

Massachusetts

UMDF Support Groups & Ambassadors

[Click here](#) for information on the New England Chapter

[Click here](#) for information on Mito Groups & Ambassadors

Federation for Children with Special Needs

1135 Tremont Street, Suite 420 – Boston, MA 02120

(617) 236-7210 | (800) 331-0688 (in MA) | Fax (617) 572-2094

fcsninfo@fcsn.org

Web site: www.FCSN.org

Federation Satellite Offices:

Worcester

(508) 798-0531

Hyannis

(508) 778-0442

Western Mass.

(413) 585-8140 or (877) 388-8180 (toll-free in 413 area only)

The Federation is a center for parents and parent organizations to work together on behalf of children with special needs and their families. We can help! Organized in 1975 as a coalition of parent groups representing children with a variety of disabilities, the Federation operates a Parent Center in Massachusetts (visit this site too for a Center in other states), which offers a variety of services to parents, parent groups, and others who are concerned with children with special needs.

Protection and Advocacy Agency

Christine Griffin, Executive Director

Disability Law Center, Inc.

11 Beacon Street, Suite 925

Boston, MA 02108

(617) 723-8455; (800) 872-9992 (V)

(617) 227-9464 (TTY); (800) 381-0577 (TTY)

E-mail: mail@dlc-ma.org

Web: www.dlc-ma.org/

Programs for Children with Special Health Care Needs

Cheryl Bushnell, Acting Director

Division for Children with Special Health Care Needs

Department of Public Health

250 Washington Street, 4th Floor

Boston, MA 02108-4619

(617) 624-5959

E-mail: cheryl.bushnell@state.ma.us

Web:

http://www.mass.gov/?pageID=eohhs2terminal&L=5&L0=Home&L1=Government&L2=Departments+and+Divisions&L3=Department+of+Public+Health&L4=Programs+and+Services+A+-+J&sid=Eeohhs2&b=terminalcontent&f=dph_com_health_g_div_perinatal&csid=Eeohhs2

State CHIP Program

(health care for low-income uninsured children)

MassHealth Enrollment Center

Central Processing Unit

P.O. Box 129124

Boston, MA 02112-9124

(888) 665-9993; (888) 665-9997 (TTY)

Web:

<http://www.mass.gov/?pageID=eohhs2agencylanding&L=4&L0=Home&L1=Government&L2=Departments+and+Divisions&L3=MassHealth&sid=Eeohhs2>

The Genesis Fund

Provides “funding for the specialized care of New England Area children with birth defects, genetic diseases, and mental retardation. The Genesis Fund also funds therapeutic programs for children with special needs, and pioneers a public service program designed to inform the public about prenatal concerns.”

40 Second Avenue Suite 510

Waltham, MA 02451

Phone: 781-890-4282

Fax: 781-487-2361

Web: www.thegenesisfund.org

MILESTONES, Inc.

- *Developmental and Diagnostic Center (Psychological Services, OT/Sensory Integration, Speech, PT)*
- *Day School / The School for Accelerated Learning*
- *Intensive Intervention / ABA, Verbal Behavior, RDI, and Floortime*
- *Pragmatic “Social Skills” Groups*
- *Educational and Behavioral Consultation*
- *Workshops/Lectures*

Contact Information:

460 Totten Pond Road

Waltham, MA 02451 / Ste 300

v: 781-895-3200 x-24

f: 781-895-3226

email: alex@AdvancingMilestones.com

website: www.AdvancingMilestones.com

Adolescent Programs

TURNING 22: MASSACHUSETTS TRANSITIONAL PLANNING PROGRAM (617-727-7600): For young persons with severe disabilities still in need of services, Chapter 688 serves as a bridge from educational services into the adult human services program. The law provides for a two year transitional process for those young adults who will lose their entitlement to special education upon graduation or reaching the age of 22 and will be unable to work 20 hours per week in competitive employment.

<http://www.doe.mass.edu/sped/688/brochure.pdf>

Allergies

FOOD ALLERGY AND ANAPHYLAXIS NETWORK (FAAN): (1-800-929-4040) Members include families, dietitians, nurses, physicians, school staff, representatives from government agencies, and the food and pharmaceutical industries. FAAN serves as the communication link between the patient and others. Its vision is to be a world leader in food allergy and anaphylaxis awareness and the issues surrounding this disease. <http://www.foodallergy.org/about.html>

Asthma Management

1. ASTHMA AND ALLERGY FOUNDATION OF AMERICA (1-800-7-ASTHMA) or New England Chapter (1-877-2ASTHMA): Publications: "You Can Control Asthma: A Book for Kids," "You Can Control Asthma: A Book for the Family," (in English and Spanish) available for \$5.50 each (discounts for quantity orders); ample selection of asthma education materials for children, families, health professionals and schools. <http://www.aafa.org/>
<http://www.asthmaandallergies.org/>

MASSACHUSETTS ASTHMA ACTION PLAN (1-800-952-6637)
http://www.mhqp.org/mhqp_attachments/asthmaActionPlan.pdf

NATIONAL ASTHMA EDUCATION AND PREVENTION PROGRAM EXPERT PANEL REPORT 2: GUIDELINES FOR THE DIAGNOSIS AND MANAGEMENT OF ASTHMA (NIH):
<http://www.nhlbi.nih.gov/guidelines/asthma/asthdln.htm>

NATIONAL ASTHMA EDUCATION PROGRAM (NIH), MANAGEMENT OF ASTHMA IN THE SCHOOLS (301-592-8573): Standards for Asthma Management, Asthma Education Materials and "Managing Asthma: A Guide for Schools". <http://www.nhlbi.nih.gov/health/public/lung/index.htm>

NEW ENGLAND ASTHMA REGIONAL COUNCIL (NEW ENGLAND ARC) (617-451-0049 x504): The New England ARC is a coalition of public agencies, private organizations and researchers in New England. ARC's members bring the diverse perspectives and resources of health, housing, education, environment, managed care and advocacy organization together to focus on asthma. Leaders with knowledge, resources and determination have joined forces to swiftly identify and implement solutions to improve the lives of those with asthma. Great resources on web; special section on housing problems. <http://www.asthmaregionalcouncil.org/about/aboutarc.html>

PARTNERS HOME CARE PEDIATRIC ASTHMA HOME CARE PROGRAM: (781-290-4200). Three-visit program includes respiratory assessment, asthma education program, trigger management and outcome report to PCP. Additional visits can be arranged if needed. Partners Home Care serves a geographic area from Newburyport in the North, to Framingham in the West, to Plymouth in the South, with regional branch offices in Beverly, Waltham, Braintree and Plymouth.
<http://www.partnershomecare.org/mch.htm>

STARLIGHT STARBRIGHT ASTHMA CD-ROM GAME: QUEST FOR THE CODE weaves education about asthma management into an engaging adventure that will have kids playing for hours. (310-479-1212) In English and Spanish; free to families of children with asthma. <http://starlightnewengland.org/>

"TEACH YOUR PATIENTS ABOUT ASTHMA": A practical and flexible guide designed to help clinicians teach adults and children with asthma. This guide is based on recommendations of the "Expert Panel Report: Guidelines for the Diagnosis and Management of Asthma" developed by the National Asthma Education Program of the National Heart, Lung, and Blood Institute. It can be found online in full text at: <http://familydoctor.org/online/famdocen/home/common/asthma/kids/219.html> (original article unavailable online)

Bereavement

THE CHILDREN'S ROOM (781-641-4741): Support groups and resources for children, teenagers and their families who are grieving the death of a loved one. <http://www.childrensroom.org>

MASSACHUSETTS INFANT AND CHILD DEATH BEREAVEMENT PROGRAM (1-800-641-7437): Offers culturally competent bereavement support and educational services to families and caregivers of infants and young children who die of all causes of death (0-3) throughout Massachusetts.

<http://www.bmc.org/pediatrics/special/SIDS/>

PARENT SUPPORT GROUP: Contact Tami May (617-732-5419). A four-session support group for families who have experienced perinatal loss. Held at Brigham and Women's Hospital, but open to all who have suffered perinatal loss.

Care Coordination

COMMUNITY CASE MANAGEMENT (1-800-863-6068): Care coordination for MassHealth members under 22 who require more than 2 hours of consecutive nursing care each day. Services include a comprehensive needs assessment, an in-person home visit, a clinically appropriate service plan, and care collaboration with other providers. <http://www.communitygateway.org/faq/ccm.htm>

MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH, DIVISION FOR SPECIAL HEALTH NEEDS: CARE COORDINATION PROGRAM (617-624-5070): Experienced staff members are located in regional health offices and selected local pediatric practices in each part of the state. Care coordinators provide information and referral to community services; case-specific consultation to parents, educators, and medical and social service providers in home and agency settings; training in public benefits to parents' groups and agency staff. <http://www.mass.gov/dph/fch/care/index.htm>

Child Care

MEDICAL DAY CARE PROGRAM (617-254-3800): Medical day care program for children with chronic but stable medical conditions.

<http://www.fchrc.org/>

PARTNERS HOME CARE TLC NURSING PRIVATE DUTY SERVICES (1-800-698-2628): Includes a variety of private pay support services for newborns, children and adults, such as homemaker/companion services, light housekeeping, grocery shopping, meal preparation and escorting to appointments. Home Health Aide/Personal Care Homemaker Services (assistance with activities of daily living), Private Duty Nursing. <http://www.partnershomecare.org/privateservices.htm>

Children with Special Health Care Needs

ABLEDATA (1-800-227-0216): A federally funded project whose primary mission is to provide information on assistive technology and rehabilitation equipment available from domestic and international sources to consumers, organizations, professionals, and caregivers within the United States. <http://www.abledata.com/>

ADAPTIVE EQUIPMENT/ORTHOTICS: From braces and adaptive equipment to home modifications. Consult ortho/PT/OT.

ATEC: ASSISTIVE TECHNOLOGY CENTER AT SPAULDING REHABILITATION HOSPITAL (617-573-2928): State of the art Assistive Technology Center provides technological solutions to increase the functional abilities of children with disabilities. <http://spauldingrehab.org/body.cfm?id=59>

ASSISTIVE TECHNOLOGY EXCHANGE, NEW ENGLAND: Assistive Technology including wheelchairs, commodes, vision and hearing devices that are no longer needed for sale or for free for those that need them. www.getatstuff.org

ASSISTIVE TECHNOLOGY PROGRAM (1-800-245-6543): Program of the Massachusetts Rehabilitation Commission to enable individuals with severe disabilities the ability to access assistive technology devices and training. http://www.mass.gov/?pageID=eohhs2terminal&L=4&L0=Home&L1=Consumer&L2=Disability+Services&L3=Assistive+and+Rehabilitative+Technology&sid=Eeohhs2&b=terminalcontent&f=mrc_c_atp_overview&csid=Eeohhs2

"DIRECTIONS: RESOURCES FOR YOUR CHILD'S CARE": An organizing notebook and resource for children with special health care needs. http://www.mass.gov/Eeohhs2/docs/dph/populations/special_needs/directions/order_form.doc

DISABILITY EXCHANGE.ORG: Web site that serves as a central resource within the Partners community for disability-related information, services and products. Provides links to disability issues covered in the media; information on workshops, lectures and other events; E-commerce function for items such as assistive hardware/software, communication devices, videos and CDs; adaptive software download: Browse Aloud—a plug-in that enables the computer to read to the user; articles, newsletters and links to additional disability sites. <http://www.disabilityexchange.org/> (website currently unavailable)

EQUIPMENT FOR SPECIAL NEEDS CHILDREN: Web site sponsored by "Exceptional Parent" magazine listing links to manufacturers of equipment for children with special needs. http://www.eparent.com/resources/wcdexpo_exhibitor_indexep.htm (website currently unavailable)

FEDERATION FOR CHILDREN WITH SPECIAL NEEDS FAMILY RESOURCE DATABASE: The Family Resource Database contains information about agencies in Massachusetts and throughout the United States which provide information and/or services to families. The database is divided into many categories as well as cross-referenced by age group and regions in Massachusetts where applicable. <http://http://fcsn.org/resources/search.php3>

FAMILY TIES RESOURCE DIRECTORY: Comprehensive Resource Directory developed by Family Ties to assist families of children with special needs to locate resources. Directory can be downloaded from internet site. <http://www.massfamilyties.org/directory.html> (website currently unavailable)

HOME MODIFICATIONS FOR INDIVIDUALS WITH DISABILITIES: LOAN PROGRAM (617-204-3636): Provides loans for access modifications to the principal residence of elders, adults with disabilities and families with children with disabilities. Based on income eligibility. <http://www.state.ma.us/mrc>

MASSACHUSETTS CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND (1-800-882-1435):

Intended to provide financial assistance to families with children experiencing a medical condition requiring services that are not otherwise covered by a private insurer, federal or state health care assistance, or other financial resource. In order to be eligible, a family must have expenses related to a child's medical condition that exceed 10% of the family's gross annual income up to \$100,000 and 15% of any portion of the annual family income that exceeds \$100,000. <http://www.mass.gov/cicrf/>

MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH, DIVISION FOR SPECIAL HEALTH NEEDS: CARE COORDINATION PROGRAM (617-624-5070): Experienced staff members are located in regional health offices and selected local pediatric practices in each part of the state. Care coordinators provide information and referral to community services; case-specific consultation to parents, educators, and medical and social service providers in home and agency settings; training in public benefits to parents' groups and agency staff. <http://www.mass.gov/dph/fch/care/index.htm>

MASSACHUSETTS DEVELOPMENTAL DISABILITIES COUNCIL Consumer Empowerment Funds: The Massachusetts Developmental Disabilities Council provides funds for individuals who are legal residents of Massachusetts with developmental disabilities and/or a family member or guardian to attend conferences or other events in Massachusetts or another state. <http://www.state.ma.us/MDDC/cefp>

MASSACHUSETTS MEDICAL HOME PROJECT: An initiative of the American Academy of Pediatrics and the Division for Special Health Needs within the Bureau of Family and Community Health in DPH. The goal is to ensure that children with special needs have access to a medical home. Consult web site for project status, resources and training opportunities. <http://www.medicalhomeinfo.org/resources/state/massachusetts.html> (website currently unavailable)

NICHCY: NATIONAL INFORMATION CENTER FOR CHILDREN AND YOUTH WITH DISABILITIES (1-800-695-0285): An information clearinghouse that provides free information on disabilities and disability-related issues such as referrals, education and family issues. Web site also in Spanish. <http://www.nichcy.org/>

NORTH SHORE CHILDREN'S HOSPITAL PEDIATRIC REHABILITATION SERVICES (978-741-1215): Multidisciplinary developmental and rehabilitation evaluations and services including Audiology, Physical Therapy, Occupational Therapy, Language, Speech and Hearing, Feeding Team, Language Learning Team Evaluations, Florence Robertson Pediatric Rehabilitation Clinic and High Risk Infant Follow Up. <http://nsmc.partners.org/web/program/pediatrics>

PARTNERS HOME CARE PEDIATRIC REHABILITATION PROGRAM (781-2904200): Team members include a Pediatric Physical Therapist, Occupational Therapist, Speech and Language Pathologist. The team conducts developmental and rehabilitation assessments, sets specific rehabilitation goals and treatments and coordinates their efforts with other programs the child may be involved in. Goal is transition to community-based outpatient and school-based services. Partners Home Care serves a geographic area from Newburyport in the North, to Framingham in the West, to Plymouth in the South, with regional branch offices in Beverly, Waltham, Braintree and Plymouth. <http://www.partnershomecare.org/mch.htm>

PASS IT ON, INC. (1-800-267-6768): A non-profit charitable organization staffed by volunteers that recycles "used but usable" medical equipment and provides it to individuals with disabilities and their families. The agency services all of eastern Massachusetts and westerly to the Worcester area. <http://passitoncenter.org/>

SPAULDING REHABILITATION HOSPITAL (617-573-7000): Multidisciplinary developmental and rehabilitation evaluations and services. Refer to internet for listing of services at each of seven outpatient sites. <http://spauldingrehab.org>

SUMMER CAMP DIRECTORY (1-800-331-0688): Published annually by the Federation for Children with Special Needs, the Summer Camp Directory Booklet provides information on 80 day and residential

summer camps, plus a listing of local community resources. It provides guidelines for selecting a camp, and suggestions for including children with disabilities in regular camps. Camp Directory is also online. www.fcsn.org/summerfun07.php

TURNING 22: MASSACHUSETTS TRANSITIONAL PLANNING PROGRAM (1-800-245-6543): For young persons with severe disabilities still in need of services Chapter 688 serves as a bridge from educational services into the adult human services program. The law provides for a two-year transitional process for those who will lose their entitlement to special education upon graduation or reaching the age of 22 and will be unable to work 20 hours per week in competitive employment <http://www.doe.mass.edu/sped/688/brochure.pdf>

UNITED HEALTHCARE CHILDREN'S FOUNDATION: A small grant program for children who meets certain criteria to help parents and caretakers pay for children's medical needs and equipment not fully covered by insurance. www.uhccf.org

Dentist

CHILDREN'S MEDICAL SECURITY PLAN DENTAL PROVIDER DIRECTORY: UNICARE (1-800-234-9778) or check online listing. Patients should call Unicare customer service to determine coverage and request precertification if needed. <http://www.cmspkids.com/covinfo.html>

<http://www.cmspkids.com>

MASSACHUSETTS DENTAL SOCIETY (1-800-342- 8747): Referrals to dentists/special needs dentistry. <http://www.massdental.org/>

Development

EARLY INTERVENTION (1-800-905-8437): Free developmental evaluation and services available to families of children birth to three years of age for whom there are developmental concerns, or whose typical development is at risk due to certain birth or environmental circumstances. <http://massfamilyties.org/ei/index.html>

Diabetes

AMERICAN DIABETES ASSOCIATION (1-800-DIABETES; 1-800-342-2383): Mission is to prevent and cure diabetes and to improve the lives of all people affected by diabetes. <http://diabetes.org>

CAMPS FOR CHILDREN WITH DIABETES: Listing at <http://www.childrenwithdiabetes.com/camps/>

CHILDREN'S DIABETES FOUNDATION (303-863-1200) is a non-profit organization dedicated solely to the support of research in childhood diabetes and to provide the best possible clinical and educational programs for children with the disease. <http://www.childrensdiabetesfdn.org>

"HELPING THE STUDENT WITH DIABETES SUCCEED: A GUIDE FOR SCHOOL PERSONNEL" can be downloaded from the internet at <http://www.ndep.nih.gov/resources/school.htm>

JUVENILE DIABETES RESEARCH FUND: Mission is to find a cure for diabetes and its complications through the support of research. Web site offers great books for children with diabetes as well as their siblings, friends and classmates. <http://www.jdrf.org/index.cfm>

Emergency Response Plan

AMERICAN ACADEMY OF PEDIATRICS EMERGENCY PLAN AND FORM: This program was developed by the AAP to assist families and health care providers in the development of emergency response plans for children with special health care needs. <http://www.aap.org/advocacy/emergprep.htm>

EMERGENCY RESPONSE PLAN: A GUIDE FOR FAMILIES (617-726-3071): Step-by-step guide for families to assist in the development of an emergency response plan for a child living at home who is at risk of an acute medical emergency. <http://www.dcf.state.vt.us/cdd/pdfs/EmergencyResponse.pdf>

Hearing Disabilities

FAMILY SIGN LANGUAGE PROGRAM (781-388-9114): Massachusetts State Association for the Deaf. Provides sign language instruction to hearing parents, extended family, and caregivers of deaf and hard of hearing infants from birth to three years of age. Family classes are taught by Deaf instructors and are free to all participants who meet the eligibility criteria. <http://msad.org/>

HEARING AID PROGRAM FOR CHILDREN (1-800-882-1435): Provides payment for hearing aids for financially eligible children through the 21st birthday.

HEARING EVALUATION PROGRAM FOR INFANTS AND TODDLERS (1-800-882-1435 OR TTY 617-624-5992): Information on where to get hearing tested. Program will pay for testing for children under 3 if testing not covered by insurance. <http://www.mass.gov/dph/fch/unhsp/index.htm>

MASSACHUSETTS COMMISSION FOR THE DEAF AND HARD OF HEARING (617-740-1600 or TTY 617-740-1700; Child specialists 617-695-7500): The Massachusetts Commission for the Deaf and Hard of Hearing is principal agency in the Commonwealth on behalf of people of all ages who are deaf and hard of hearing. Services include case management, interpreter services, technology services including telecommunication and assistive listening devices, independent living services, information services, and such other services as it determines are needed. <http://www.mass.gov/mcdhh/>

Western Mass. Office:

436 Dwight St Ste 204

Springfield, MA

413-788-6427 voice & tty

RESOURCE DIRECTORY FROM THE MASSACHUSETTS COMMISSION FOR THE DEAF AND HARD OF HEARING (617-740-1600 or TTY 617-740-1700): Comprehensive directory of resources available in PDF format. http://mass.gov/Eeohhs2/docs/mcdhh/resource_directory.pdf

Housing

MASS ACCESS (617-742-0820): A registry of accessible housing in Massachusetts for people with disabilities. <http://massaccesshousingregistry.org/registry/registrymax.nsf/webpages/home?open>

Medications

INDIGENT PRESCRIPTION PROGRAMS: Programs administered through drug companies which provide samples to patients who are unable to pay for their prescription medications. Applications can be obtained from the drug company and/or physician. Applications usually need to be submitted by the physician to the drug company, samples are delivered to the physician's office and the patient picks them up at the office. For a copy of the "Directory of Pharmaceutical Indigent Assistance," which lists all pharmaceutical companies and products available, contact:
http://www.cancersupportivecare.com/drug_assistance.html

INTERNATIONAL ACADEMY OF COMPOUNDING PHARMACISTS (IACP) (1-800-927-4227): Organization for compounding pharmacist, a pharmacist that prepares customized prescription medication to meet individual patient needs. Internet site has a locator for pharmacists.
http://www.iacprx.org/site/PageServer?pagename=home_page

MEDICAL ASSISTANCE PROGRAM (1-800-462-1120): Children receiving MassHealth may be eligible for coverage for certain OTC (over-the counter) medication. Prescription required.

Mental Health

MASSACHUSETTS GENERAL HOSPITAL SCHOOL PSYCHIATRY.ORG: This web site was created for clinicians, clinicians-in-training, educators, and parents to help identify and support the needs of children and adolescents with psychiatric conditions, particularly in the school setting. The material in this web site is appropriate for clinicians who work in schools (e.g., school psychologists, guidance counselors) and those who work in mental health settings (e.g., psychiatrists, psychologists, social workers). Clinicians will find a broad range of material here, from diagnostic screening tools to practical strategies that can be recommended to families to ease a young person's stresses at home and at school.
<http://www.massgeneral.org/madiresourcecenter/schoolpsychiatry>

PAL: PARENT/PROFESSIONAL ADVOCACY LEAGUE is the statewide organization of the Federation of Families for Children's Mental Health. PAL provides support, education, and advocacy around issues related to children's mental health. PRN (Parent Resource Network) Line: 1-866-815-8122; parents/family members and adolescents can obtain support and get information on mental health services.
<http://ppal.net/default/>

Newborns

CAR SEATS (1-800-CAR-SAFE): Listing of local car seat loan programs and car seat safety information. Sponsored by DPH.

Nutrition

FOOD STAMPS (1-800-249-2007): Free coupons to buy groceries. *Eligibility:* There are certain income, savings and property qualifications but may qualify even if own a home, receive unemployment insurance, working, have a car, have no children. <http://www.gettingfoodstamps.org/>

PKU SPECIAL DIETARY FOOD AND FORMULA PROGRAM (1-800-882-1435): Pays for special food and formula for uninsured children with PKU and other related metabolic conditions.

Palliative Care

"END OF LIFE CARE FOR CHILDREN", published by Texas Children's Cancer Council.

<http://www.childendoflifecare.org>

EPERC: End of Life/Palliative Resource Center. Assists those involved in all aspects of end of life (EOL) education including a list of core resources for EOL educators and opportunities for training, extramural funding, and pending conferences. Seeks to create a community of online educational scholars who will enable us to advance the field of EOL education, and, ultimately, the care of patients.

<http://www.eperc.mcw.edu/>

HEALTH CARE DIMENSIONS PEDIATRIC PROGRAM: HOSPICE FOR KIDS (1-800-696-6424): A unique program designed to meet the medical and psychosocial needs of terminally ill children and adolescents. Medical services are coordinated with the attending physician. The focus is on the family as the unit of care including siblings and other extended family. <http://www.hcdhospice.org/program.htm>

MASSACHUSETTS COMMISSION ON END OF LIFE CARE: END OF LIFE RESOURCE GUIDE (617-624-5424): This guide has been developed to make it easier for the public to find out about end of life care resources and services that are available within the Commonwealth.

http://www.endoflifecommission.org/end_pages/guide.htm

Parent Support

EXCEPTIONAL PARENT (1-877-372-7368): Magazine about children and young adults with special health care needs. <http://www.eparent.com>

FAMILY TIES OF MASSACHUSETTS (1-800-905-TIES): Family TIES is a statewide information and support network provided by and for families of children with special needs. Publish a directory of resources for families "Resources for Families of Children with Special Needs", available for download from web site: <http://www.massfamilyties.org/>

FEDERATION FOR CHILDREN WITH SPECIAL NEEDS (1-800-331-0688): Parent run organization which helps parents and children obtain the educational, therapeutic and advocacy resources they need to live with disabilities. Provides education and training for parents and professionals. Especially helpful with questions parents have about special education. The staff members are parents of children with special needs. Publish a newsletter, program directories and sponsor a resource library and speaker's bureau.

<http://www.fcsn.org/>

MAXWELL AND ELEANOR BLUM PATIENT FAMILY LEARNING CENTER AT MASSACHUSETTS GENERAL (617-724-7352): Resource center with professional staff, volunteers, books, periodicals, pamphlets, computer access to web site to help locate information concerning children's medical conditions/medical needs.

1. <http://www.massgeneral.org/pflc/index.asp>

NICHCY: NATIONAL INFORMATION CENTER FOR CHILDREN AND YOUTH WITH DISABILITIES (1-800-695-0285) is the national information and referral center that provides information

on disabilities and disability-related issues for families, educators, and other professionals.

<http://nichcy.org/index.html#about>

NORD (NATIONAL ORGANIZATION FOR RARE DISORDERS) (1-800-999-6673): Information for children/families on rare pediatric problems. <http://www.rarediseases.org/>

PARENT STRESS HOTLINE (1-800-632-8188): A 24-hour hotline, the Parental Stress Line is staffed by trained volunteer telephone counselors who care and are concerned about the preservation of families.

PDD/Autism

1. AUTISM SOCIETY OF AMERICA: (1-800-588-9239). <http://www.saras-autism-diet.freeservers.com>

BUILDING BLOCKS PROGRAM (978-762-8352): Developmental Program through Early Intervention for children with Pervasive Developmental Delay or Autism. Children are referred through their local EI Programs. <http://www.nsar.org/frame/family/buildingblocks/>

COMMUNITY AUTISM RESOURCES (1-800-588-9239): Services and resources are provided at no cost to: parents, family members, professionals, and interested community members who live within service region. <http://www.community-autism-resources.org>

LADDERS PROGRAM (781-449-6074): LADDERS is a highly-focused multidisciplinary program designed to diagnose and assist families to deal with the full range of neurological developmental disorders. Medical and multidisciplinary staff are specialized in the diagnosis and treatment of Pervasive Developmental Delay and Autism. A major strength of the program is the development of comprehensive and effective rehabilitation plans for each patient that are communicated to the family and the referring physician. Care is taken to help the family locate appropriate resources. Long term follow-up care is provided via periodic consultations, if desired by the referring physician. www.ladders.org

Public Benefit Programs

CHILDREN'S MEDICAL SECURITY PLAN (Massachusetts) (1-800-531-2229): Health Insurance Program that provides children and adolescents with access to primary care and preventive services. Benefits include well child care; family planning and limited dental, emergency, mental health, durable medical equipment and prescription drug coverage. Any child age 18 or younger who lives in Massachusetts, is currently uninsured for primary or preventive health care, and is not eligible for primary or preventive health care coverage through MassHealth is eligible for coverage under CMSP. <http://www.cmspkids.com/>

COMMONHEALTH (Massachusetts) (1-800-841-2900): A program to purchase MassHealth (Medicaid) coverage for Massachusetts residents with disabilities through a sliding fee based on income and family size. May also serve as a secondary insurer in some cases. <http://www.hcfama.org/index.cfm/fuseaction/Page.viewPage/pageId/328>
Tips for families at web address: <http://www.massfamilyvoices.org>

DEPARTMENT OF TRANSITIONAL ASSISTANCE (formerly Welfare) (1-800-249-2007): Food stamps, Transitional Aid for Needy Families (TANF) and other assistance. <http://www.state.ma.us/dta/index.htm>

F.O.R. FAMILIES (1-800-624-5442): Home visiting program whose primary goal is to help homeless families while they are temporarily sheltered in motels awaiting shelter placement and/or permanent housing. Services are free and participation is voluntary. Home visiting services are available for families who are receiving Emergency Assistance [EA] from the Department of Transitional Assistance [DTA] because they are homeless and living in motels temporarily. <http://www.mass.gov/dph/fch/forfams.htm>

HEALTH INSURANCE PREMIUM PAYMENT PROGRAM (HIPP) (1-800-462-1120): Reimbursement program for employer sponsored health insurance or a form of group insurance for families with a child with a disability on Mass Health. Family tip sheet. <http://www.state.ma.us/dma/>

HEALTHY START (Massachusetts) (1-888-665-9993): A program of prenatal care which offers information, referral, support and advocacy to pregnant women in Massachusetts, and may also cover the cost of obstetrical care for those women who meet eligibility requirements. HOTLINE assists pregnant women to apply for Healthy Start/Medicaid. <http://www.massresources.org/pages.cfm?contentID=51&pageID=13&subpages=yes&dynamicID=700>

KAILEIGH MULLIGAN (Massachusetts) (1-800-408-1253): A Medicaid program that does not count parent income for Medicaid eligibility. It is intended to enable children with severe medical conditions that require technological dependence and/or skilled nursing care to be cared for at home. Tip sheet for families online. <http://www.mass.gov/dph/fch/care/kaileighmulligan.htm>

MASSHEALTH (MEDICAID) (1-800-841-2900). Offers a broad range of health-care services by paying for part or all of a MassHealth member's health insurance, or paying medical providers for services given to MassHealth members. Qualified MassHealth members may be able to get doctor visits, prescription drugs, hospital stays, and many other important services. *Eligibility:* Income eligible families, children under 19, children receiving AFDC or SSI, children with Kaileigh Mulligan. <http://www.state.ma.us/dma/>

PUBLIC BENEFITS INFORMATION LINE (1-800-882-1435): Provides information on state programs that help finance health care for children with disabilities and chronic illness. Also provides information and referral for DPH Case Management services and the Infant Hearing Evaluation and Infant/Toddler Hearing Aid Program. <http://www.mass.gov/dph/shcn/ssi.htm> (website currently not available)

SSI (Federal) (1-800-772-1213): A monthly cash benefit and Massachusetts Medicaid coverage for payment of Medical bills. *Eligibility:* Child under 18 who is blind or has a serious illness or handicapping condition AND meets income eligibility guidelines. (*Infants/children hospitalized for a full calendar month may not need to meet income eligibility guidelines while hospitalized.*)

Resource References

DISABILITY RESOURCES MONTHLY (DRM) GUIDE TO RESOURCES ON THE INTERNET: A listing of resources for the disabled. <http://www.disabilityresources.org>

[FAMILY TIES RESOURCE DIRECTORY](http://www.massfamilyties.org/directory.html): Comprehensive Resource Directory developed by Family Ties to assist families of children with special needs to locate resources. Directory can be downloaded from internet site. <http://www.massfamilyties.org/directory.html>

FEDERATION FOR CHILDREN WITH SPECIAL NEEDS FAMILY RESOURCE DATABASE: The Family Resource Database contains information about agencies in Massachusetts and throughout the United States which provide information and/or services to families. The database is divided into many categories as well as cross-referenced by age group and regions in Massachusetts where applicable. <http://fcsn.org/index.php>

Respite

EARLY INTERVENTION REGIONAL CONSULTATION PROGRAM: Team available to a child's early intervention team which can provide consultation regarding respite services. Child must be enrolled in an Early Intervention Program. <http://www.criterionchild.com/reg.html>

RESPITE: State respite managed through the Department of Public Health (1-800-882-1435) or the

Department of Mental Retardation (617-727-5608).

School

A PARENTS GUIDE TO SPECIAL EDUCATION (1-800-331-0688): Written by the Federation for Children with Special Needs in collaboration with the Massachusetts Department of Education, the Guide is meant to serve as a resource for parents, and the organizations that serve them. The Guide contains the most current and accurate information available regarding the special education system in Massachusetts. <http://www.fcsn.org/parentguide/pgintro.html>

IEP/CHAPTER 766: Local school system provides for tests, assessments and delivery of Special Education services. Contact the Special Education Services Coordinator of the local Public School System.

MASSACHUSETTS DEPARTMENT OF EDUCATION (781-338-3300): Oversees the public education of all children in Massachusetts and is responsible for ensuring that all the provision of Chapter 766 (the MA special education law) is met. Can provide a copy of the law to consumers. <http://www.doe.mass.edu/>

MASSTART: (Massachusetts Technology Assistance Resource Team) (508-792-7880) is a collaborative service that helps families and schools plan for the health care and safety of children and adolescents with special health needs at school, especially those assisted by medical technology. <http://www.mass.gov/dph/fch/masstart.htm>

SCHOOL HEALTH PLAN: Plan developed by child, parent, school nurse and physician for the management of medical problems at school. Contact school for their plan format.

STUDENTS WITH CHRONIC ILLNESS: GUIDANCE FOR FAMILIES, SCHOOLS AND STUDENTS: A Guide for working with the school when a child has a chronic illness. <http://www.nhlbi.nih.gov/health/public/lung/asthma/guidfam.htm>

State Agencies

MASSACHUSETTS COMMISSION FOR THE BLIND (617-727-5550): Provides services to meet the individual needs of eligible registered legally blind children. <http://www.mass.gov/mcb/>

MASSACHUSETTS COMMISSION FOR THE DEAF AND HARD OF HEARING (1-800-882-1115; TTY 1-800-530-7570): Provides services for individuals who are deaf or hard of hearing including interpreters, case management, children's services, services related to technology, general information. <http://www.state.ma.us/mcdhh/>

MASSACHUSETTS DEPARTMENT OF MENTAL RETARDATION (617-727-5608): A Commonwealth of Massachusetts Human Service Agency whose Mission is to provide services and support to individuals with mental retardation and their families. <http://www.fcsn.org/aboutus/ed/ed16.php>

MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH: DIVISION FOR SPECIAL HEALTH NEEDS (1-800-882-1435): Plans, implements and evaluates public health programs for children with special health care needs and their families. <http://www.mass.gov/dph/fch/dshn.htm>

MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH, DIVISION FOR SPECIAL HEALTH NEEDS: CARE COORDINATION PROGRAM (617-624-5070): Experienced staff members are located in regional health offices and selected pediatric practices in each part of the state. Care coordinators provide information and referral to community services; case-specific consultation to parents, educators, and medical and social service providers in home and agency settings; training in public benefits to parents' groups and agency staff. <http://www.mass.gov/dph/fch/care/index.htm>

MASSACHUSETTS REHABILITATION COMMISSION (1-800-245-6543): The Massachusetts Rehabilitation Commission (MRC) assists individuals with disabilities to live independently and to go to work. MRC is the agency of the Commonwealth responsible for Vocational Rehabilitation Services, Independent Living Services, and for eligibility determination for the SSI/SSDI (federal) benefits programs for Massachusetts citizens with disabilities. <http://www.mass.gov/mrc>

Transportation

AMERICAN ACADEMY OF PEDIATRICS POLICY STATEMENTS (1-800-336-5475): Policy Statements "Safe Transportation of Newborns at Hospital Discharge", "Safe Transportation of Premature and Low Birth Weight Infants," "Transporting Children with Special Health Care Needs," "School Bus Transportation of Children with Special Needs" and Parent Education Guides "Car Seat Shopping for Children with Special Needs," "Car Seats for Children with Special Needs—Premature Babies, Casts and Wheelchairs." <http://www.aap.org/>

DEPARTMENT OF TRANSPORTATION TOLL-FREE HOTLINE FOR AIR TRAVELERS WITH DISABILITIES (1-800-778-4838; TTY 1-800-455-9880).

HANDICAPPED PERSONS PLATES AND PLACARDS (617-351-9222): Special handicapped license plates to enable disabled individuals to park in handicapped spaces. Applications available through the web site. Some town/city halls will issue temporary placards. http://www.state.ma.us/rmv/medical/plates_placs.htm

MEDICAID TRANSPORTATION PROGRAM (1-800-841-2900 x.1): Non-Emergency Transportation Service such as door to door non-emergency transportation to and from medical provider when public and private transportation resources are not available. Requires prior authorization. Parent tip sheet and Sample Application Form

THE RIDE (617-222-5123 or 1-800-533-6282): MBTA's paratransit service provides advance notice, door-to-door transportation to those who, because of physical, cognitive, psychiatric, or sensory disability are unable to use general public transportation. The RIDE has wheel- chair equipped vans and covers the same communities that are served by MBTA buses, subway trains, or streetcars. http://www.mbta.com/riding_the_t/accessible_services/?id=7108

Wish Programs

MAKE A WISH FOUNDATION (617-451-WISH): A wish program for children living in Massachusetts between the ages of 2 1/2 and 18 with a life-threatening or terminal disease. <http://www.mass.wish.org/home.html>

TOYS FOR TOTS (617-737-0500)

Starlight Foundation (1-617-241-9911) Starlight grants wishes to children ages 3 through 18 who are suffering from chronic, serious or life threatening illnesses.

www.starlightnewengland.org

Other

1. CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND (1-800-882-1435): Fund intended to provide financial assistance to families with children experiencing a medical condition requiring services that are not otherwise covered by a private insurer, federal or state health care assistance, or any other financial resource. In order to be eligible, a family must have expenses related to a child's medical condition that exceed 10% of the family's gross annual income up to \$100,000 and 15% of any portion of the annual family income that exceeds \$100,000. <http://www.state.ma.us/cicrf/>

COMFORT CARE DO NOT RESUSCITATE (DNR) VERIFICATION PROGRAM (617-753-8300): Program to identify patients who have DNR orders. Enables EMT's and first responders to withhold resuscitation and to provide palliative, or "comfort" measures . Administered through DPH. <http://www.mass.gov/dph/oems/comfort/ccare.htm>

DIAPERS FOR INCONTINENT CHILDREN: For children over three receiving MassHealth with a disabling condition (1-800-882-1435).

MASSACHUSETTS COMMUNITY ACTION AGENCIES: Visit this web site to learn about a host of community based programs. <http://www.masscap.org/agencies.html#ssca>

MASSPRO FLUCLINICS: Visit this web site to get information on community-based flu clinics. <http://flu.masspro.org/>

MEDIC ALERT KIDS SMART (1-888-633-4298): Medic Alert Identification Program for children. <http://www.medicalert.org>

SPECIAL MEDICAL FUND (1-800-882-1435) (DPH): Helps families pay expenses related to their child's special health care needs, when it has been determined that private or public benefits are not available for the service or item being requested. (e.g. medical bills not covered by health insurance, medications, respite, special equipment, medical supplies, etc.)

<http://www.merck.com/mmhe/index.html>

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