



**Boston
Children's
Hospital**

Until every child is well™

Down Syndrome
Program

Resource Guide Families of Children with Down Syndrome



About This Guide

Resources are important for everyone, but they are especially important for families of children with Down syndrome. At the Down Syndrome Program, we understand that navigating this system can be tough. We made this guide to help families learn about services and programs that can support their child's health and well-being from birth to transition to adulthood. We encourage you to read this guide and talk to your providers!

Table of Contents

Down Syndrome Organizations

Research

Healthcare and Social Services

Nutrition

Family Support

Education

Social and Recreational Activities

Transition to Adulthood

Timeline of Healthcare Guidelines and Resources

Down Syndrome Organizations

National Down Syndrome Congress (NDSC)

781-221-0024 | www.ndsccenter.org

Provides information, advocacy and support about all aspects of life for people with Down syndrome and an optional phone call from a First Call parent.

National Down Syndrome Society (NDSS)

1-800-221-4602 | www.ndss.org

Dedicated to being the national advocate for the value, acceptance, and inclusion of people with Down Syndrome.

Northern New England Down Syndrome Congress (NNEDSC)

603-479-1589 | www.nnedsc.net

A chapter of the National Down Syndrome Congress and an affiliate of the National Down Syndrome Society. This is a great resource for information and support for families throughout northern New England! As a member, you can apply for a support grant to help the costs of activities and medical expenses.

Massachusetts Down Syndrome Congress (MDSC)

1-800-664-MDSC (6372) | www.mdsc.org

The premier resource hub for Down Syndrome information, advocacy, and networking in Massachusetts. Get connected to local support groups, attend annual conferences, and explore the various opportunities for families to gather! Check out the [Parents' First Call Program](#), which is a volunteer network of parents who are available as a resource for new families. Each new family gets a free one-year membership, a new parent package, and a phone call from a First Call parent.

Research

LuMind Foundation

508-630-2177 | www.lumindfoundation.org

Dedicated to stimulating research and developing new treatments to improve cognition for people with Down Syndrome.

Down Syndrome Research Foundation

604-444-3773 | www.dsrf.org

Dedicated to bridging research and practice for Down syndrome education. Researchers work with families and professionals to study how people with Down syndrome learn and to create education programs.

Global Down Syndrome Foundation

303-321-6277 | www.globalsyndrome.org

Dedicated to improving the lives of people with Down syndrome through research, medical care, education and advocacy.

Clinical Trials on Down Syndrome

www.clinicaltrials.gov

Provides patients, families, doctors, researchers, and the general public with information about clinical studies on Down syndrome.

DS-Connect: The Down Syndrome Registry

www.dsconnect.nih.gov

Helps to link people with Down syndrome to doctors and scientists working on research to improve their health and quality of life.

Healthcare and Social Services

Medicaid: MassHealth/CommonHealth

1-888-665-9993 | www.mass.gov/MassHealth

MassHealth pays for healthcare for certain low- and medium-income people. Some families qualify for MassHealth Standard, while other families whose income or resources are above the limits of MassHealth Standard may be eligible for CommonHealth. CommonHealth charges a premium for MassHealth through a sliding fee based on income and family size. At age 18, all individuals with Down syndrome who are eligible for SSI are automatically enrolled in MassHealth.

MassHealth Standard/CommonHealth Premium Assistance (MSCPA)

1-800-862-4840

Once enrolled in MassHealth, a family can get help from MSCPA. MSCPA reimburses the working parent for his/her share of the premium for employer-based private health insurance. The reimbursement helps to maintain health coverage for family members who are not covered by MassHealth. The private insurance coverage also remains the primary insurer for the child with disabilities.

Supplemental Security Income (SSI)

1-800-772-1213 | www.ssa.gov/applyfordisability

Provides monthly cash benefits and automatic MassHealth health insurance coverage for a child with special medical needs. Families with low to middle income and limited resources may be eligible for SSI. Eligibility for children under 18 is based on their parents income/assets. At age 18, all individuals with Down syndrome are eligible for SSI based on their own personal income/assets.

Early Intervention

1-800-905-TIES (8437) | www.massfamilyties.org

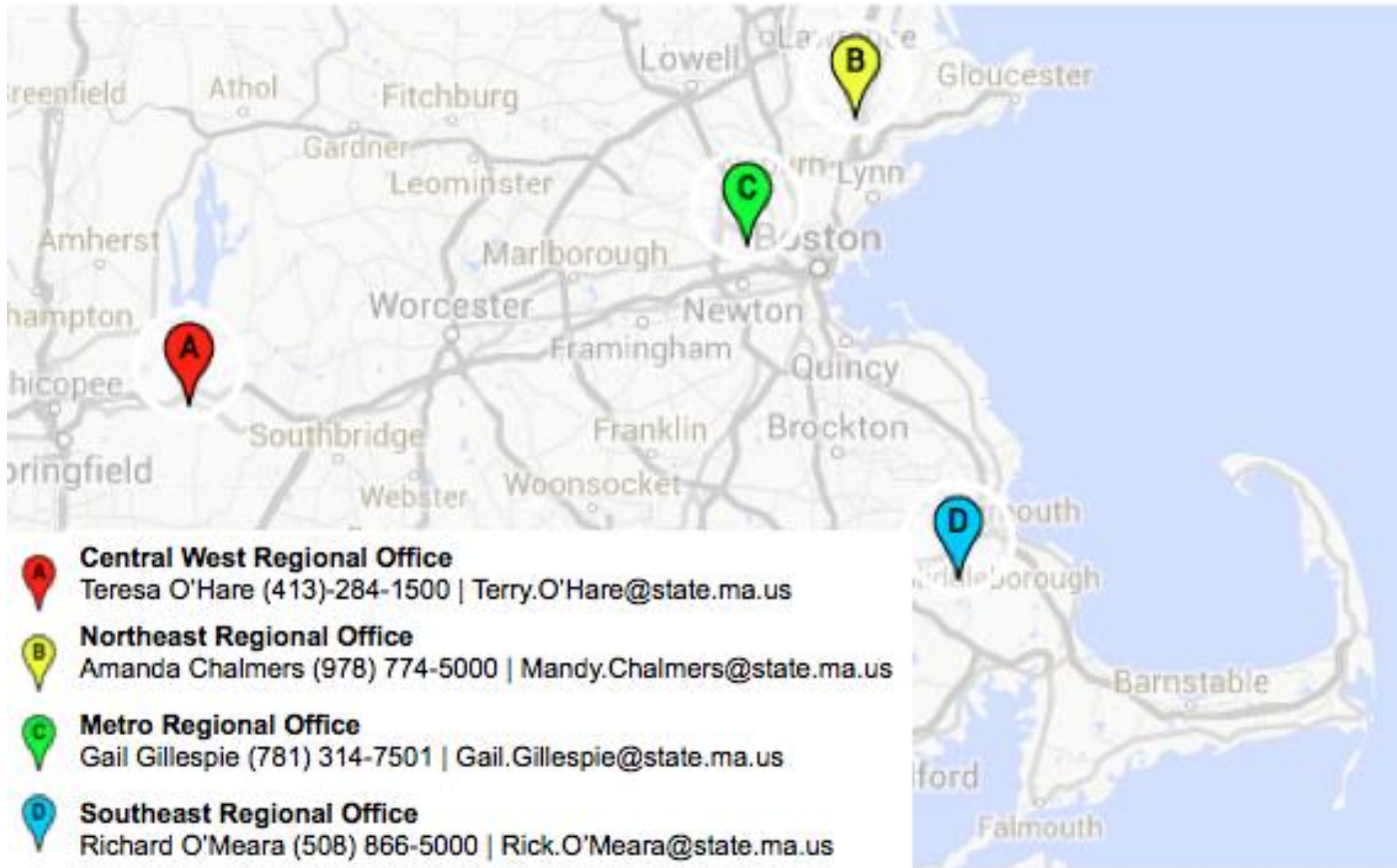
EI is part of Family Ties and the Massachusetts Department of Public Health. It is a MUST program that offers family-centered services to help children with developmental delays and disabilities, from birth to three years old. These services can include physical therapy, occupational therapy, speech therapy, social and educational services, family counseling, assistive technology, and transition services.

Health Care Guidelines for Children with Syndrome

The American Academy of Pediatrics (AAP) has developed a special guide to help parents and families of children with Down syndrome. This document focuses on medical topics that affect physical health. Other issues can affect social and school success. While these issues may not require doctors or other medical resources, they are still important issues for children with Down syndrome.

<https://www.healthychildren.org/English/health-issues/conditions/developmental-disabilities/Pages/Children-with-Down-Syndrome-Health-Care-Information-for-Families.aspx>

Department of Developmental Services Regional Contacts



The map displays the state of Massachusetts with four regional office locations marked by colored pins: A (red), B (yellow), C (green), and D (blue). Location A is in the west, B is in the northeast, C is in the metro area, and D is in the southeast. Major cities like Lowell, Boston, Worcester, and Springfield are labeled.

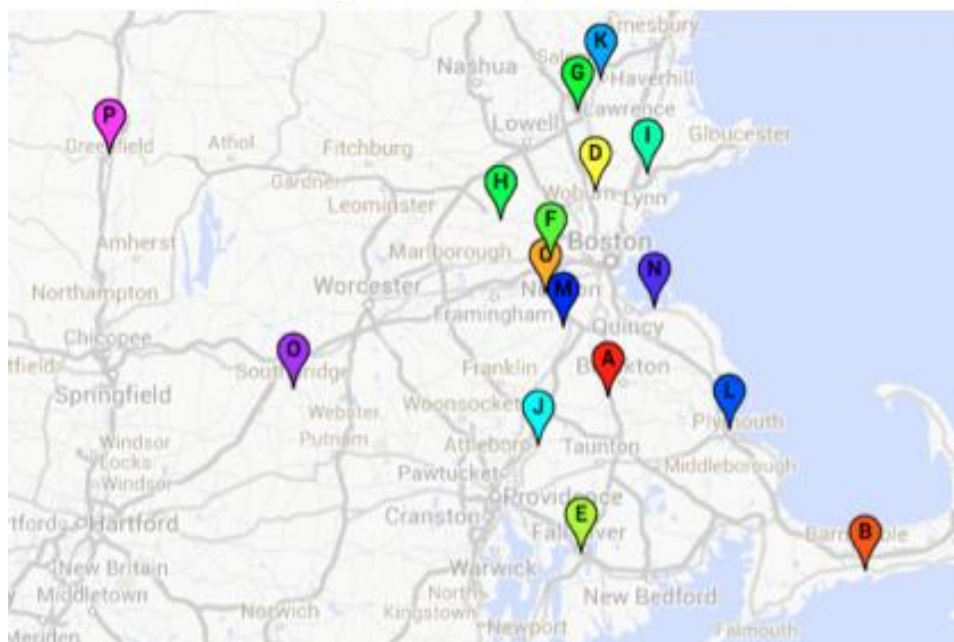
- A** **Central West Regional Office**
Teresa O'Hare (413)-284-1500 | Terry.O'Hare@state.ma.us
- B** **Northeast Regional Office**
Amanda Chalmers (978) 774-5000 | Mandy.Chalmers@state.ma.us
- C** **Metro Regional Office**
Gail Gillespie (781) 314-7501 | Gail.Gillespie@state.ma.us
- D** **Southeast Regional Office**
Richard O'Meara (508) 866-5000 | Rick.O'Meara@state.ma.us

Massachusetts Department of Developmental Services (DDS)

617-727-5608 | www.mass.gov/dds

Offers service coordination and family support services. Care coordinators can work with families to identify needs and help them access specific programs and services. These include family education, support groups, respite, social and recreational programs, and the Family Leadership Series (annual workshop).

Arc Regional Chapter Contacts



- A:** Brockton Area Arc / 508-583-8030 / www.brocktonareaarc.org
- B:** The Arc of Cape Cod / 508-790-3667 / www.arcofcapecpd.org
- C:** Charles River Center / 781-942-4888 / www.crarc.org
- D:** The Arc of East Middlesex / 781-942-4888 / www.theemarc.org
- E:** The Arc of Greater Fall River / 508-679-0001
- F:** Greater Waltham Arc / 781-899-1344 / www.gwarc.org
- G:** The Arc of Greater Lawrence / 978-975-8587 / www.classinc.org
- H:** Minute Man Arc for Human Services / 978-287-7900 / www.minutemanarc.org
- I:** North Shore Arc / 978-762-4848 / www.nsarc.org
- J:** The Arc of Northern Bristol County / 508-226-1445 / www.arcbc.org
- K:** The Arc of Greater Haverhill-Newburyport / 978-373-0552
- L:** The Arc of Greater Plymouth / 508-732-9292 / www.thearcogp.com
- M:** South Norfolk County Arc / 781-762-4001 / www.snarc.org
- N:** The Arc of South Shore / 617-335-3023 / www.arcsouthshore.org
- O:** The Arc of Southern Worcester County/Center for Hope / 508-764-4085
- P:** United Arc of Franklin and Hampshire Counties / 413-774-5558

ARC of Massachusetts

781-891-6270 | www.arcmass.org

At the state level, Arc provides education and advocacy. At the local level, Arc offers a variety of support services for families and individuals. This includes early intervention (from birth to age 3), family and in-home support services, recreational activities, and help with employment, housing, and transportation.

Nutrition

Women, Infants, and Children Nutrition Program (WIC)

www.mass.gov/wic

Provides free healthy food, nutrition counseling and support, and breastfeeding support to families that qualify. You may be eligible if you are pregnant or a new mom with children under five and meet income and residence criteria.

Supplemental Nutrition Assistance Program/Food Stamps (SNAP)

www.mass.gov/snap

Helps low-income families to buy healthy food in almost every supermarket.

Family Support

Massachusetts Family Ties

1-800-905-TIES (8437) | www.massfamilyties.org

Family Ties offers a statewide network of information and support for families of children with special needs. Check out their parent-to-parent program and [Resource Directory](#) to get connected to the family support services and programs near you!

Massachusetts Family Voices

www.fcsn.org/mfv

Family Voices at the Federation of Children with Special Needs serves as a network for families, friends, and professionals to share information and resources for education, advocacy, and healthcare for children with special needs.

Federation for Children with Special Needs (FCSN)

1-800-331-0688 | www.fcsn.org

A Massachusetts-based organization that provides information, advocacy, and support for parents of children with disabilities. Check out their free workshops on education, advocacy, and transition to adulthood!

Education

Down Syndrome Education

www.dseinternational.org/en-us/ | www.downsed-usa.org | www.seeandlearn.org/en-us/

Supports research and offers evidence-based learning materials to help parents and professionals meet the unique learning needs of children with Down Syndrome. Explore their online classes and selection of books, films, and apps for parents and teachers! Check out the [See and Learn Program](#), which offers fun tools to promote development of language, memory, and number skills!

National Down Syndrome Society Education Resources

www.ndss.org/Resources/Education/

Provides information about education and Down Syndrome, such as education laws, the Individualized Education Plan, the Inclusion Model, and school transition.

Down Syndrome Foundation of Orange County Learning Program

www.dsloc.org/learning-program

Offers an online version of their on-site program, which consists of activities that add to formal teaching in literacy and math. Families can join live sessions in real time or view recorded sessions in their free time. There are also free learning strategies and program activities in the [LP Archive!](#)

Tar Heel Reader

www.tarheelreader.org

Offers a huge collection of free easy-to-read books, which can be translated to different languages and accessed through multiple interfaces such as touch screens. You can even write your own book!

Starfall

www.starfall.com

Teaches the basics of reading and math through interactive books and phonics games.

Handwriting Without Tears K-5

www.hwtears.com/hwt

Offers developmentally appropriate activities to help kids develop key school readiness, keyboarding, and handwriting skills.

Woodbine House Publishing Company

www.woodbinehouse.com

Offers a wonderful special-needs collection of books, CDs, and DVDs on many topics related to Down Syndrome, Autism Spectrum Disorder, and much more!

Signing Times

www.signingtime.com

Recommended for families who want to help their child learn sign language to support communication development! Each new family can get a free Signing Time DVD (Baby Signs Volume 1) at the Down Syndrome Program.

Signing Savvy

www.signingsavvy.com

The most complete online American Sign Language dictionary, with thousands of free teaching videos!

iPhone, iPad, and iPod Apps for Special Education

www.scribd.com/doc/24470331/iPhone-iPad-and-iPod-touch-Apps-for-Special-Education

A list of apps for special education on many topics such as speech, language, reading, writing, music, art, etc.! Many are free or low cost!

Social and Recreational Activities

Massachusetts Family Ties Resource Guide

(781) 774-6736 | www.familyties.org/info/directory.php

ARC Massachusetts

(781) 891-6270 | www.thearcofmass.org/resources/recreation/

Offer a complete list of the many community social and recreational activities around Massachusetts.

Opening Doors

(617) 287-4300 | www.openingdoorsforyouth.org

Connects families to resources for recreational activities, as well as post-secondary education and job training.

Special Olympics of Massachusetts (SOMA)

(978) 774-1501 | www.specialolympicsma.org

Offers 28 Olympic-type sports programs for people aged 2 and beyond to play with peers from their community or only with Special Olympics athletes.

Challenger Leagues

(570) 326-1921 | www.littleleague.org

Helps youth with disabilities, aged 5-18 or until the completion of high school, to enjoy playing baseball.

Youth Soccer TOPSoccer (The Outreach Program for Soccer)

(978) 466-8812 | www.mayouthsoccer.org

Helps youth with disabilities aged 4-19 to enjoy playing soccer.

Advocates in Motion – Massachusetts Down Syndrome Congress (AIM – MDSC)

(800) 664-MDSC | www.mdsc.org

A social and recreational program on Sundays for teens and young adults with Down Syndrome.

Federation for Children with Special Needs Summer Fun Camp Directory

www.fcsn.org/camps/

Provides a summer planning guide and directory of over 200 camps serving children with disabilities.

Therapeutic Horseback Riding Centers for Special Needs Riders

www.specialneedsma.com/hippotherapy.htm

Provides a listing of places that offer therapeutic horseback riding throughout Massachusetts.

Boston Ballet – Adaptive Dance Program

www.bostonballet.org/community/adaptive-dance.html For more info: eci@bostonballet.org

Established in 2002, Adaptive Dance provides creative movement instruction for individuals with disabilities ages 2-adult at Boston Ballet's Newton, Boston, and North Shore studio locations.

Boston Conservatory – Dance Program for Young Adults with Down syndrome

Late teens to early 20's Step by Step dance class.

<https://www.berklee.edu/berklee-institute-arts-education-and-special-needs/step-step-dance>

Transition to Adulthood

Federation for Children with Special Needs | www.fcsn.org

- Turning 14: An Introduction to the Transition Planning Process Workshop → 617-236-7210
- Planning a Life: Making the Most Out of High School for Students with Disabilities Conference → Terri McLaugh 617- 236-7210 x336 or tmclaugh@fcsn.org
- Transition Toolkit → www.slideshare.net/fcsn/transition-101-high-school-to-adulthood
- Family Guide to Transition Services in Massachusetts → www.fcsn.org/transition_guide

For teens and young adults

- **Boston Center for Independent Living | www.bostoncil.org**
 - Transition Internship Program - A great opportunity for young adults with disabilities aged 16-22 to get work experience. Interns work for \$10/hour, 10-20 hours/week, from June to August.
 - Transition to Adulthood Program - Offers peer-to-peer mentoring, skills training, referral to services, and advocacy support → Jamie Mell 617-338-6665 or jmello@bostoncil.org
- **B-SET (Boston Special Education Transition Program) for Career, College, and Community Living** → www.massadvocates.org/B-SET.php or 617-357-8431
- **Massachusetts Rehabilitation Commission | www.mass.gov/eohhs/gov/departments/mrc/**
 - Turning 22 Independent Living Program - Helps people with severe physical disability and mobility problems to live on their own after graduating high school or turning 22 → 617-204-3851 or 800-223-2559
 - Transitioning to Adult Program - Provides mentorship, independent living skills training, and self-advocacy services for special education students aged 14-22 → MaryEllen MacRae 617-204-3618
- **Mass General Hospital Aspire Teens Programs**
→ www.massgeneral.org/children/aspire/services/teen-programs.aspx or 617-726-0060
- **Easter Seals of Massachusetts Youth Transition Services | www.easterseals.com**
 - Provides assistive technology, rehabilitation therapy, social and recreational activities, job training and leadership training → 508-751-6390 or youthtransition@eastersealsma.org
- **Partners for Youth with Disabilities | www.pyd.org**
 - Young Entrepreneurs Project - Offers career development training → Alex Freeman 617-556-4075 x25 afreeman@pyd.org
 - Making Healthy Connections - Helps transitioning youth to understand their health care needs, how to use community resources and how to sustain healthy lifestyles → Susan Nicastro 413-584-0455x13 or snicastro@pyd.org (Springfield), Deep Chinappa 617-586-4075x20 or dchinappa@pyd.org (Boston)

For all families

- Youth on the Move: A Roadmap for Transition → www.youth-move.org
- Transition from School to Adult Life → www.thearcofghn.org/pdfs/Transition%20FS%202011.pdf
- Chapter 688 or "Turning 22 Law" (Massachusetts Department of Education) → www.doe.mass.edu
- Planning for Life After Special Education in Massachusetts → www.dlc-ma.org/manual

- Central Mass Transition Resource Guide – information on state agencies and transition services → [www.hudsonsepac.com/Central%20Massachusetts%20Transition%20Resource%20Guide%202 .pdf](http://www.hudsonsepac.com/Central%20Massachusetts%20Transition%20Resource%20Guide%202.pdf)
- Family Information Guide to Assistive Technology and Transition Planning → www.ctdinstitute.org

For individuals with autism spectrum disorder

- Transitioning Teens with Autism Spectrum Disorders
→ www.autismconsortium.org/attachments/Transition_Manual-8.12.pdf
- Transition Toolkit → www.autismspeaks.org/family-services/tool-kits/transition-tool-kit

Transitioning to Adult Health Care Providers

- Transition Planning for Adolescents with Special Health Care Needs and Disabilities: A Guide for Health Care Providers → www.communityinclusion.org/article.php?article_id=184%20
- National Health Care Transition Resources → www.gottransition.org/resources/index.cfm

Postsecondary Options

- Advising High School Students with Disabilities on Postsecondary Options → heath.gwu.edu
- Post-Secondary Education Links Fact Sheet → www.disabilityinfo.org/MNIP/DB/FSL
- College Options for Those with Intellectual Disabilities → www.thinkcollege.net

Employment

- School Days to Pay Days Employment Planning Guide → www.communityinclusion.org/schooldays
- Job and Career Tips for People with Disabilities → www.do2learn.com/JobTIPS/

Educational Opportunities for Parents

Federation for Children with Special Needs – Advocacy Training/Free workshops
<https://fcsn.org/trainings/>

Massachusetts Families Organizing for Change – Must do leadership series and other workshops
<http://mfofc.org/>

Greater Massachusetts Special Needs Events Resource Site
<http://www.spedchildmass.com/downs-intellectual-disability-events-massachusetts/>