



Maternal Child Health Resource Directory

2008 EDITION

BRINGING CARE HOME



A listing of community resources compiled by:
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The Partners Home Care Maternal Child Home Visit Program provides specialized in-home, family-centered care to women experiencing high-risk pregnancies, new mothers and their infants, as well as high-risk infants, children and adolescents experiencing medical challenges. The Maternal Child Health (MCH) team is comprised of a clinical nurse specialist; maternal child health nurses who specialize in prenatal, postpartum, high-risk infant and pediatric care and community health; nutritionists; lactation consultants and counselors; pediatric therapists; social workers; and home health aides. Specialists with advanced training and experience in Maternal Child Health, pediatrics, IV therapy, pulmonary and cardiac disease, diabetes, wound and ostomy care, neurology, oncology, palliative care, rehabilitation and mental health are available for consultation and patient care.

MCH nurses work together with the family and referring physician in the development of a plan of care that focuses on the assessment, management, support, education and coordination of care for children and their families. Families are assisted in the identification of practical, psychological, social and economic solutions for challenges they may be facing. Nurses are skilled in the management of a variety of high risk family situations such as post partum depression, domestic violence, child abuse, financial hardship, chronic and life threatening illness, substance abuse, and the care of families in shelters. Staff work closely with families and community based services in making referrals and coordinating care.

Prenatal Program

Prenatal visits focus on the assessment, management, support, and education of the woman and family experiencing a high-risk pregnancy. Nurses manage a variety of high-risk issues, such as:

- preterm labor
- gestational diabetes
- maternal medical problems
- hyperemesis gravidarum
- hypertension in pregnancy
- IV therapy
- multiple gestation
- teen pregnancy

Maternal-Infant Program

Maternal-Infant visits are designed to provide specialized follow-up for mothers and infants with identified risks and complications following delivery. During the visit, the nurse provides assessment of the mother and the newborn, patient education, physical restoration of the mother, establishment of breast and/or bottle feeding, newborn care and psychosocial adaptation to parenthood. The program includes:

- early maternity discharge
- high-risk maternal infant home visit
- hyperbilirubinemia
- premature infant
- medically fragile infant
- multiple births
- Neonatal Abstinence Syndrome
- teen parents
- post-partum depression
- post-partum complications
- cesarean wound care

Pediatric Program

Nurses manage a variety of pediatric problems, including:

- high-risk infants
- asthma
- diabetes
- cardiac
- failure to thrive
- lead poisoning
- oncology
- Cystic Fibrosis
- medically fragile children
- post-operative follow-up
- spica cast/traction management
- Sudden Infant Death Syndrome
- palliative care

Specialized Skills

The Partners Home Care Maternal Child Nursing Team is skilled in specialized treatments such as: IV therapy; N/G tube management; G-tube care; tracheostomy care; capillary blood testing; portacath access; central line management; home oxygen; suction and nebulizer treatment.

Pediatric Rehabilitation Services

Pediatric Therapy services include a case manager, a pediatric physical therapist, occupational therapist, and speech and language pathologist. The team conducts developmental and rehabilitation assessments, sets specific rehabilitation goals and treatments and coordinates its efforts with other programs the child may be involved in.

**For additional information or to make a referral, call the Partners Home Care Central Intake Office
781-290-4200**



MATERNAL CHILD HEALTH RESOURCE DIRECTORY

**Partners Home Care Maternal Child Home Care Program:
For referrals – 781-290-4200**

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MATERNAL CHILD HEALTH RESOURCE DIRECTORY

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ADOLESCENT PROGRAMS

HEALTHY FAMILIES: (617-727-8957) Provides strengths-based, family-centered, intensive home visiting services for all first-time parents ages 20 and under across Massachusetts. Participants can enroll during pregnancy or any time prior to the child's first birthday. They can continue to receive services until their child turns three.

<http://www.mctf.org/sp.aspx?id=225>

MASSACHUSETTS ALLIANCE ON TEEN PREGNANCY: (617-482-9122) Dedicated to ensuring that state policies and programs effectively address the complex issues associated with teen pregnancy. Publish "A Teen Parent Guide to Massachusetts Public Benefits and Services"

<http://www.massteepregnancy.org/about/index.html>

PFLAG; Parents, Families and Friends of Lesbians and Gays (202-467-8180) PFLAG promotes the health and well-being of gay, lesbian, bisexual and transgendered persons, their families and friends through: support, to cope with an adverse society; education, to enlighten an ill-informed public; and advocacy, to end discrimination and to secure equal civil rights. Web site contains publications and resources for adolescent issues.

<http://www.pflag.org/about/mission.html>

ROCA: (1-617-889-5210) Roca is a grassroots, multicultural human development and community building organization based in Chelsea and serving the communities of Chelsea, Revere, East Boston and Lynn, Massachusetts. In partnership with Massachusetts General Hospital, Roca hosts an evening health clinic for young people.

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

TOUGH LOVE AMERICA: A self-help program for parents, teenagers and communities dealing with "out of control" behavior. The TOUGHLOVE® Parenting Program is a loving solution that empowers families to overcome denial, take action, and take control. TOUGHLOVE provides parents with accurate, actionable information about the problems they and their children face, and the parenting tools to confront and surmount them.

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

TRANSITION PLANNING FOR ADOLESCENTS WITH SPECIAL HEALTH CARE NEEDS AND DISABILITIES: INFORMATION FOR FAMILIES AND TEENS (2000): A wonderful guide for transitioning teens with special

needs into adulthood. Available through the Institute for Community Inclusion.

http://www.communityinclusion.org/article.php?article_id=184&staff_id=33

TURNING 22: MASSACHUSETTS TRANSITIONAL PLANNING PROGRAM: 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

ALLERGIC CHILD.COM: READING FOOD LABELS: Web site provides specific information on how to read food labels to determine if product contains ingredients the child is allergic to.

http://www.allergicchild.com/how_to_read_a_label.htm

FOOD ALLERGY AND ANAPHYLAXIS NETWORK: (FAAN). (1-800-929-4040) FAAN publishes several newsletters and provides books, booklets, videos, and other products designed to educate about food allergy. 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>

KIDS WITH FOOD ALLERGIES: (1-215-230-5394) Membership gives access to database of hundreds of recipes that are milk-free, egg-free, soy-free, nut-free, peanut-free, wheat-free, gluten-free, sesame-free, fish-free, and more.

<http://www.kidswithfoodallergies.org/recipes.html>

ASTHMA MANAGEMENT

ASTHMA AND ALLERGY FOUNDATION OF AMERICA: (1-800-7-ASTHMA or New England Chapter (1-877-2 ASTHMA) Publications: "You Can Control Asthma: A Book for Kids," "You Can Control Asthma: A Book for the Family" (in English and Spanish) available for purchase (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/>

BOSTON PUBLIC HEALTH COMMISSION HEALTHY HOMES PROGRAM: PHYSICIAN OR SELF REFER: (1-617-534-5966) Communities: Allston, Brighton, Boston, Charlestown, Chinatown, Dorchester, East Boston, Jamaica Plain, Mattapan, Roslindale, Roxbury, South Boston, South End. Home visits include home evaluation for asthma triggers along with recommendations for remediation. Will assist/coach families to work with housing issues. Healthy Homes programs include varying degrees of asthma education and communication with PCP. The programs provide free mattress and pillow covers, and other free materials.

CAMBRIDGE HEALTH ALLIANCE HEALTHY HOMES PROGRAM: PREFER PHYSICIAN REFERRAL, ACCEPT SELF REFERRALS: (1-617-665-3831) Communities: Cambridge, Somerville, Everett, Revere, Malden. Contact: Alison Morris; Alicia Morris. Home visits include home evaluation for asthma triggers along with recommendations for remediation. Will assist/coach families to work with housing issues. Healthy Homes programs include varying degrees of asthma education and communication with PCP. The programs provide free mattress and pillow covers, and other free materials.

NATIONAL ASTHMA EDUCATION AND PREVENTION PROGRAM EXPERT PANEL REPORT 3: GUIDELINES FOR THE DIAGNOSIS AND MANAGEMENT OF ASTHMA. (NIH) <http://www.nhlbi.nih.gov/guidelines/asthma/asthgdln.htm>

NATIONAL ASTHMA EDUCATION PROGRAM (NIH), MANAGEMENT OF ASTHMA IN THE SCHOOLS: (1-301-592-8573) 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): (1-617-451-0049) 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: (1-781-290-4200). 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 and Bridgewater. <http://www.partnershomecare.org>

STARLIGHT STARBRIGHT ASTHMA GAME: QUEST FOR THE CODE weaves education about asthma management into an engaging adventure that will have kids playing for hours. Game now available online. <http://asthma.starlightprograms.org/>

BEREAVEMENT

THE CHILDREN'S ROOM (1-781-641-4741) Support, groups and resources for children, teenagers, and their families who are grieving the death of a loved one. <http://www.childrensroom.org/>

MASSACHUSETTS CENTER FOR SUDDEN INFANT DEATH SYNDROME (SIDS): (1-800-641-SIDS). Offers culturally competent bereavement support and educational services to families and caregivers of infants who die of all causes of Sudden Infant Death Syndrome. Support includes: 24 hour telephone crisis intervention and information, home visits by specially trained bereavement counselors, parent support group meetings and peer support contacts. <http://www.bmc.org/pediatrics/special/SIDS/>

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/>

BREASTFEEDING

BREASTFEEDING.COM. Internet resource for breastfeeding mothers and mothers to be featuring information, tips, resources and products. <http://www.breastfeeding.com/>

BREAST PUMP FOR PURCHASE OR RENT: MEDELA (1-800-435-8316) <http://www.medela.com/>

CAMBRIDGE MEDICAL SUPPLY COMPANY: (1-617- 876-3810). Provide information on insurance coverage and arrange for delivery of breast pump to home.

HOLLISTER AMEDA (1-877-992-6332) Information on breastfeeding, breastfeeding supplies, lactation and breast pump rental. <http://www.medela.com/>

MADELA: (1-800-435-8316) Information on breastfeeding, breastfeeding supplies, lactation and breastpump rental. <http://www.medela.com/NewFiles/healthcare2.html>

LA LECHE LEAGUE: (1-800-LA-LECHE). <http://www.lalecheleague.org/>

MASSACHUSETTS BREASTFEEDING COALITION: The Massachusetts Breastfeeding Coalition (MBC) is an alliance of organizations and individuals involved in maternal/child health whose purpose is to promote, protect and support breastfeeding in the Commonwealth. Provides educational programs and materials.

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

MASSACHUSETTS BREASTFEEDING RESOURCE GUIDE: (Call 1-617-624-6153 for free copy or download from internet). Comprehensive reference including listing of lactation consultants, programs, policies and references developed by the Massachusetts Breastfeeding Coalition and printed by WIC.

<http://massbfc.org/resources/order.html>

NURSING MOTHERS COUNCIL/BACE (BOSTON ASSOCIATION FOR CHILDBIRTH EDUCATION): (1-617-244-5102). Breastfeeding information, supplies and counselors.

<http://www.bace-nmc.org/>

OUTPATIENT BREASTFEEDING CONSULTATION: Consult local birthing hospitals. Some hospitals have outpatient breastfeeding consultation for nominal fee.

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 (1-800-882-1435) 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

DEPARTMENT OF EARLY EDUCATION AND CARE: (1-617-988-6600). Massachusetts agency which is responsible for the licensing of child care providers in the state of Massachusetts. Web site is a fantastic resource to assist families to evaluate their child care options, locate licensed providers and assess income eligibility for voucher programs.

<http://www.eec.state.ma.us/>

PEDICARE MEDICAL DAY CARE CENTER: (1-617-254-3800). Medical day care program for children with chronic medical conditions.

<http://www.franciscanhospital.org/Home/ProgramsServices/Educational/PediCare/page.aspx/1029>

PARTNERS PRIVATE CARE: (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/privatecare.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 the hospital orthopedic, occupational therapy or physical therapy departments.

ATEC: ASSISTIVE TECHNOLOGY CENTER AT SPAULDING REHABILITATION HOSPITAL: (1-617-573-2927). State of the art Assistive Technology Center provides technological solutions to increase the functional abilities of children with disabilities

<http://spauldingrehab.org/atc>

MASS REHAB 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/mrc/>

CARE COORDINATION TOOLKIT: This web based tool kit is intended for professionals who coordinate care for children in Washington state, but is applicable as a model for anyone attempting to create supports for children with special health care needs.

<http://www.cshcn.org/resources/carecoordination.cfm>

CASTASTROPHIC 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.

<http://www.state.ma.us/cicrf/>

DPH COMMUNITY SUPPORT LINE: (1-800-882-1435) A toll free line that offers assessment, technical assistance, information about public benefits, other state programs, and community resources. Staffed by social workers with extensive experience in assisting families of children and youth with special health needs.

“DIRECTIONS: RESOURCES FOR YOUR CHILD’S CARE” An organizing notebook and resource for children with special health care needs. Available for download at:

<http://www.mass.gov/dph/fch/directions/>

Hard copy order form available at:

http://www.mass.gov/Eeohhs2/docs/dph/populations/special_needs/directions/order_form.doc

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/resources/search.php>

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>

HOME MODIFICATIONS FOR INDIVIDUALS WITH DISABILITIES: LOAN PROGRAM (1-617-204-3742) Provides loans for access modifications to the principle residence of elders, adults with disabilities and families with children with disabilities. Based on income eligibility.

<http://communitygateway.org/faq/loan.htm>

KIDS WITH TUBES: (1-617-825-6364) Kids with Tubes is an organization run by parents offering a variety of support services for parents and caregivers of tube-fed children. Its mission is to provide forums for the sharing of information and mutual support. We aim to bring together families whose children have feeding tubes (NG-, G-, GJ-, J- and/ or NJ-tubes) without regard to the children’s underlying diagnoses. In addition, Quarterly Seminars and the group’s newsletter, Kids with Tubes News, provide an opportunity for professionals who are in the field of caring for tube-fed children to gain not only important information but also an appreciation for parent perspectives on the issues involved.

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

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 resources.

<http://www.mass.gov/cicrf/>

MASSACHUSETTS CONSORTIUM FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS: The Massachusetts Consortium for Children with Special Health Care Needs is a working group dedicated to improving systems of care for children and families in the state.

<http://www.neserve.org/maconsortium/index.html>

MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH, DIVISION FOR SPECIAL HEALTH NEEDS: CARE COORDINATION PROGRAM (1-800-882-1435) 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: (1-617-770-7676 ext. 115) 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.mass.gov/mddc/cefp/index.htm>

MGH COORDINATED CARE CLINIC PROGRAM: (1-617-643-0606) For families of children with medically complex healthcare needs, provides help with arrangement of visits with pediatric specialists, facilitation of communication and collaboration among specialists, development of comprehensive, coordinated treatment plans, consultations with social workers, physical therapists, and other allied health professionals and help with diagnostic dilemmas

http://www.massgeneral.org/children/specialtiesandservices/coordinated_care/default.aspx

NICHY: 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: (1-978-741-1215) Multidisciplinary developmental and rehabilitation evaluations and services including Audiology, Physical therapy, Occupational Therapy, Language, Speech and Hearing, Feeding Team, Language Learning Team Evaluations, Neurodevelopment Center, Multidisciplinary Evaluation Center, Florence Robertson Pediatric Rehabilitation Clinic and High Risk Infant Follow Up.

<http://nsmc.partners.org/web/program/pediatrics>

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.

SPAULDING REHABILITATION HOSPITAL: (1-617-573-7000). Multidisciplinary developmental and rehabilitation evaluations and services. Refer to internet for listing of services at each of eight outpatient sites.
<http://spauldingrehab.org>

TRANSITION PLANNING FOR ADOLESCENTS WITH SPECIAL HEALTH CARE NEEDS AND DISABILITIES: INFORMATION FOR FAMILIES AND TEENS (2000): (1-617-355-4664) A wonderful guide for transitioning teens with special needs into adulthood. Available through the Institute for Community Inclusion.
http://www.communityinclusion.org/article.php?article_id=100&staff_id=33

TURNING 22: MASSACHUSETTS TRANSITIONAL PLANNING PROGRAM: 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>

COMMUNITY BASED RESOURCES

COMMUNITY BASED RESOURCES: Consult town/city Department of Public Health; town web sites and/or community health centers.

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

DENTIST

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

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

MASS HEALTH FINE DENTAL PROVIDER SEARCH PAGE: DPH Internet search page for Mass Health Members to locate a dentist.
<https://masshealthdental.net/MemberServices/FindProvider.aspx>

DEVELOPMENT

BRIGHT FUTURES RESOURCE GUIDE: (1-888-275-4772 for complementary copy) The Bright Futures Family Pocket, written especially for families, complements Bright Futures materials used by health professionals. Family Voices developed the guide so that families will have access to the wealth of information Bright Futures provides. It also encourages the family/practitioner relationship that are so important to children's health. This guide is a quick reference for families, highlighting the six important child health topics. The guide is organized by the four, Bright Futures age groups or stages of development.
http://www.brightfuturesforfamilies.org/pocket_guide.shtml

EARLY HEAD START: (1-617-573-1600) Comprehensive child development programs serving low income pregnant woman, infants and toddlers.
<http://www.ehsnrc.org/ProgramLocator/ehssites.cfm>

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://www.massfamilyties.org/ei/index.html>

HEAD START: (1-617-565-1128) Comprehensive child development programs to increase school readiness for low income children age 3- 5 and their families. Services involve parents and include education, medical, dental, nutrition and mental health. Services are responsive and appropriate to each child's and family's developmental, ethnic, cultural, and linguistic heritage and experience. Family must have income below the poverty line or be receiving public assistance; i.e. SSI or TANF benefits.
<http://www.acf.hhs.gov/programs/hsb/hsweb/index.jsp>

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://www.diabetes.org>

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

CHILDREN'S DIABETES FOUNDATION: (1-303-863-1200) 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 this disease.
<http://www.childrensdiabetesfdn.org>

DIABETES HELP FINDER RESOURCE GUIDE: Massachusetts Department of Public Health Diabetes Prevention and Control Program. Call 1-800-952-6637 for single copy.
<http://www.maclighthouse.com/CatalogPageFrameSet.htm>

"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>

LIFE CLINIC HEALTH MANAGEMENT SYSTEMS: Web site providing a comprehensive explanation of Type I and 2 Diabetes in Children. Covers explanation of diagnosis, treatment, diet management.

http://www.lifeclinic.com/focus/diabetes/childrenteen_main.asp

DOMESTIC VIOLENCE

DSS CHILD AT RISK HOTLINE: (1-800-792-5200). To report child abuse, access follow-up services including crisis intervention and emergency services, counseling, protective child care, parent aid services, substitute care and case management.

<http://www.jbcc.harvard.edu/programs/hotline.htm>

EMERGENCY SHELTER: Consult your social service department or the Haven program at MGH or the Passageway program at Brigham and Women's Hospital.

HAVEN: (1-617-724-0054). An MGH based program for domestic violence.

<http://www.massgeneral.org/visitor/haven.htm>

JANE DOE: Resource for information and service for those experiencing domestic violence.

<http://www.janedoe.org/safety.htm>

MASSGENERAL HOSPITAL FOR CHILDREN CHILD PROTECTION TEAM: (1-617-724-0285)

http://www.massgeneral.org/children/specialtiesandservices/child_protection/default.aspx

NORTH SHORE MEDICAL CENTERS CHILD ABUSE ASSESSMENT PROGRAM: (1-978-354-2819) NSMC Child Abuse Assessment Program provides integrated support services in cases of suspected child maltreatment. Medical examinations by trained, supportive medical personnel. Services include: Medical examination; Consultation and support for hospital personnel, community physicians, allied health professionals, and others.; Case coordination; and Collaboration with the Essex County District Attorney, local police, and the Department of Social Services.

http://nsmc.partners.org/web/service/pediatrics_abuse_assessment

PASSAGEWAY (1-617-732-8753 or 1-617-732-6660; Beeper #31808 () Brigham and Women's domestic violence advocacy, consultation, training, awareness and community linkage program.

<http://www.brighamandwomens.org/communityprograms/Passageway.aspx>

SAFELINK: (1-877-785-2020; 1-877-521-2601 (TTY)) Massachusetts statewide multilingual domestic violence hotline.

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: (1-617-726-3071) 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.

dlozowski@partners.org

EMERGENCIES AND DISASTERS: KEEPING CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS SAFE: Family Voices Guide to preparation for emergencies for children with special health care needs. PDF version available on internet.

http://www.familyvoices.org/pub/general/Disasters_&Emergencies.pdf

EMERGENCY RESPONSE PLAN: "DIRECTIONS: RESOURCES FOR YOUR CHILD'S CARE" (1-800-882-1435) available in English and Spanish) "Directions" is an organizing notebook and a resource guide for families of children with special health care needs. Refer to Chapter 4. "Being prepared for an emergency". Contains template for keeping a record of child's medical information for emergency personnel and advises families on how to notify ambulance, fire, police, and utility companies about their child's special needs. Available for download at:

<http://www.mass.gov/dph/fch/directions/>

Hard copy order form available at:

http://www.mass.gov/Eeohhs2/docs/dph/populations/special_needs/directions/order_form.doc

PARTNERS LIFELINE PROGRAM: (1-800-910-4225). Offers a variety of options for calling a 24 hour response center or a third party in an emergency. Options include a Personal Help Button (PHB), worn on the wrist or around the neck or a telephone link for people with limited physical abilities; a selection of electronic switches specially designed for small movements such as a puff, a sip on a tube, a roll of the head, or the blink of an eye.

<http://www.partnershomecare.org/lifeline.htm>

HEARING DISABILITIES

FAMILY SIGN LANGUAGE PROGRAM:

(1-781-388-9114) 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.

http://www.mass.gov/Eeohhs2/docs/dph/com_health/prego_newborn/hear_screen_financial_guidelines.pdf

HEARING EVALUATION PROGRAM FOR INFANTS AND TODDLERS: (1-617-624-5957). Information on where to get hearing tested. Program will pay for testing for children under 3 if testing not covered by insurance.

<http://www.infanthearing.org/states/massachusetts/index.html>

MASSACHUSETTS COMMISSION FOR THE DEAF AND HARD OF HEARING: (1-617-740-1600 or TTY 1-617-740-1700 Child specialists 1-617-695-7500). 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.

www.mass.gov/mcdhh

RESOURCE DIRECTORY FROM THE MASSACHUSETTS COMMISSION FOR THE DEAF AND HARD OF HEARING: (1-617-740-1600 or TTY 1-617-740-1700) Comprehensive directory or resources available in PDF format.

http://mass.gov/Eeohhs2/docs/mcdhh/resource_directory.pdf

HEAT, HOUSING AND UTILITIES

DEPARTMENT OF PUBLIC UTILITIES: (1-800-392-6066)

Contact for families experience problems which cannot be solved with their utility companies.

<http://www.mass.gov/dpu>

FUEL ASSISTANCE PROGRAM: (1-800-632-8175). Federally funded Low Income Home Energy Assistance Program (LIHEAP) assists low-income individuals and families with the cost of heating their homes in winter.

<http://www.mass.gov/dhcd/components/cs/Fuel/default.htm>

MASS ACCESS: (1-617-742-0820) A registry of accessible housing in Massachusetts for people with disabilities

<http://massaccesshousingregistry.org/registry/registrymax.nsf/webpages/home?open>

MASSACHUSETTS COALITION FOR THE HOMELESS: (1-781-595-7570) Resource for homeless individuals and families.

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

SAFE AND SANITARY HOUSING: (1-800-392-6090). Under the jurisdiction of the local Board of Health. The regulations protecting the health, safety and well being of Massachusetts citizens are found in Chapter II of the State Sanitary Code entitled "Minimum Standards of Fitness for Human Habitation". Standards are outlined on the web site. For additional information contact local board of health.

<http://www.state.ma.us/sec/cis/cissfsn/sfsnidx.htm>

HIV

HIV RESOURCE GUIDE 2005 published by the Massachusetts Department of Public Health, HIV/AIDS bureau. Download from:

http://www.mass.gov/dph/aids/resource_guide.pdf

MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH HIV/AIDS BUREAU: (1-617-624-5300). The Bureau's mission is to assist in preventing the spread of the HIV epidemic and the development of appropriate, cost-effective health and support services which will maintain patients in the least restrictive setting.

<http://www.mass.gov/dph/aids/>

MASSCARE (MASSACHUSETTS COMMUNITY AIDS RESOURCE ENHANCEMENT) DEPARTMENT OF PUBLIC HEALTH (1-617-624-5070). The MassCARE Program was designed to ensure access to and enhance statewide capacity to provide coordinated, comprehensive, family-centered, culturally and linguistically competent counseling, testing, and care for individuals living with HIV

<http://www.mass.gov/dph/fch/masscare.htm>

HOME CARE

PARTNERS HOME CARE MATERNAL INFANT AND PEDIATRIC HOME CARE PROGRAM: (1-781-290-4200).

Specialized in-home family centered prenatal, post-partum, high-risk infant; general pediatric and adolescent programs for patients with a broad range of medical and social challenges. Staff experienced in complex medical problems and their specialized treatments. Partners Home Care serves a geographic area that covers Eastern Massachusetts, with regional branch offices in Beverly, Chelsea, Waltham, Braintree and Bridgewater.

<http://www.partnershomecare.org>

PARTNERS PRIVATE CARE: (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/privatecare.htm>

LEAD POISONING

CHILDHOOD LEAD POISONING PREVENTION PROGRAM (CLPPP): (1-800-532-9571).

Established for the prevention, screening, diagnosis, and treatment of lead poisoning, including the elimination of sources of poisoning through research and educational, epidemiological, and clinical activities. CLPPP provides a range of both primary and secondary prevention services to the children of Massachusetts, their families and others with an interest in the prevention of lead poisoning. CLPPP also provides coordinated and comprehensive nursing case management.

<http://www.state.ma.us/dph/clppp/clppp.htm>

MEDICATIONS

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=lookup_survey

MASS HEALTH OTC MEDICATIONS: (1-800-462-1120)

Listing of OTC medications covered by certain Mass Health Plans when patient has a prescription from a physician.

<http://www.mass.gov/Eeohhs2/docs/masshealth/pharmacy/nonlegend.pdf>

MEDICAL ASSISTANCE PROGRAM:

MASSMEDLINE: (1-866-633-1617) MassMedLine is a free, confidential service available to all Massachusetts residents who are trying to find programs to help with the cost of medications or seeking information regarding their medications.

www.massmedline.com

PARTNERSHIP FOR PRESCRIPTION ASSISTANCE

(1-888-4PPA-NOW) Offers a single point of access to more than 475 public and private patient assistance programs, including more than 180 programs offered by pharmaceutical companies.

<https://www.pparx.org/Intro.php>

MENTAL HEALTH

MASSACHUSETTS CHILD PSYCHIATRY ACCESS PROJECT:

Project to linking child psychiatry consultation to primary care. 90% Massachusetts Primary Care sites currently enrolled.

<http://mcpap.typepad.com/>

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/school-psychiatry/>

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 866-815-8122, parents/family members and adolescents can obtain support and get information on mental health services.

<http://www.ppal.net/default/>

MULTIPLES

MASSACHUSETTS MOTHERS OF TWINS ASSOCIATION (1-781-989-3222). Referrals to support groups and programs for parents with multiple births.

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

MOST (MOTHERS OF SUPERTWINS) (1-631-859-1110) A national multiples support group.

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

TRIPLET CONNECTION: (1-435-851-1105) A national triplet support group.

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

TRIPLETS, MOMS AND MORE: (1-339-927-2365). A support network for Parents and Parents to be of Triplets and More.

<http://www.geocities.com/tmandmore/>

NEWBORNS

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

SEATCHECK.ORG (1-866-SEATCHECK) Car seat inspection locator service.

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

HEALTHY BABY/HEALTHY CHILD: (1-800-711-1180)

The Healthy Baby/Healthy Child program provides free home visits conducted by public health nurses and advocates, who provide health education and case management services. These services are available to pregnant women and parenting families with children up to three years of age. Its mission is to promote the well-being of families residing in the city of Boston.

<http://www.bphc.org/programs/program.asp?b=1&d=5&p=19>

HEALTHY FAMILIES: (1-617-727-8957) Provides strengths-based, family-centered, intensive home visiting services for all first-time parents ages 20 and under across Massachusetts.
<http://www.mctf.org/sp.aspx?id=225>

JEWISH FAMILY & CHILDREN'S SERVICES: CENTER FOR EARLY RELATIONSHIP SUPPORT (1-781-647-5327) Offer a variety of free programs for parents of newborns including Visiting Moms, support groups, new mother/senior nurturing rooms, specialized home consultations and feeding support. Home visits for post partum depression are offered on a sliding scale.
<http://www.jfcsboston.org/>

PARTNERS HOME CARE MATERNAL INFANT AND PEDIATRIC HOME CARE PROGRAM: (1-781-290-4200). Specialized in-home family centered prenatal, post-partum, high-risk infant; general pediatric and adolescent programs for patients with a broad range of medical and social challenges. Staff experienced in complex medical problems and their specialized treatments. Partners Home Care serves a geographic area that covers Eastern Massachusetts, with regional branch offices in Beverly, Chelsea, Waltham, Braintree and Bridgewater.
<http://www.partnershomecare.org>.

PARTNERS PRIVATE CARE: (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/privatecare.htm>

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/>

FOOD PANTRIES:

Community based programs which provide food for needy families. Contact Town Clerks, local churches.

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.

PROJECT BREAD FOOD SOURCE HOTLINE: (1-800-645-8333) Hotline counselors refer callers to food resources in their communities as well as information about food stamps and other nutrition programs.
http://www.projectbread.org/site/PageServer?pagename=end_foodsourcehotline

RESOURCE GUIDE FOR PEDIATRIC OVERWEIGHT TREATMENT SERVICES IN MASSACHUSETTS. Call 1-800-952-6637 for single copy.
<http://www.maclearninghouse.com/>

WIC: (1-800-WIC-1007). Provides free food and nutritional information to help keep pregnant women, infants and children under five healthy and strong. Generally strong breastfeeding support. Eligibility: Pregnant, postpartum or breastfeeding woman, infant or child under 5 years of age, a nutritional need and meets income guidelines.
<http://www.fns.usda.gov/wic/>

WIC FORMULA DATABASE: The WIC Formula Database includes infant formulas, exempt infant formulas and medical foods approved for use in the WIC program.
<http://grande.nal.usda.gov/wicworks/formulas/FormulaSearch.php>

ONCOLOGY

AMERICAN CANCER SOCIETY: Information for Professionals and Patients re: cancer, treatment, alternative and complementary therapies and bookstore.
<http://www.cancer.org/docroot/home/index.asp>

ASSOCIATION OF CANCER ONLINE RESOURCES: Pediatric Oncology Resource Center. This site was created by and for people who know young people who are recovering from cancer. There are resources, web links and references.
<http://www.acor.org/ped-onc>

ASSOCIATION OF PEDIATRIC ONCOLOGY NURSES: APON is the professional organization for pediatric hematology/oncology nurses and other pediatric hematology/oncology healthcare professionals.
<http://www.apon.org/i4a/pages/index.cfm?pageid=3288>

"BACK TO SCHOOL: TEENS PREPARE FOR SCHOOL RE-ENTRY" Starlight Starbright Children's Foundation. Free video program is for teens with serious illness. Teens who have dealt with going back to school after an extended absence due to an illness share their stories and advice for first days back – how to survive and thrive.
www.starlight.org

CHILDREN'S CANCER WEB: A Guide to Internet Resources for Childhood Cancer: An independent non-profit site, providing a directory of childhood cancer resources.
<http://www.cancerindex.org/ccw>

KIDS' CANCER PAGES (Call 1-503-244-3141 for a hard copy.) National resource directory on childhood cancer. Recognized by the National Cancer Institute as "the most comprehensive guide for families currently available;" this comprehensive directory is packed with information on all aspects of pediatric cancer. Online search at:
http://www.childrenscancerassociation.org/resources_and_programs/kids_cancer_pages/browse.php

"PAIN MANAGEMENT IN CHILDREN WITH CANCER"
published by the Texas Children's Cancer Council.
<http://www.childcancerpain.org>

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. Assist 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/>

PARTNERS HOSPICE: (1-781-894-1100). 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. All Partners Hospice patients receive a collaborative plan of care that is managed by an interdisciplinary team of physicians, nurses, social workers, home health aides, and chaplains. The hospice approach addresses the symptoms of the illness, as well as the patient's and family's emotional and spiritual concerns.
<http://www.partnershospice.org>

MASSACHUSETTS COMMISSION ON END OF LIFE CARE: END OF LIFE RESOURCE GUIDE. (1-617-624-5424) 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

PARTNERSHIP FOR PARENTS: (1-831-763-3070) A web site by parents for parents of children with serious illness. Veteran parents share suggestions related to managing the many challenges these families face.
<http://www.partnershipforparents.org/>

PARTNERS TRANSITIONS FOR KIDS: (1-781-290-4200; 1-888-775-5070) The Transitions for Kids program provides family centered care for children with life threatening and life limiting illnesses. The focus of the program is on comprehensive support to children and their families including assessment of the child for progression of the disease and complications of its management; collaboration with the family and medical team in the management of symptoms; the development of a pain management plan, helping the family access public benefit programs and community resources, and assisting the family to find resources to assist them with suffering, grief and bereavement. Partners Transitions works collaboratively with Hospice Programs in assisting families with transition to Hospice. Partners Home Care serves Eastern Massachusetts, with regional

branch offices in Beverly, Waltham, Chelsea, Braintree and Bridgewater.
<http://www.partnershomecare.org/transitions.htm>

PEDIATRIC PALLIATIVE CARE NETWORK: (1-800-882-1435) The goal of the Pediatric Palliative Care Network is to improve the quality of life of the entire family through its support and services. Services are provided through 10 agencies in Massachusetts, all skilled in pediatric palliative care. The Pediatric Palliative Care Network serves the unmet physical, emotional, social and spiritual needs of children in Massachusetts with life-limiting illnesses. Our services are provided at no cost to children 18 years old or younger who have a life-limiting illness.
www.mass.gov/ppcn

PARENT SUPPORT

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

MASSACHUSETTS DOWN SYNDROME CONGRESS: (1-800-664-6372) New parent packet and other resources for new parents of children diagnosed with Down Syndrome. Provide information and resources to parents, professionals, self-advocates and all people who wish to gain a further understanding of Down syndrome.
<http://www.mdsc.org/>

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>

PARENTS WITH CHRONIC ILLNESS

RAISING AN EMOTIONALLY HEALTHY CHILD WHEN A PARENT IS SICK by Paula Rausch. Available through bookstores and Amazon.com.

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.

PATIENT EDUCATION

HOSPITAL BASED WEB SITES: Online pediatric patient education materials sponsored by the Partners Hospitals.

Brigham and Women's Hospital:
<http://www.brighamandwomens.org/newbornmedicine/default.aspx>

MassGeneral Hospital for Children:
<http://www.massgeneral.org/children/childhealthatoz/articles.aspx>

North Shore Children's Hospital:
<http://nsmc.staywellsolutionsonline.com/HealthCenters/PediatricLibrary/>

Newton Wellesley Hospital :
<http://www.nwh.org/itemList.asp?categoryID=185>

KESSLER HEALTH EDUCATION LIBRARY AT BRIGHAM AND WOMEN'S HOSPITAL (617-732-8103) Books, journals, videos and internet resources on a broad range of topics related to pregnancy, childbirth, breastfeeding and parenting. Professional librarians and trained staff to assist you with access to our print, audiovisual and Internet resources.
<http://www.brighamandwomens.org/healtheducation/>

MAXWELL AND ELEANOR BLUM PATIENT FAMILY LEARNING CENTER AT MASSACHUSETTS GENERAL (1-617-724-7352) 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.
<http://www.massgeneral.org/pflc/index.asp>

NORTH SHORE CHILDREN'S HOSPITAL FAMILY RESOURCE CENTER: (1-978-354-2660) The Family Resource Center serves children, adolescents, families and professionals.
http://nsmc.partners.org/web/support/pediatrics_resource_center

THE DORIS K. BARBER MEMORIAL LIBRARY AT SPAULDING REHABILITATION HOSPITAL: (617-573-2415) offers a library collection of books, journals and online searches, an assistive technology center and a community information network for individuals with disabilities
<http://www.spauldingrehab.org/education/medicallibraries#stoc2>

PDD/AUTISM

AUTISM WAIVER SERVICES: (1-617-727-5608) This three year model program is called the Children's Autism Spectrum Disorders Home and Community-Based Services Waiver Program. Waiver services are supplemental to special education services provided under IDEA (Individuals with Disabilities Education Act). Program will service 80 children under the age of 9. The child must meet the level of care required for services in an Intermediate Care Facility for the Mentally Retarded (ICF/MR) as assessed by DMR.
www.mass.gov/dmr

BUILDING BLOCKS PROGRAM: (1-978-762-8352). Developmental Program through Early Intervention for children with Pervasive Developmental Delay or Autism. Children are referred through their local EI Programs.
<http://www.n sarc.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.
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.
http://www.massgeneral.org/mghfc/MGHfC_medspec_ladders.htm

PHYSICIAN FINDERS

MASSGENERAL HOSPITAL FOR CHILDREN: Physician finder for all MassGeneral Hospital for Children sites:
<http://massgeneral.photobooks.com/>

MASSGENERAL HOSPITAL FOR CHILDREN: Search for specialty physicians and programs.
<http://www.massgeneral.org/children/default.aspx>

NEWTON WELLESLEY HOSPITAL: Search for specialty physicians and programs:
<http://www.nwh.org/categoryList.asp?categoryID=222>

NSMC NORTH SHORE CHILDREN'S HOSPITAL: Search for specialty physicians and programs.
<http://nsmc.partners.org/web/program/pediatrics>

PARTNERS PHYSICIAN DATABASE SEARCH:
http://www.partners.org/find/find_searchdb.html

SPAULDING REHABILITATION HOSPITAL: Search for specialty physicians and programs.

<http://spauldingrehab.org/>

MASSGENERAL HOSPITAL FOR CHILDREN (MGHfC) ACCESS AND NEW APPOINTMENT CENTER: (Patients: 1-888-MGHfC4U (644-3248); Referring physicians should call 1-888-MGHfC11 (644-3211). Specially trained representatives are available to schedule appointments and facilitate new patient registration, and when appropriate, they link patients to MGH satellite locations so appointments can take place in the most convenient site possible. The center also offers many benefits to referring physicians, including direct access to MGHfC specialists for help with questions or concerns about navigating the hospital's services
http://www.massgeneral.org/children/professionals/referring/access_center.aspx

POST PARTUM DEPRESSION

DEPRESSION AFTER DELIVERY: (1-800-944-4PPD). Information for new parents and referrals to local providers and support groups.

<http://www.depressionafterdelivery.com/>

JEWISH FAMILY & CHILDREN'S SERVICES: CENTER FOR EARLY RELATIONSHIP SUPPORT (1-617-558-1278) Offer a variety of free programs for parents of newborns including Visiting Moms, support groups, new mother/senior nurturing rooms, specialized home consultations and feeding support. Home visits for post partum depression are offered on a sliding scale.

http://www.jfcsboston.org/fcs/early_relationship.cfm

POSTPARTUM SUPPORT INTERNATIONAL (PSI). (1-800-944-4PPD) Web based information, self assessment and links to local support groups.

<http://www.postpartum.net/>

PRENATAL

HEALTHY START: (Massachusetts) (1-888-488-9161; 1-800-841-2900). 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.hspmoms.com/>

HEALTHY BABY/HEALTHY CHILD: (800-711-1180) The Healthy Baby/Healthy Child program provides free home visits conducted by public health nurses and advocates, who provide health education and case management services. These services are available to pregnant women and parenting families with children up to three years of age. Its mission is to promote the well-being of families residing in the city of Boston.

<http://www.bphc.org/programs/program.asp?b=1&d=5&p=19>

MASS HEALTH PRENATAL (1-800-841-2900). Offers health care benefits right away to a pregnant woman for up to 60 days. During the 60 days, the Division will decide if the pregnant woman can get another MassHealth coverage type.

<http://www.state.ma.us/dma/>

PREGNANCY/ENVIRONMENTAL HOTLINE (1-800-322-5014) The Pregnancy / Environmental Hotline provides confidential and non-judgmental counseling for pregnant women exposed to a potential teratogen based on currently available medical information.

<http://www.genetics.missouri.edu/Motis/links.htm/>

WHAT TO EXPECT.COM. Prenatal educational website for expectant parents.

<http://www.whattoexpect.com/preconception/landing-page.aspx>

PUBLIC BENEFIT PROGRAMS

THE CHILDREN'S MEDICAL SECURITY PLAN (MASSACHUSETTS) (1-888-665-9993). 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. Premiums depend upon family size and income.

<http://www.state.ma.us/dph/bfch/mcfh>

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 (1-800-624-5913) 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>

HEALTHY START: (Massachusetts) (1-888-488-9161; 1-800-841-2900). 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.hspmoms.com/>

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.

MASS HEALTH: 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/>

DPH COMMUNITY SUPPORT LINE: (1-800-882-1435) A toll free line that offers assessment, technical assistance, information about public benefits, other state programs, and community resources. Staffed by social workers with extensive experience in assisting families of children and youth with special health needs.

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 which is expected to last at least 12 months AND meets income eligibility guidelines. <http://www.socialsecurity.gov/pubs/10026.html#Introduction>

RESOURCE LOCATORS

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

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

DPH COMMUNITY SUPPORT LINE: (1-800-882-1435) A toll free line that offers assessment, technical assistance, information about public benefits, other state programs, and community resources. Staffed by social workers with extensive experience in assisting families of children and youth with special health needs.

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>

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/resources/search.php>

INTERNET GUIDELINES: Sponsored by the Maxwell and Eleanor Blum Patient and Family Learning Center at Massachusetts General Hospital. (617-724-7352) Helpful guidelines on how to use the internet and how to evaluate an internet web site. http://www.massgeneral.org/pflc/howto_evaluate.asp

MASSCARES RESOURCE LOCATOR (Sponsored by the Executive Office of Health and Human Services) This tool will help you find local and statewide organizations that can provide services such as housing, food, financial assistance, benefits and child care. <http://www.masscares.org/RLocator/>

RESPITE

EARLY INTERVENTION REGIONAL CONSULTATION PROGRAM: (1-978-632-4432). Team available to a child's early intervention team which can provide consultation regarding respite services. Child must be enrolled in an eligible 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 (1-617-727-5608).

SAFETY

CHILDHOOD INJURY PREVENTION PROGRAM: (1-617-534-5394). CIPP of the Boston Public Health Commission combines education, technology and legislation to reduce the risk of injury to children. Training, safety supplies and educational literature are offered to the community to facilitate behavioral and environmental changes. <http://www.bphc.org/programs/program.asp?b=2&p=212>

POISON CONTROL CENTER: (1-800-222-1222) New national number allows caller to place call from anywhere in USA, call directed to local regional Poison Control Center. <http://www.maripoisoncenter.com/>

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>

504 PLAN: Massachusetts Department of Education Website references regarding school 504 plans for children with disabilities who are not eligible for an IEP. Also pertains to children with certain health problems.

<http://www.doe.mass.edu/sped/parents.html?section=s504-ada>

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. IEP Process can be downloaded at <http://www.doe.mass.edu/sped/iep/>

MASSACHUSETTS DEPARTMENT OF EDUCATION: (1-781-338-300) 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) (1- 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. Templates can sometimes be found by searching condition specific web sites.

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/guid-fam.pdf>

SMOKING

CEASE: (1-800-TRY TOSTOP) The CEASE Module was developed to help child healthcare clinicians tailor their office setting to address parental tobacco use in a routine and effective manner. Implementation strategies employed by the CEASE Module demonstrate how to link parents who want to quit smoking with state or national smoking cessation services through the use of a flexible set of materials. The CEASE Module guides child healthcare clinicians in each evidence-based step of addressing parental tobacco use. <http://www.ceasetobacco.org/>

PARTNERS HEALTHCARE SYSTEM TOBACCO TREATMENT RESOURCE CENTER (WEBSITE). Comprehensive list of resources for clinicians and patients on why to quit, how to quit and what can help to quit. Individuals seeking support programs can explore the options of both In-Person and Telephone Based support programs. <http://www.partners.org/stopsmoking>

TRY-TO-STOP TOBACCO RESOURCE CENTER: (1-800-TRY-TO-STOP) QuitWorks is a collaboration of the Massachusetts Department of Public Health and Massachusetts health plans. The program offers telephone-based tobacco treatment to patients who are referred by their health care providers, linking them to the full range of the state's tobacco treatment services. <http://www.quitworks.org/welcome/trytostop.php>

STATE AGENCIES

MASSACHUSETTS COMMISSION FOR THE BLIND: (1-617 727-5550.) 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: (1-617-727-5608). 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.mass.gov/dmr/>

MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH: DIVISION FOR SPECIAL HEALTH NEEDS ((617-624-5070). 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 (1-800-882-1435). 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 REHABILITATION COMMISSION: (800-245-6543). The Massachusetts Rehabilitation Commission (MRC) assists individuals with disabilities to live independently and 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. www.mass.gov/mrc

SUBSTANCE ABUSE

ALANON; ALA-TEEN: (1-888-4ALANON). Support for family members affected by alcoholism and other substance abuse. Separate groups for adolescent family members.
<http://www.al-anon-alateen.org/>

MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH BUREAU OF SUBSTANCE ABUSE SERVICES: (1-800-327-5050) The Bureau of Substance Abuse Services oversees the substance abuse and gambling prevention and treatment services in the Commonwealth. Responsibilities include: licensing programs and counselors; funding and monitoring prevention and treatment services; providing access to treatment for the indigent and uninsured; developing and implementing policies and programs; and tracking substance abuse trends in the state.
<http://www.state.ma.us/dph/bsas/bsas.htm>

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICE AND SAMSHA'S NATIONAL CLEARINGHOURS FOR DRUG AND ALCOHOL INFORMATION: (1-800-729-6686) Excellent free resources for teens, professionals and parents on smoking, drinking and drug use.
<http://ncadi.samhsa.gov/>

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 TRAVELLERS WITH DISABILITIES: (1-800-778-4838 TTY 1-800-455-9880)
http://www.faa.gov/passengers/passengers_disabilities/

HANDICAPPED PERSONS PLATES AND PLACARDS: (1-617-351-9222) 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; 1-800-682-1062; 1-800-497-4648 (TTY) Non-Emergency Transportation Service such as door to door non-emergency transportation to and from medical provider when patient is not able to access public transportation and/or private means of transportation. Requires physician to complete PT-1 (Prescription for Transportation form – available from physician or MassHealth). Can be completed by one physician for another physician's visits. Will need names

of physicians and number of time patient has/expected to have an appointment, patients Mass Health Number and Social Security Number. The fax number to submit a PT-1 is (617) 988-2925 or (617) 988-2927. There is an approximate, four-day turnaround from the time the form is submitted. PT-1s are required for each doctor's office a member attends, and anytime there is a change in the prescription (such as the number of visits). Once approved, patient will be given the name of the transportation company to call for their transportation. Will need to arrange several days in advance.
<http://www.mass.gov>

THE RIDE (1-617-222-5123 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.mbt.com/riding_the_t/accessible_services/?id=7108

WISH PROGRAMS

MAKE A WISH FOUNDATION: (1-617-367-9474) A wish program for children living in Massachusetts between the ages of 2 and 18 with a life-threatening or terminal disease.
<http://mass.wish.org/home.html>

GLOBE SANTA: (1-617-929-2007) Refer to Boston Globe in late fall for specifics. Generally requires a letter from a social worker.
<http://www.globesanta.org/t>

TOYS FOR TOTS: (1-617-737-0500) The mission of the U.S. Marine Corps Reserve Toys for Tots Program is to collect new, unwrapped toys during Oct., Nov. and Dec. each year and distribute those toys as Christmas gifts to needy children in the community in which the campaign is conducted.
<http://www.toysfortotsma.org/>

OTHER

CASTASTROPHIC 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.
<http://www.state.ma.us/cicrf/>

COMFORT CARE DO NOT RESUSCITATE (DNR) VERIFICATION PROGRAM: (1-617- 753-7300). Program to identify patients who have DNR orders. Enables EMTs 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).

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FLEXIBLE SPENDING ACCOUNTS:

Programs which pay for expenses related to the child's special health care needs, not covered by insurance. Consult Social Service, Case managers. Massachusetts Department of Public Health Program described on website.

MASSPRO FLU CLINICS: Visit this web site to get information about 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.com/home/Homegradient.aspx>

PARTNERS LIFELINE PROGRAM: (1-800-910-4225). Offers a variety of options for calling a 24 hour response center or a third party in an emergency. Options include a Personal Help Button (PHB), worn on the wrist or around the neck or a telephone link for people with limited physical abilities; a selection of electronic switches specially designed for small movements such as a puff, a sip on a tube, a roll of the head, or the blink of an eye.

<http://www.partnershomecare.org/lifeline.htm>

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.)



SERVING EASTERN MASSACHUSETTS

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