

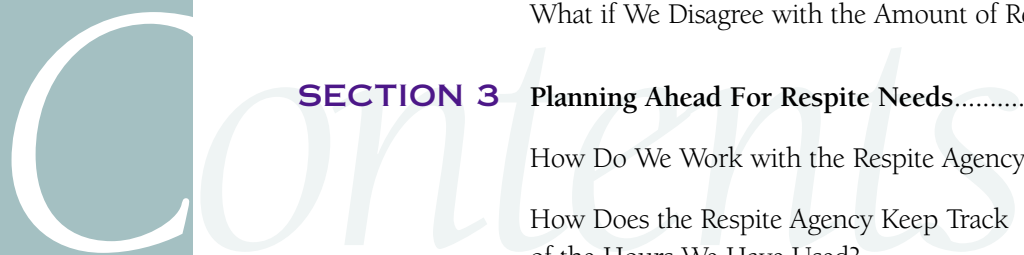
Making it happen



**LET'S TALK
ABOUT RESPITE**

**A GUIDE TO IN-HOME
RESPITE SERVICES**





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Introduction

Let's talk about respite. In this booklet we will explain what respite is and what you can expect from the respite services you will receive through Harbor Regional Center. We will also give you tips on working with the respite agency and the respite worker so your family can get the most out of these services.



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At Harbor Regional Center we define respite as a break, rest or relief from the additional demands placed on a family raising a son or daughter with a developmental disability. Respite services are planned and scheduled to meet specific needs at specific times, and are time-limited.

For example, you might use respite if you want to go to church, do things with your other children, or just go out with your spouse or a friend, knowing that your child with a disability is being cared for by a capable person.

As a rule, the regional center does not provide respite services for families with babies or very young children. This is because babies and very young children with disabilities are not greatly different from typical children of that age in the amount of care and supervision they require. An exception may be made if a child has medical needs.

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HOW IS RESPITE PROVIDED? The regional center contracts with respite agencies whose trained employees come to your home at scheduled times to help look after your disabled son or daughter. Respite workers understand disabilities. They are trained in a comprehensive program approved by the regional center. In this training program, they learn about developmental disabilities and how to care for people with disabilities. They also are taught CPR and First Aid.

If you prefer to recruit your own designated caregivers, you may prefer the option of self-directed respite. In this model, you will receive services through a respite agency, but you will recruit and select your own respite worker (or workers), who are then hired by an agency to provide respite services only to your family. The agency pays your respite worker for authorized hours which have been scheduled and arranged between you and your worker. The agency also takes care of all employer responsibilities, such as required paperwork, payroll taxes, worker's compensation, liability insurance, etc.

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INFORMATION IN THIS BOOKLET APPLIES TO TWO KINDS OF IN-HOME RESPITE SERVICES.

1. The first kind of respite includes routine care and supervision. It may also include light meal preparation or help with other homemaking tasks.
2. The second kind of respite includes personal care in addition to the routine care and supervision. Personal care includes things such as help with bathing and dressing; feeding by mouth; help with getting around, changing position, or transferring to and from a wheelchair; and general skin care (cleansing and applying lotion).



A respite worker may supervise your son or daughter in taking a dose of medication that you have prepared ahead of time, if that medicine doesn't have to be given by a nurse or doctor. Certain other special health care needs, such as the need for assistance with catheters, gastrostomies, or colostomies, may be met by respite workers who have completed specialized training. If your son or daughter has serious

medical needs or is dependent on medical equipment such as a feeding or breathing tube, you should ask your HRC Counselor about services through a home health agency which employs nurses and nurse assistants.

IS THERE A COST ASSOCIATED WITH RESPITE

CARE? In 2005, a California law took effect called “The Family Cost Participation Program.” This law applies only to respite and child care services, and requires parents to share with regional centers the responsibility for obtaining these services for their children. It applies only to families of minors who are not receiving Medi-Cal, and whose family income is above a certain minimum.

If your family income is below the minimum amount for your family size, you will not be required to provide a share of your respite services. However, if you do meet all of the above criteria for the Family Cost Participation Program, your family’s share of responsibility for respite services will be determined on a sliding scale, according to your family income and size.

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Your Counselor will provide you with more information in a booklet entitled “A Parent’s Guide to the Family Cost Participation Program,” answer any questions you may have, and assist you in determining whether you will be responsible for a portion of your respite services. You can also find the current sliding scale for family income, and more information about the Family Cost Participation Program on the HRC Web site at www.harborrc.org.

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WHAT DETERMINES HOW MUCH RESPITE

WE RECEIVE? No two clients and no two families are alike. That’s why different families receive different amounts and different kinds of respite services.

Many families have friends, relatives, or neighbors who can help them care for their child with a disability. Other families may get financial support for respite services from other sources. For example, families receiving SSI, SSA, or AFDC may be eligible for In-Home Supportive Services (IHSS) provided through the County Department of Social Services. For families who do not have

these kinds of help or who need more help, the regional center may provide respite services.

The number of respite hours your family receives and the length of time you receive them are determined by your planning team. This team includes, at least, you and your HRC Counselor. The team looks at things such as how much support you have at home – for example, if you are a single parent family or if you have friends or relatives who can help out – and whether you can get financial support from other sources to pay for respite. They also look at your child’s particular needs as compared to those of a child without a developmental disability. For example, they consider whether he or she has challenging behaviors or other special needs.

WHAT IF WE DISAGREE WITH THE AMOUNT OF RESPITE AUTHORIZED?

Our clients and families always have the right to appeal a regional center decision if they don’t agree with it. If you would like to appeal a decision about respite, just let your Counselor know, and he or she will give you the proper form to complete to begin the appeal process.

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Respite is most effective when it is used according to a plan. Your family's need for respite should be discussed at the annual IFSP meeting. During this meeting, you and your Counselor can discuss what you expect the need to be for the coming year. The planning team authorizes services, usually for a period of 12 months.

While most respite occurs in the home according to a regular schedule, your respite plan may call for using the hours in other, different ways.

- For example, some parents find they get the most benefit from respite when they use a large number of hours at one time, perhaps while their son or daughter visits a licensed home for out-of-home respite, if available.
- Or, you may wish to use a combination – using a portion of your total respite hours through a regularly-scheduled respite option, combined with a block of your respite hours through an out-of-home respite option.

You should think about your respite needs and options over the entire year, decide what plan would be best for you, and discuss this with your Counselor.

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HOW DO WE WORK WITH THE RESPITE AGENCY?

After your family's needs have been assessed and you are approved for respite services, your Counselor will give you the name and telephone number of the respite agency that will provide your services, or work with you in providing self-directed respite services.

To schedule respite agency services, you must call the agency during their regular business hours. It is best if you can plan on a regular time each week or each month, and schedule your respite services as much in advance as possible. The longer in advance you can plan, the greater the likelihood that the agency has a worker available to send to your home. It also increases your chances of having the same worker each week or each month. Having the same worker each time usually makes the service process go more smoothly.

Respite agencies can sometimes meet a family's unplanned request for services – for example, if the family has an emergency. Many times, however, they may not be able to do so. For this reason, it is

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always better to plan for your needs in advance if you can. If your plans change and you need to cancel or reschedule services, it is most important that you contact the respite agency coordinator as soon as you know you need to change.

You should also be aware that respite agencies usually have a policy of not providing services on holidays. We also want you to know that when you receive respite services from a respite agency, the regional center does not authorize fewer than four respite hours per month. And you may not use fewer than two hours or more than eight hours of in-home respite service on any given occasion.

If you have selected the option of self-directed respite, the caregivers you recruit will be hired by the agency – and the agency will take care of all the necessary employer-employee arrangements. Then the scheduling and ongoing supervision of authorized respite service hours will be between you and your authorized caregivers.

HOW DOES THE RESPITE AGENCY KEEP TRACK OF THE HOURS WE HAVE USED?

Respite agencies have systems to track how many hours you use and how many you have left. The agencies need to track these hours because they do not get paid unless they actually provide the services to you. In addition, they get paid only up to the number of hours that were authorized.

These requirements also apply to self-directed respite workers employed by an agency.

It is a good idea for you to have your own system for keeping track of your hours. You could use a calendar that you have at home, or you may prefer to use the respite care services log that we have included in the back of this booklet. (You will need to make copies for use on an ongoing basis.)

MAY WE SAVE HOURS FROM ONE MONTH TO THE NEXT?

When you are assessed and approved for respite care services, you will receive an authorization for a certain number of respite hours per month. Any unused hours will not be carried over into the following month. You are also not allowed to use or “borrow” from a future month.

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WHAT HAPPENS IF OUR NEED FOR RESPITE

CHANGES? Your family member's needs and your family circumstances will change over time. This means that the need for respite will change. Once you have used the respite services for some time, you may find that you no longer need respite or you need fewer hours a month. Or, you may feel that you need additional hours each month. Because of this, we always review the need for respite services at least annually.

IS IT OKAY FOR US TO ASK THE WORKER TO TAKE CARE OF OUR OTHER CHILDREN?

Harbor Regional Center does not pay for respite (or baby-sitting) for any of your children who are not our clients. If you would like the respite worker to care for a brother or sister who is not a client, you may pay the respite agency for this service. The first thing you must do if you want this additional service is request it from the respite agency *before* the

worker comes to your house. If the agency agrees to provide this extra service, you will be responsible for paying the additional charges. You must work directly with the respite agency on the payment arrangements because the regional center does not get involved in these matters.

If you have self-directed respite, you will have to make your own separate arrangements for the care of your other children by the caregiver of your choice.

WHAT IF THE RESPITE WORKER IS UNRELIABLE?

You and the respite worker should agree on the time that he or she will arrive and leave your home. You are responsible for signing the worker's time card, so you should review the card to be certain that the hours written on the card are the hours that were actually provided. You may also want to record those hours on your calendar or respite log.

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We all have occasions when we are late for something, and your respite worker will probably be no exception. If he or she is frequently late or extremely late, however, you should contact the respite agency and report this. It is unacceptable for workers to be consistently late, and the agency will want to take appropriate action. If the respite agency is unable to solve the problem, you should call your regional center Counselor so he or she can deal with the problem personally.

If your self-directed respite worker is unreliable, you may want to consider recruiting someone else to take his/her place.

WHAT ELSE DO WE NEED TO KNOW? Families have

sometimes asked us if they need to supply meals to respite workers. The answer is no. Respite agency personnel are responsible for their own meals. While you may choose to provide meals or snacks for the respite worker, it is not necessary or even expected.

Respite workers should not use your telephone except when it is required by their agency's rules. They may need to use the phone to call their agency or make an emergency call, but they should not use your phone to make personal calls. If you find that a worker has used your phone for personal calls, you should report this to the respite agency. If the misuse is serious – for example, if it results in long distance charges to you – you should also report it to your regional center Counselor.



If you have any other type of problems with the respite worker, or if you have questions about the conduct of your worker, you should not hesitate to call the respite agency. If they seem unable to solve the problem, you should call your regional center Counselor.

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WHAT IF WE HAVE OTHER QUESTIONS? Whenever you have a question about a service that is provided by Harbor Regional Center or one of our service providers, you should feel free to call your Counselor to get the information you need. If your Counselor does not know the answer, he or she will find out who does and get the information for you. If your Counselor is not available when you call and you need an answer right away, you may ask to speak to our “officer of the day” or your Counselor’s supervisor. Remember, there is always someone from Harbor Regional Center available to help you.



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