

Respite tips from other parents

Finding people to provide respite care

- Enlist relatives, friends, and neighbors. Let them know what you need.
- Connect with other parents and take turns giving each other a break. Or create a “respite bank” with friends.
- Hire teachers, aides and others from your child’s school and Early Intervention program. Advertise at other neighborhood schools, too.
- Build relationships with your child’s nurses. They may be able to provide respite or recommend a trusted colleague.
- Contact nearby colleges to find students in allied health, special education, nursing, or related fields.
- Send out queries on listservs, blogs or social networking sites that support parents or professionals.
- Encourage older children to develop their skills so that parents can take a short break.

Making the most of family time

- Take family walks, go swimming together.
- Enroll your child in lessons so you can spend that time with your other child(ren).
- Be active in Scouting and youth groups. As a volunteer, you get to spend time with other volunteer parents, and they don’t have to figure out your child’s needs.
- If it isn’t possible to find respite for the child who most needs it, make plans for your other children to get away, via after school programs, day trips or weekend trips with relatives, Scout groups, etc.

Finding time for yourself

- Enroll your child in after-school activities like Scouts, clubs, or dance classes. Alternate drop-off and pick-up responsibilities with another parent.
- Go to a movie while your child is at school.
- Use your lunch hour at work to take a real break. Go out with a friend for lunch or coffee.
- Let your child spend some time watching TV or online, as appropriate, to give yourself some space.
- Go to the library for quiet time.
- Take advantage of small pockets of time, even if it’s just 15 minutes to read, knit, whatever you enjoy.
- Each week, schedule one night off for yourself and one night off for your partner.
- Explore the possibility of sending your child to summer sleep away camp.
- See friends when possible and stay in touch. Talk on the phone.

More tips from parents

- Even if you get funding for respite care, you can increase the pay rate by adding your own funds.
- Save money to bring a caregiver with you when your family travels.
- Join a support group, or connect with parent organizations to attend their workshops and training sessions. Take advantage of leadership opportunities as a way to get involved and meet other parents who care for children with special needs. Work with them to get voices heard at the state level about what families need.

Respite care gives parents of children with special health care needs a needed break from caregiving. For the purposes of the research that went into this brochure, respite care was defined as:

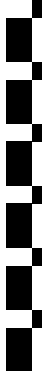
Temporary, short-term care of a child aged 21 or younger by non-parents, either at home, at the respite caregiver’s home or elsewhere, but excluding care provided at daycare, in pediatric nursing homes, or by in-home nursing staff or personal care attendants (PCAs).

We surveyed Massachusetts families of children with special needs, and found that many don’t know about respite programs at all, or don’t know how to find them. This was especially true for families whose children began receiving services after age 3.

We also found that 71% of families agree or strongly agree that it is a challenge to find respite workers.

The “Respite Tips” in this brochure—strategies for making the most of limited respite resources—were all provided by parents who responded to our survey.

The information about publicly-funded respite services was provided by five Massachusetts state agencies: the Departments of Public Health, Mental Retardation, Mental Health, and Children and Families; and the Massachusetts Commission for the Blind.



Getting a Break:

A Roadmap to Respite Care

for Massachusetts Families of Children with Special Health Care Needs



Prepared through a collaboration of the

Massachusetts Consortium for
Children with Special Health Care Needs
and the
Massachusetts Family-to-Family Health
Information Center



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WITH SPECIAL NEEDS

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Are you eligible for publicly-funded respite services?

Many Massachusetts families of children with special needs don't know about respite programs, or don't know how to find them. This chart was created to help families find the respite they need.

PLEASE NOTE:

THINGS CHANGE

Eligibility rules for respite care services can change. So can the amount of respite care funding that is available for eligible families. Your family's income and other circumstances can change, too. All of these can affect whether or not your family is able to get publicly-funded respite care. To be certain, check with the contacts listed at right.

IF YOUR CHILD DOESN'T RECEIVE PUBLIC SERVICES

To be eligible for respite funding from any of these agencies, your child must already be registered and, for most agencies, actively receiving its services. If that's not the case, the **Massachusetts Family-to-Family Health Information Center** can help you determine which services your family may qualify for. Call them at **1-800-331-0688, extension 210**.

Information provided by state agencies to the Community-Based Systems of Care Work Group of the Massachusetts Consortium for Children with Special Health Care Needs and the Massachusetts Family-to-Family Health Information Center. Respite service descriptions were approved by each state agency prior to publication.

If your child with special needs is:	You <i>might</i> be eligible for publicly-funded respite services...	How it works:	For more information, contact:
Under age 3 and currently receiving Early Intervention (EI) services through the MA Department of Public Health (DPH)	...through DPH's Early Intervention Program, if your child has complex or extensive medical needs or multiple disabilities, qualifies for EI's Regional Consultation Program, and you can demonstrate financial need.	Priority is given to families with low to moderate incomes. Note that while some Regional Consultation Program activities are available to children who are not currently enrolled in EI, to be eligible for respite funding your child must be currently receiving EI services.	Your EI service coordinator, or 1-800-905-8437
Age 3-22 and currently receiving Care Coordination services through the MA Department of Public Health (DPH)	...through DPH's Care Coordination Program, if your child has complex care requirements, multiple disabilities, or other special health needs; you can demonstrate financial need, and funding is available.	If you receive Family Support funding from the Care Coordination Program, you can use it toward the cost of respite care, including in-home care, after school programs and camp. There is a maximum annual amount \$600 per year, per family, however additional funds may be available if there is more than one child with special health needs in the family, or in case of emergency. Priority is given to families with low or moderate incomes.	Your DPH care coordinator, or 1-800-882-1435
Age 3-17 and receiving services from the MA Department of Mental Retardation (DMR)	...through DMR, if your child lives at home and has a diagnosis of developmental disability, you are determined eligible by DMR's regional office, and funding is available.	A children's coordinator is assigned to your family to guide you through the process. A family support plan is written and then, <i>if funding is available</i> , you may use the funds you receive from DMR to pay for respite services. You decide whether to find someone on your own to provide respite care, or use a family support agency to help you find someone.	Your DMR coordinator, or your DMR Area Office. Get listings at http://www.dmr.state.ma.us:70/
Age 3-19 and receiving services through the MA Department of Mental Health (DMH)	...through DMH, if your child has a qualifying diagnosis and your family meets the "needs and means" test, meaning that the services needed are not available through other sources (such as private or public insurance or school).	When determining eligibility for DMH services, a case manager from the regional DMH office works with your family to decide which services would be most helpful. One of those services is flexible funding, which can be used toward the cost of respite care. Your case manager can provide you with information about vendor agencies, support and recreational programs including camp and Saturday activities, and respite services (in-home and periodic short- or long-term out-of-home).	Your DMH case manager, or 1-800-221-0053
Age 0-22 and in the custody of the MA Department of Children and Families (DCF)	...through DCF. Respite care funding for foster families is based on the need for respite as identified in your foster family service plan. Families in which children in DCF custody reside with their parents may also be eligible, and should contact the DCF Area Office to discuss respite needs as far in advance as possible.	Foster families are eligible for up to 10 days per year of respite care. Normally, other foster parents provide care in their home, or a DCF licensed and contracted provider provides care in your home. Your DCF social worker coordinates the process: the DCF Area Office approves the funding, and DCF pays the respite provider directly. If your child is medically complex and respite care cannot be provided, he or she may qualify for short-term care in a pediatric nursing home, based on the availability of beds. Your DCF social worker can help coordinate this referral.	Your assigned DCF social worker in the Area Office, or 1-800-548-4802
Registered with the Massachusetts Commission for the Blind (MCB)	...through MCB, if your child is receiving services or you request services, and you meet the Title XX income guidelines.	Your family and MCB case manager identify service needs. If respite is identified as a service need, income guidelines are met and funding is available, limited respite funding may be provided.	Your MCB Children's Services Social Worker or 1-800-4411, ext. 7819