Starting Points for Service Coordinators working with children with medically complex care needs

Background

Children with complex medical needs may require specialized care. The Health Policy Commission in Massachusetts defines children with medically complex care needs as those children with serious, chronic, and often multiple, medical, behavioral, or developmental health conditions, as well as significant functional limitations and considerable health service needs.

To increase the capacity of systems of care that are coordinated, comprehensive, culturally competent, and family-centered for infants and toddlers from birth to age 3 with special health care needs, the EI Division contracts with Medically Complex Care Consultation (MC3) programs. These programs assist early intervention service (EIS) programs in meeting the needs of children with medical complexities. Moreover, they support the early intervention system by expanding the skills and knowledge of providers and service coordinators to improve results and outcomes for children enrolled in early intervention in their natural environment.

What is a Medically Complex Care Consultation (MC3) program?

TheDepartment of Public Health EI Division contracts with regional-based MC3 programs to provide consultation to EIS programs and families enrolled in these programs for supporting children with medically complex care needs. An MC3 program supports EIS programs by providing training, consultation, and family support funds. This support also includes sharing evidence-based best practices, expanding educators' expertise, and resources for providing services to children with medically complex needs.

Reasons for referral

All EIS programs will receive general consultation, training, and education from the MC3 program in their region to support their capacity to serve children with medical complexities.

Children enrolled in Early Intervention with complex special health care needs, multiple disabilities, and medically complex care requirements should be referred to the MC3 program in their region.

* Service coordinators that make a referral for a child on their caseload with medically complex care needs will be contacted within 45 days of referral. They will be provided with consult on best practices for development of an IFSP, resources in their area, and toolkits for how to support continuity of care from the MC3 program in their region.

**MC3 programs provide:**

* Child-specific consultation and technical assistance to EIS programs and service coordinators for children with medically complex care needs:
  + Consultation to support the development of IFSPs that enhance therapeutic goals and assist with best practices for implementation in natural settings
  + Consultation to EIS programs and service coordinators on transitioning out of Part C services and referrals to other programs such as Care Coordination
  + Toolkits for EIS programs and families to help connect to resources.
* Family support including:
  + Family support funds
  + Contact information and relevant resources
  + Referral to Care Coordination if eligible
  + Provide family trainings
  + Support families and EIS programs in making appropriate referrals for identifying and accessing necessary medical equipment
* Education and training including:
* Quarterly training to all service coordinators in the awarded region on best practices for working with children with medically complex care needs.
* Training to EIS programs and service coordinators on applicable toolkits and available resources.

MC3 program referral process:

EIS programs and service coordinators can make a referral by:

* Accessing an MC3 program **referral form** at your early intervention program.
* Submitting the completed form to the MC3 program consultant serving your program via email. You can find the contact information for each MC3 program in our list of [MC3 Consultant Contacts](https://www.mass.gov/info-details/early-intervention-ei-regional-consultation-programs#find-an-early-intervention-regional-consultation-program)
* The MC3 Program Consultant from your region will then contact you to schedule an intake.

If you have a question or concern about whether to refer, contact the MC3 program consultant serving your EIS program.

**Things to consider:**

* Refer early as possible so service coordinators, providers, and families may fully benefit from the MC3 program’s services.
* Service coordinators play a vital role in learning best practices, identifying resources, and attending trainings provided by the MC3 Program.
* Obtain family consent if needed for sharing additional personally identifiable information.

**Parent resources**

* [Complexchild.org](https://complexchild.org/)

Complex Child includes medical information and personal experiences written by parents of children with healthcare needs and disabilities.

* [Courageous Parents Network](https://courageousparentsnetwork.org/)

Courage Parents Network (CPN) is a non-profit organization that supports families of children with serious illnesses and the clinicians who care for them. CPN provides a variety of resources, including videos, podcasts, guides, and blog posts designed to empower, orient, and equip parents and providers with the information and support they need.

* [The Federation for Children with Special Needs](https://fcsn.org/)

The Federation has multiple initiatives to support, educate, and empower families and professionals around the education, health, and community needs of children with children with special needs including:

* + [Family Ties](https://fcsn.org/family-ties/)
  + [Parent to Parent of Massachusetts Program](https://fcsn.org/p2p/)
  + [Family Advisor Program](https://fcsn.org/familyadvisor/)
  + [Family Leadership Development](https://fcsn.org/leadership-for-parents-families/)
  + [Mass Family Voices](http://fcsn.org/mfv/)

Financial assistance

* [Grants and Funding Opportunities | MA Developmental Disabilities Council](https://www.mass.gov/guide/grants-and-funding-opportunities)

Find information on grants, fellowships and other forms of funding to improve the lives of individuals with intellectual/developmental disabilities.

* [Mass211](https://www.mass211.org/)

Find quick and easy information on behavioral health, food insecurity, utility assistance, domestic violence, transportation, runaway assistance, and youth homelessness. Available for free, 24/7.

* [Home Energy Assistance Program (HEAP)](https://www.mass.gov/info-details/learn-about-home-energy-assistance-heap)

The Massachusetts home energy assistance program (HEAP) is a free resource to help eligible households pay a portion of winter heating bills.

**Complex care resources**

* [MASSSTART](https://www.mass.gov/info-details/learn-about-masstart)

MASSTART providers help families and schools plan for the health care and safety of children with special health care needs, especially those who are assisted by medical technology.

* [Care Coordination](https://www.mass.gov/care-coordination-for-children-and-youth-with-special-health-needs)

Care coordinators help families obtain services, including community-based resources, and provides consultation to parents, educators, and medical and social service providers.

* [Living Without Limits](https://livingwithoutlimits.org/)

Living Without Limits blends service and technology to provide safety and support, granting the highest level of independent living for older adults and people living with disabilities.

* [Massachusetts Department of Developmental Services](https://www.mass.gov/orgs/department-of-developmental-services)

The Department of Developmental Services provides supports for individuals with intellectual and developmental disabilities, including autism spectrum disorder, to enhance opportunities to become fully engaged members of their community.

* [Pediatric Palliative Care Network](https://www.mass.gov/pediatric-palliative-care-network-ppcn)

The Pediatric Palliative Care Network provides support and services at no-cost for eligible children ages 22 and younger with life-limiting illness and their families.

* [Department of Early Education and Care](https://www.mass.gov/orgs/department-of-early-education-and-care)

The Department of Developmental Services provides supports for individuals with intellectual and developmental disabilities, including autism spectrum disorder, to enhance opportunities to become fully engaged members of their community.

Additional resources

Determine eligibility for entitlements, based on family’s financial situation.

* [Community Support Line](https://www.mass.gov/community-support-line)

Community Support Line is a free statewide resource that provides information on public benefits and eligibility, technical assistance, and resources for families and providers caring for children and youth with special health needs. Call (800) 882-1435 for more information.

* [MassHealth CommonHealth](https://www.mass.gov/info-details/masshealth-commonhealth)

MassHealth CommonHealth offers healthcare coverage to individuals with disabilities whose income is too high for MassHealth Standard. MassHealth CommonHealth benefits are similar to MassHealth Standard benefits. If you have a disability, you may be eligible for CommonHealth even if you have private insurance or Medicare.

* [Kaleigh Mulligan Program – MassHealth](https://www.mass.gov/info-details/health-plans-and-programs-for-seniors-and-people-who-need-long-term-care-services)

The Kaleigh Mulligan program provides home care for children ages 18 and younger with severe health care needs. Call us at (800) 841-2900 (TTY: 800-497-4648) for more information.

* Catastrophic Illness in Children Relief Fund

The Catastrophic Illness in Children Relief Fund (CICRF) provides financial relief to eligible Massachusetts families caring for children and youth ages 22 and younger with medically related expenses that are not covered by insurance, federal or state assistance, fundraising, or any other financial source.

* [MassHealth Community Care Management](https://www.mass.gov/the-masshealth-community-case-management-ccm-program%22%20HYPERLINK%20%22https://www.mass.gov/the-masshealth-community-case-management-ccm-program)

The Community Case Management program provides continuous skilled nursing services, including home nursing, for MassHealth Standard and MassHealth CommonHealth members.

* [Supplemental Security Income (SSI)](https://www.ssa.gov/ssi)

SSI provides monthly payments to children and individuals with disabilities and older adults who have little or no income or resources.

* [WIC](https://www.mass.gov/orgs/women-infants-children-nutrition-program)

WIC is a nutrition program that provides healthy foods, nutrition education, breastfeeding support, and referrals to healthcare and other services, free of charge, to Massachusetts families who qualify. Call (800) 942-1007 to learn about eligibility and how to apply.

* [Supplemental Nutrition Assistance Program (SNAP)](https://www.mass.gov/snap-benefits-formerly-food-stamps)

SNAP provides food benefits to low-income families to supplement their grocery budget so they can afford the nutritious food essential to health and well-being.