

Massachusetts

Bureau of Family and Community Health

Contact Person: Cheryl Bushnell
Director

Telephone: (617) 624-5959
Fax: (617) 624-5990

Address: Bureau of Family and Community Health
Massachusetts Department of Public Health
250 Washington Street, 5th Floor
Boston, MA 02108-4619

Email Address: cheryl.bushnell@state.ma.us

Web Site: <http://www.state.ma.us/dph/shcn/shcn.htm>

Toll-free Hot Line: For Child SSI/Public Benefits
Information for Early Intervention
and other disability
resource information

Telephone: 1-800-882-1435

MISSION STATEMENT

The Division for Special Health Needs plans, implements and evaluates public health programs for individuals with disabilities or special needs throughout the lifespan. The division seeks to promote optimal health and prevent secondary conditions among children, youth and adults with disabilities. To achieve this, the division ensures that individuals with special needs have access to a comprehensive array of health and related services, including population-based primary and preventive services and services that are specifically targeted to meet disability-related needs. The division works to include individuals with disabilities and their families in planning and policy making, so that programs meet family-identified needs.

I. DIRECT HEALTH CARE SERVICES

Direct health care services are defined as services generally delivered between a health professional and a patient in an office, clinic or emergency room. For example, well child care visit; visit to doctor for an acute health care condition (e.g. earache); follow-up visit to a specialist for a chronic condition (e.g. asthma, diabetes, sickle cell disease), physical therapy, occupational therapy, respiratory therapy, inpatient and outpatient medical services, allied health services, lab, etc.

DSHN does not provide direct health services. It is the payor of last resort for early intervention services provided under Part C of IDEA, and pays for occasional, non-reimbursable health services through the newly created Catastrophic Illness in Children Relief Fund, described below.

II. ENABLING SERVICES

Enabling services are defined as services that allow or provide for access to and the derivation of benefits from the array of basic health care services and includes such things as transportation, translation services, outreach, respite care, health education, family support services, purchase of health insurance, case management, coordination of Medicaid, WIC and education.

ENABLING SERVICES (PROVIDED OR PAID FOR):

Enabling services provided include: care coordination, technical assistance (concerning benefit programs, entitlements and the like), information and referral, family-to-family support, flexible support funds (to meet non-reimbursable expenses), respite family-run outreach and education programs, support groups (in some targeted areas). The division maintains a hotline, which provides access to information and referral and serves as the EI Welcome Directory.

Coordination of Financial Benefits:

Several programs provide payment of last resort as described above. Families are assisted in efforts to obtain and coordinate private insurance and publicly financed services.

Coordination of Services:

Coordination of services is a central objective of the program and a major focus of its activity. Care coordination is provided to children deemed medically eligible for SSI and other children with significant medical needs. It is a requirement for children receiving home-based services under a Medicaid waiver. Family and Community Support also strive to coordinate care with Early Intervention, which is administered by the Division for Special Health Needs.

Excluded Enabling Services:

We do not pay for reimbursable care or any ongoing or costly clinical care.

ELIGIBILITY CRITERIA FOR ENABLING SERVICES

Age:

- (1) No age limits for technical assistance, information and referral, or family-to-family support.
- (2) Limited and extended care coordination to age 18.
- (3) Funded in-home family supports for temporary services and respite available up to age 18 or 22 with approval of director.

- (4) Children referred by multiple sources including: SSI outreach, hospital, pediatrician, EI, and self-referral.
- (5) Special Medical Fund: the Division acts as payor of last resort for: hearing evaluations up to age 3, hearing aids up to age 21, other non-reimbursable, short-term expenses related to care for a child with special health care needs, penicillin for children with sickle cell disease through age 6, rheumatic fever and seizure control medications for individuals of all ages, and medically necessary foods for children with PKU and other metabolic conditions.
- (6) Medical Review Team, multidisciplinary and multiagency team convened by division to certify children as appropriate for pediatric nursing home placement up to age 22.
- (7) Children 0-3 are eligible for Early Intervention.
- (8) Parents (and emancipated minors) may apply for assistance from the Catastrophic Illness in Children Relief Fund for expenses up to the child's 18th birthday.

Residency:

Physical residency in Massachusetts with intention to remain is required for all services except technical assistance and information and referral.

Medical:

For services listed under (1) above, no limits based on medical eligibility. DPH care coordinators also serve children with all types of special health care needs at practices selected to be sites for enhanced DPH care coordination. There are no excluded conditions for care coordination in this setting, as long as a child meets the MCHB definition of "special needs". Otherwise, children are eligible for intensive DPH care coordination when they have complex or serious medical conditions and a need for services.

Eligible Conditions:

Specific services listed under (5) are available to individuals with the specific medical conditions indicated. Care coordination is provided to families with children who have complicated medical conditions and an identified need for services.

Excluded Conditions:

No conditions are specifically excluded from services listed above, except that children whose diagnoses make them categorically eligible for services from another state agency (e.g. mental retardation) are not eligible for intensive DPH care coordination listed under (2), above.

Financial:

General Financial Eligibility:

There are no financial eligibility limits on services except those for which the Department is payor of last resort. Payor of last resort programs are available to those without insurance coverage for a particular covered service.

The “Catastrophic Illness in Children Relief Fund” is specifically intended to serve families when the out-of-pocket costs of their child’s care exceed 10% of family income (15% of income over \$100,000/year). Once that threshold is crossed no family is excluded from receiving assistance. The Commission, which oversees the fund, is, however, required to assure that the fund is payor of last resort.

Financial Eligibility for Initial Screening:

Not applicable. We do not provide clinical services. Developmental screening is, however, available for all children 0-3 years of age through Early Intervention, for which we are lead agency.

Family Co-Payment or Financial Participation Requirements:

No family co-payments are currently required. The Catastrophic Illness Relief Fund Commission is currently developing a sliding scale based on family expenses above the 10-15% cut-off points will be apportioned between the fund and the family. This is intended to stretch the fund to ensure its availability to low income families. Early Interventions is evaluating the merits of a sliding scale based on which privately insured families would be asked to share cost of services, which exceed the legislatively mandated cap on insurance coverage for EI. Financial need is taken into account in prioritizing families for DPH care coordination and respite services provided as part of the EI system.

HOW/WHERE ENABLING SERVICES ARE PROVIDED:

Services are provided by phone, at DPH regional offices, at selected pediatric primary care practices, or in the home. A special service for technology-assisted children (described below) provides assistance in school settings.

Specialty Clinics/Programs:

No specialty clinics are run by the program; support is provided for pediatric HIV and failure to thrive programs described below.

SPECIALIZED OR UNIQUE ENABLING SERVICES, SPECIAL GRANTS, WORKSHOPS, ETC.:

Specialized services include:

- State-funded multidisciplinary clinic services for children experiencing growth failure;
- A parent-to-parent support program staffed by parent consultants;
- A hospital initiative effort with (6) tertiary pediatric centers located throughout the state to enhance discharge planning and to increase the knowledge and skills of hospital staff concerning community-based services;
- While it is primarily a screening program (see “Population-Based Services” below) the Universal Newborn Hearing Screening Program is also responsible for enabling services to children identified with hearing loss and their families. A full-time coordinator and a parent consultant track and ensure access and entry to care of all newborns identified with

hearing loss in the state; they follow children and families from screening, through notification and diagnoses and into Early Intervention;

- A program funded under Title IV of the Ryan White CARE Act, which provides intensive care coordination and supports to families with children affected or infected with HIV and to HIV infected adolescents; and
- A new initiative which entails outstationing of DPH care coordinators in selected pediatric practices in an effort to enhance and promote access to medical homes for children with special health care needs in Massachusetts.

Advisory Councils/Boards:

The division is part of the bureau of Family and Community Health, which has a broad-based advisory council. The division does not currently have an overarching advisory council; specific division programs do, however, have active advisory groups. Those which relate to the enabling programs of the division are: the Early Intervention Interagency Coordinating Council, the MassCARE Coordinating Committee and Family Advisory Network (FAN), both of which advise the division on implementation of our Ryan White Title IV program, the Mass Partnership for Transition, which is a multiagency clearinghouse related to adolescent transition, and the Massachusetts Consortium for Children with Special Health Care Needs, which serves, among other things, as the advisory group for the division's current initiative related to care coordination the medical home.

Consumer Involvement:

All of the advisory groups listed above include consumers. In addition, parent consultants fill a direct enabling role through the Family TIES program, which provides information and referral and family-to-family support in DPH regional offices. Parent consultants employed on a regional basis by the EI program also assist other families by providing technical assistance around opportunities for parent involvement in EI programs and around resources available to enrolled families, developing family support groups and publication of a system-wide parent-to-parent newsletter. Parent consultants also enhance enabling services funded through purchase of service by serving on review teams and other bodies that influence service delivery at the policy level.

Priorities/Procedures for Development:

The 2010 objectives for children with special health care needs provided a framework for activities of the division. Enabling services are intended to expanding system capacity to: provide medical homes for children with special health care needs, ensure adequate financing for all the health needs of children and their families, promote family-friendly services, and systems, ensure access to screening, and facilitative effective transition. Involvement of families at every level is a key strategy for achievement of these objectives.

AIDS/HIV Coverage:

All services described in (1) and (2) above are available to children and families with HIV. In addition, the Division for Special Health Needs administers the MassCARE Pediatric/Family HIV Grant, which provides community-based care in five high-risk

communities across the state linked with sophisticated AIDS specialty care. This grant also supports parent involvement in AIDS policy activities related to care of children and families.

III. POPULATION-BASED SERVICES

Population-based services are defined as prevention services and personal health services that are developed and available for the entire MCH/CSHCN population of the state rather than for individuals on a one-on-one situation. Disease prevention, health promotion, and statewide outreach are major components. Common among these services are newborn screening, lead screening, immunizations, SIDS counseling, oral health, injury prevention, nutrition, and outreach/public education.

POPULATION-BASED SERVICES (PROVIDED OR PAID FOR):

The division is responsible for two screening systems that are available to all children in the state. First it manages the Universal Newborn Hearing Screening Program, which has achieved almost 100% screening of newborns in the state. Second, it casts a broad net carrying out its Part C “child find” responsibilities: at present EI serves more than 22,000 children annually, but an additional 5,000+ children are referred and receive developmental assessment through the EI system. Although this is not population-based in the broadest sense, it does ensure that all children have access to referral and assessment.

HOW/WHERE POPULATION-BASED SERVICES ARE PROVIDED:

Same as “Enabling Services” above.

SPECIALIZED OR UNIQUE POPULATION-BASED SERVICES, SPECIAL GRANTS, WORKSHOPS, ETC.:

None specifically listed. Contact the Program directly for more information.

IV. INFRASTRUCTURE BUILDING SERVICES

Infrastructure building services are defined as services that address the development and maintenance of comprehensive health services systems. Infrastructure building services include: needs assessment, evaluation, planning, policy development, coordination, quality assurance, standards development, monitoring, training, applied research, development of information systems and systems of care (which are family-centered, community-based, etc.), development and maintenance of health services standards/guidelines, training, data and planning systems, etc.

INFRASTRUCTURE BUILDING SERVICES:

Division activities that contribute to system infrastructure are:

- Administration of state’s Early Intervention system, including ongoing training of EI providers and parents and oversight of program certification and quality assurance;

- The Family TIES program, which makes training opportunities available to parents on a continuous basis;
- Ongoing and proactive training of providers and parents on access to public benefit programs. The division employs a full-time specialist whose job is to plan and conduct training of this nature, provide technical assistance to interested parties on benefit programs, and manage a hotline through which information is available to benefit programs;
- Active participation in a statewide Consortium for Children with Special Health Care Needs, which seeks to identify gaps in service and promote collaborative strategies to resolve those gaps;
- Participation (along with our Bureau’s Office of Statistics and Evaluation) in the development of an Integrated Special Needs Data System, which will offer access on a selective basis to aggregate and/or individualize information to public health staff, providers and consumers;
- A collaborative project with Medicaid, other state agencies, payers, and providers to develop and implement strategies to enhance managed care for CSHCN;
- Ongoing training of medical and social service providers and parent groups concerning SSI and other public benefit programs; and
- A consultation program for school nurses to assist school systems to address the needs of children dependent on technology.

HOW/WHERE INFRASTRUCTURE BUILDING SERVICES ARE PROVIDED:

Same as “Enabling Services” above.

SPECIALIZED OR UNIQUE INFRASTRUCTURE BUILDING SERVICES, SPECIAL GRANTS, WORKSHOPS, ETC.:

Legislatively Mandated:

The Bureau of Family and Community Health Advisory Council was established in 1982 per order of the Commissioner of Public Health and operates at the discretion of the Commissioner. It was not established by statute.

OUT-OF-STATE SERVICES FUNDED BY THE PROGRAM:

No out-of state services.

STATUTORY/REGULATORY AUTHORITY OF THE PROGRAM:

OBRA 89 Amendments to Title V;
 Ch 347, Acts of 1936, General Laws of MA (authorizes DPH for Title V provisions);
 Laws governing Spec Med programs:
 Hearing Evaluation Acts of 1971, Ch 1095;
 Rheumatic Fever Act of 1960, Ch. 111 14A;
 Epilepsy Program Acts of 1967, 111 4G;
 Nutrition Services Acct. 4530-5000;

Medical Review Team is established by statute.
Ch 159, Section 207, Act of 2000, General Laws of MA (establishes Catastrophic Illness
in Children Relief Fund).