding temporary care for your child a problem?
- ❖ Is it important that you and your spouse/partner enjoy an evening alone or with friends, without the responsibility of caring for your child with special needs.³
- ❖ Do you need time to relax and refresh so that you will be better able to meet the care needs of your child?
- ❖ If you had appropriate care for your child with special needs, would you use the time for a special activity with your other children?
- ❖ Do you think that you would be a better parent if you had a break now and then?

² Some questions were adapted from *NICHCY briefing paper: Respite care*. National Information Center for Children and Youth with Disabilities. (1996). Washington, DC: Author.

³ Respite provides care for your child with a disability. In most cases, you will need to make other arrangements for the care of your other children.

- ❖ Are you concerned that in the event of a family emergency there is no one with whom you would feel secure about leaving your child?
- ❖ Do you avoid going out because you feel you would be asking too much of your family or friends to care for your child with a disability?
- ❖ Does your child require a caregiver who has specific experience and/or special training to meet his or her care needs? (Example: experience using specialized medical equipment)?



Relaxation

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

Enjoyment

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

Stability

Respite improves the family's ability to handle daily responsibilities and increases stability.

Preservation

Respite helps preserve the family unit.

Involvement

Respite allows families to be more involved in community activities.

Time Off

Respite allows families to take a needed vacation, spend time together, or time alone.

Enrichment

Respite makes it possible for family members to enrich their own growth and development.

From *NICHCY briefing paper: Respite care*. National Information Center for Children and Youth with Disabilities. (1996). Washington, DC: Author.

Is my family eligible for respite care services?

Community Mental Health Services Program

Your local Community Mental Health Services Program (CMHSP) can determine whether your family is eligible for Community Mental Health Services including respite care services. Eligibility for services is determined based on several factors including the nature and severity of your child's disability. Priority is generally given to families with the greatest need for this service.

Non Medicaid Eligible

If your family is found to be eligible for respite, the cost of respite services will be decided based on your family's ability to pay as determined by CMHSP guidelines.

The amount of respite that your family receives will vary depending on your family's needs.

Respite may be the only support need identified by your family. You are not required to receive treatment from the CMHSP in order to receive respite.

Medicaid Eligible

If your child is Medicaid enrolled and your family is eligible for CMHSP services, your family may be eligible for respite. Respite care services must meet the “Medical Necessity Criteria” that is outlined by Medicaid. The concept of “Medical Necessity” **does not** mean that your child must be physically ill in order for you to receive respite services. If you would like more information about Medical Necessity Criteria, you can ask your supports coordinator or log on to the Department of Community Health Website: www.michigan.gov/mdch, Medicaid Policy Bulletins, MSA Bulletin 04-03.

For more information regarding Medicaid or CMHSP services, log on to the Association for Children’s Mental Health in Michigan Website at www.acmh-mi.org to download a copy of *A Parent’s Guide to Obtaining Mental Health Services for Children in Michigan*.

Person Centered Planning/Family Centered Practice

In order to receive respite services from the CMHSP, respite must be identified through a planning process referred to as Person Centered Planning (PCP)/ Family Centered Practice. Person Centered Planning/Family Centered Practice recognizes that the needs of

your child with a disability are best met when the whole family receives the support they need.



The purpose of this process is to identify the needs of your family and honor your choices and preferences. However, keep in mind that the services offered by the CMHSP may not meet *all* of your needs and preferences as some needs may be better met by community and other natural supports.

Community supports may include other agencies or organizations in your area that offer services to families. Natural supports refer to your personal support network of friends, relatives, neighbors or other individuals with whom you share a trusting relationship.

The details regarding respite services should be decided during the Person Centered Planning/ Family Centered Practice Process. Both the type of respite as well as the amount of respite needed by your family should be included in a document referred to as the Individual Plan of Service (IPOS) or Family Plan of Service.

Types of respite care

There are many different ways respite may be provided. Respite care programs vary in the following ways:

- ❖ Who provides care for your child
 - Provider trained by your family
 - Provider trained by the respite program
 - Provider trained by the program and by your family

- ❖ Where respite takes place
 - In your home
 - Outside of your home
 - Out in the community
 - At a home, center, or facility

- ❖ What type of setting
 - Individual (your child + provider)
 - Group (group of children + provider(s))

The following types of respite programs may be available in your community.

Family Friend

Respite is provided by an individual chosen by your family. Respite can take place in your home, at the home of the respite provider, or in the community.

One-to-One

Respite is provided by an individual trained by the respite program and takes place in your home or in the community.

Camps

Day and overnight camps offer respite opportunities for parents while providing fun and/or educational experiences for children.

Respite Home

Respite is provided by individuals trained by the respite program in a licensed home or facility in the community.

Group Settings

Program trained staff provide care to a group of several children in a licensed facility such as a church, school, or community center.

Table 1 Types of Respite Care

Type of Respite	Who?	How?	Where?
Family Friend	Family trained provider	Individual	In home or Out of home
One to One	Program trained provider	Individual	In home or Out of home
Camp	Program trained provider	Group Setting	Out of home
Respite Home	Program trained provider	Group Setting	Out of home
Group Setting	Program trained provider	Group Setting	Out of home

Planning respite

The type of respite that is right for your family will depend on what is available in your community as well as your family’s unique needs and preferences.

Identifying the specific reason that your family needs respite may help clarify the type of respite that will work best. For example, if your goal is to spend time at home relaxing or taking a nap, you may require privacy. In this case, out of home respite may be the best option. Identifying the reasons for respite will also help you plan how to use your respite time effectively.

- 1) Start by brainstorming a list of all of the reasons that you need respite.
- 2) Next, rank the reasons in order of importance. While all of your respite needs may not be met, prioritizing will help ensure that your most important needs will be addressed first.
- 3) Use a table like the example in Table 2 to help clarify the amount and type of respite you will need to meet each respite goal. Start with a blank table and fill in your own reasons for respite in order of importance. To calculate the total amount of respite needed,

determine how often you need respite and the length of time required. Also include the type of respite that will best meet each respite need.

Table 2
Examples of Possible Use of Respite Time⁴

Reason for respite	How often?	Length of Time	Total Amt. ⁵	Type of Respite (in home vs. out of home)
Primary Caregiver would like to spend time with partner/spouse	One day per week	2 hrs	8 hrs/mo	Out of home
Primary Caregiver needs one on one time with other child	Twice a month	2 hrs	4 hrs/mo	No preference
Primary Caregiver would like time to relax at home.	Two days per week	2 hrs	8 hrs/mo	Out of home
Primary caregiver would like to join support group	One day per week	1 Hr	4 hrs/mo	In home

⁴ To discuss additional respite options that may be available to your family contact your caseworker.

⁵ The amount of respite available to families through CMHSP will vary depending on the needs of each individual family.

Finding the right fit for your family



Families often worry about the quality of care their children will receive during respite. Families may be concerned about how the respite provider will handle emergencies, deal with challenging behaviors, comfort their child, or manage their child's special needs.

These are all valid concerns that are common among parents. If your family is to benefit from respite services you must have peace of mind when leaving your child in the care of the respite provider. In order for your family to feel comfortable, it is important to take the time to find the right fit for your family.

If you have concerns, as most parents do, it is important to begin addressing them by discussing them with your supports coordinator and/or the respite program.

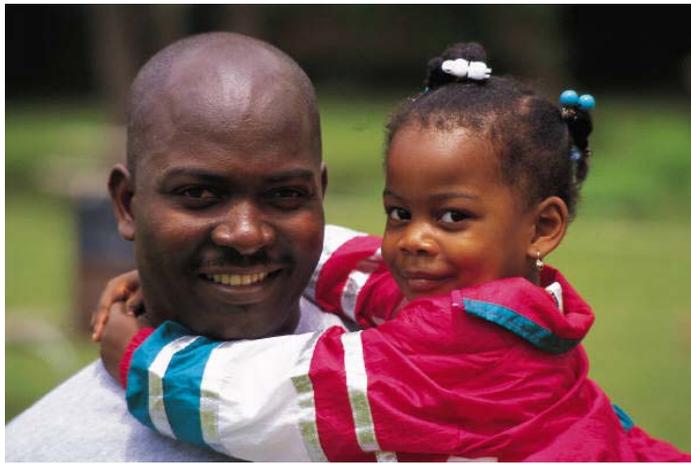
The following is a list of questions that many parents need to have answered about respite

services.⁶ Decide which questions are important for your family and be sure to ask your supports coordinator or the respite program.

- ❖ Can the respite worker come to my home?
- ❖ Can respite services take place outside of my home?
- ❖ Do providers have CPR/First Aid training?
- ❖ What other types of training do providers receive?
- ❖ How will my family be involved in preparing the provider to meet the specific needs of my child?
- ❖ Will my family be able to participate in training the provider?
- ❖ Can I meet/interview the provider beforehand?
- ❖ Will the provider care for my other child(ren)? If so, will there be an additional cost to me?
- ❖ Can I request the same respite worker every time?
- ❖ Is there a policy for emergency situations?
- ❖ How are out of home care facilities monitored for health/safety?
- ❖ When the provider comes to my home to care for my child, how is insurance and liability handled?

⁶ Some questions were adapted from *NICHCY briefing paper: Respite care*. National Information Center for Children and Youth with Disabilities. (1996). Washington, DC: Author.

- ❖ What happens if the provider is not a good fit for my family?
- ❖ In group respite situations, what is the staff to child ratio?
- ❖ What qualifications are required for respite workers?
- ❖ Are respite workers required to provide references?
- ❖ Are sex offender checks or criminal history checks required for respite workers employed by your program?
- ❖ What are the programs expectations for my child's behavior?
- ❖ What are the discipline policies?
- ❖ If my child is upset or crying, how will the staff respond?



Choosing a Respite Program

Choosing a respite program is similar to shopping for quality childcare. There are many resources available to families on the subject of quality childcare. Families will want to consider the factors that indicate a quality program such as the skill of the individuals providing care to your child and the safety of an out-of-home facility. The following internet resources offer checklists and other valuable information to help parents find quality childcare and/or respite.

Michigan Association for Child Care Providers
www.childcareservices.com

Child Care Aware
www.childcareaware.org

Child Care Resources
www.childcare.org

Locating Respite Providers

To find out more about what programs and providers are available in your community, you may start by talking to your CMHSP supports coordinator. You may also try looking in your phone book or searching the internet. The Arch National Respite Locator Service is a good online resource. It allows you to search for

providers in your area according to your child's age and type of disability.

Arch National Respite Locator Service
<http://www.respitelocator.org/locatorsearch/searchpage.htm>

Hiring Your Own Respite Worker

Choosing and training your own respite provider may be an option available to your family. When hiring your own respite care provider, interviews should be focused on choosing a provider that is trustworthy, experienced, and a good fit for your family. Try using questions⁷ like the ones below:

- ❖ Tell me about yourself.
- ❖ What type of experience do you have caring for or working with children?
- ❖ Have you worked with children with special needs?
- ❖ Why are you interested in providing respite care?
- ❖ Why do you enjoy spending time with children?
- ❖ Tell me about your views regarding discipline.

⁷ Some of these questions were adapted from "Get good Child Care: 30 Revealing Questions to Ask," Susan H. Kueffer, Working Mother, May 1989 in *PARTners: A Manual for Family Centered Respite Care*.

- ❖ Tell me how you might handle a situation in which my child was upset, scared, or crying?
- ❖ Tell me about your interests and hobbies. Would you like to share any of these with my child?
- ❖ Can you provide contact information from individuals who have seen you interact with children who can serve as a reference?
- ❖ Would you feel comfortable taking my child out in the community?
- ❖ May I complete a background check?

Background Checks

Families hiring their own respite care provider may be interested in completing background checks.

Michigan criminal background checks can be completed at the following website:

<http://mi-mall.michigan.gov/ichat>

Sex offender checks are free and can be completed at:

<http://www.mipsor.state.mi.us/>

Observing the respite provider

Whether you plan to hire your own provider or use a respite care program, you may feel more comfortable leaving your child if you plan an opportunity to observe the respite worker interact with your child. You may choose to arrange a short meeting or trial run in which you are present while the provider cares for your child. When you observe the provider, look for signs that the provider feels comfortable caring for your child, interacts with your child in a positive and caring manner, and is attentive to his or her needs.

Preparing the respite provider

Parents are clearly the experts on caring for their own children and should have the responsibility of preparing the respite provider to meet the individual care needs of their child. This is true when choosing and training your own respite provider as well as preparing providers who work for a program.



You will need to provide basic information as well as more specific information about your

child's unique needs. You will probably need to meet with your provider in advance to discuss your child's needs or to provide hands on training.

It is also helpful to provide written plans and instructions that are well organized and easy for your provider to reference at a moments notice. The following list outlines important topics to cover with your provider.⁸

Emergency Information

- ❖ Physician's name and phone number
- ❖ Hospital address and phone number
- ❖ Fire department/ambulance/poison control
- ❖ Who to contact in an emergency

Medication

- ❖ List of medications/dosage information
- ❖ Medication side effects that may be observed
- ❖ Instructions for administering medication

Seizures

- ❖ Is a seizure likely to occur during respite?
- ❖ What happens before, during, after a seizure?
- ❖ Procedures provider should follow
- ❖ Should the provider contact you?

⁸ Adapted from questions on the sample forms provided in *A practical guide to respite for your family*, Delinger-Wray M. & Uhl M. (1996). Richmond, VA: The Respite Resource Project.

Adaptive Equipment

- ❖ How is it used?
- ❖ When it is used?
- ❖ Is supervision required?

Discipline/Behavior

- ❖ What behaviors may be a challenge?
- ❖ How would you like provider to handle these behaviors?
- ❖ Are there any behaviors that your child may engage in that could be dangerous?

Meals

- ❖ Does your child require a special diet?
- ❖ Food allergies/reactions
- ❖ Does your child feed him/herself?
- ❖ What type of assistance is required?
- ❖ Food likes and dislikes
- ❖ Special equipment/special food preparation

Naps/Bedtime

- ❖ Usual bedtime/naptime
- ❖ Is your child resistant at bedtime?
- ❖ Nighttime fears (dark, storms, noises etc.)
- ❖ Sleep difficulties (waking, falling asleep, nightmares, etc)

Toileting/Diapering

- ❖ Does your child need assistance in the bathroom?
- ❖ What type of assistance is required?
- ❖ If your child wears diapers, are there any special instructions?

Communication

- ❖ Does your child use any special communication equipment or techniques?
- ❖ Is your child verbal?
- ❖ Is it likely to be difficult to understand your child?
- ❖ Ways to interpret nonverbal communication

Emotional Needs

- ❖ Does your child have any specific fears?
- ❖ Is separation anxiety likely?
- ❖ Best ways to comfort your child
- ❖ Would you like to be contacted if your child is upset/crying?

Household Information

- ❖ Favorite games, toys, movies
- ❖ TV, computer use/rules
- ❖ Household rules
- ❖ Security alarms/locks
- ❖ Answering the phone/door
- ❖ Location of clothing, food, diapers, first aid



Respite follow-up

Families will want to talk to the respite provider to find out if everything went smoothly. If problems are identified, decide what steps can be taken to minimize these issues the next time the provider cares for your child. Be sure to provide the respite worker with feedback. He or she will need to know what is working well and what needs improvement.

Families should also take the time to talk to and observe their child after the respite care experience to make sure that he or she felt comfortable. If you notice that your child is unhappy or behaving out of character, be sure to take your child's feelings seriously. Always discuss any concerns you may have with the respite care provider, respite program, or your supports coordinator.

The following is a list of questions that may be helpful to use when talking to your child.⁹

- ❖ Tell me about your time with ___?
- ❖ What did you do?
- ❖ Did you like ___?
- ❖ Was he/she nice to you?
- ❖ Would you like to spend time with ___ again?
- ❖ What did you like best/least?

⁹ Adapted from questions in *A practical guide to respite for your family*. Delinger-Wray M. & Uhl M. (1996). Richmond, VA: The Respite Resource Project.

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