Public Case Management & Care Coordination Programs for Children with Special Health Care Needs in the Commonwealth of Massachusetts:

Results of a State Agency Survey



Prepared by:

Massachusetts Consortium for Children with Special Health Care Needs
New England SERVE

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This document summarizes the results of a survey of Massachusetts state agencies offering case management or care coordination services to children with special health care needs. The survey was conducted during the winter of 1999-2000 on behalf of the Massachusetts Consortium for Children with Special Health Care Needs under the auspices of New England SERVE.

Because our goal was to understand case management and care coordination programs directly run by or overseen by state agencies, we did not survey any private full-service Managed Care Organizations who may contract with Massachusetts Department of Medical Assistance to provide health services that may include care coordination.

Please address any program-specific questions to the state agency that provides that service. A downloadable .pdf version of this document is available on the New England SERVE Web Site at www.neserve.org.

The members of the Massachusetts Consortium and the staff of New England SERVE would like to thank Joshua Sharfstein, MD, for his detailed efforts to compile this information. We also express our appreciation to the eleven state agencies that participated in this project and applaud their ongoing efforts to provide family centered care coordination services to Massachusetts children and families.

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Та	ble 1: Summary of State Agency Services and Cont	act Information
	Summary of Case Management /Care Coordination Programs Serving CSHCN	Contact Information
1. Division of Medical Assistance	DMA is initiating a case management program designed to serve children with significant medical needs enrolled in the Mass Health Primary Care Clinician Plan (PCC Plan) or those in fee for service Medicaid. This program will also offer coordination of certain services not covered through DMA-contracted Managed Care Organizations (MCOs). (DMA contracted MCOs provide their own case management services for enrollees for covered/contracted benefits)	Pauline Edmonds: 617-210-5631
2. Department of Mental Health (DMH)	DMH provides case management services to eligible clients, including: 1) completion of an assessment of client needs; 2) development of an individual service plan with the client and family; 3) review of program specific treatments plans; 4) coordination or monitoring coordination of services. DMH case management may also include: 1) assisting the client to access other services; 2) outreach to the client and family; 3) providing intensive support or advocacy as needed.	Western MA: 413-587-6293 Central MA: 508-363-3386 Northeast MA: 978-863-5048 Metro Suburban MA: 508-242-8009 Southeast MA: 508-897-2046 Boston: 617-626-9260
3. Department of Mental Retardation (DMR)	DMR operates the "medically fragile" program that provides intensive short-term case management supports to those families with severely medically involved children. The goal of the program is to identify and access community resources, provide parental supports and develop a coordinated plan of services that will assist families in caring for their child at home.	Western MA: 413-731-7742 x 313 Central MA: 508-792-7790 x138 Northeast MA: 978-774-5000 x523 Southeast MA: 508-886-5000 x350 Boston 617-624-7549
4. Department of Public Health (DPH)	DPH case managers help families identify, obtain and coordinate services they need to care for their child with complex medical needs; they work with hospitals and state and community agencies to promote comprehensive, coordinated systems of care for children and their families.	617-624-5966
5. Early Intervention (EI)	The DPH contracts with community-based programs to provide Early Intervention Services. Each EI program identifies an appropriate specialist to serve as case manager for each enrolled child, helping the family of that child obtain and coordinate services included in the child's individualized family service plan.	Ron Benham: 617-624-5929
Department of	DSS has established a pilot program that enrolls certain medically involved children living in foster care in a DMA-contracted managed care organization. A nurse practitioner is assigned to each enrolled child and takes the lead in coordination of the delivery of necessary medical services and supplies and helps support the foster parent in accessing medical care for the enrolled child. This pilot program is called "Special Kids, Special Care."	Kathy Betts: 617-748-2326

Та	ble 1: Summary of State Agency Services and Cont	
	Summary of Case Management /Care Coordination Programs Serving CSHCN	Contact Information
7. Commission for the Deaf & Hard of Hearing (MCDHH)	MCDHH is the primary state agency serving deaf and hard of hearing individuals in Massachusetts. The Commission has run a case management program since 1987.	Andrea Koenig: 617-695-7500
8. Mass. Commission for Blind (MCB)	Each of the Commonwealth's six service regions under the Executive Office of Health and Human Services has an MCB Children's Services Social Worker. Their function is to provide a range of information and needed direct and purchased services to legally blind children, and by extension, to their families.	Director of Children's Services: 617-626-7480
9. Mass. Rehabilitation Commission (MRC)	MRC provides case coordinators for individuals with severe disabilities. Individuals can choose from several different providers in their geographical area to provide these services. Case coordinators develop a supported living service plan with the consumer and usually come to the consumer's home 3 to 5 hours per week, depending on need, to help them manage their lives more effectively. Services include any area that the consumer wishes to have help with, including hiring/firing/managing PCA's, budgeting and paying bills, scheduling doctor appointments, problem-solving with housing issues, transportation issues, etc.	Turning 22 Program Coordinator: 617-204-3627
10. Division of Medical Assistance (DMA) Primary Care Clinician Plan/ Behavioral Health Program	DMA contracts with a private vendor to provide a full range of behavioral health services to Primary Care Clinician Plan (PCC) enrollees. The vendor's Intensive Clinical Management (ICM) program is designed to target members who are considered high risk and/or high utilizers of acute behavioral health services. The program provides one point of contact at the vendor for authorizing and monitoring care as well as the services of a community support program for ICM clients, which can provide support in the community.	Western MA: 413-858-1808 Central MA: 508-890-6404 Northeast/Greater Boston: 617-350-1925 Metro Boston: 617-350-1923
11. State Head Injury Program (SHIP)	The SHIP Case Management Services are primarily provided to adults with traumatic brain injury (TBI) but can assist families with children with TBI in educating and advocating for needed services.	800-223-2559

Table 2: Eligibility Criteria

	Lower age	Upper age	Medical	Develop- mental	Geography	Finances	Exclusions	Other
1. Division of Medical Assistance (DMA)	В	21	Not yet determined	Not yet determined	State	-	n/a	Program just getting started
2. Department of Mental Health (DMH)	В	18	Qualifying mental disorder	-	State	-	If child qualifies for DMR, then primary agency is DMR. If in DSS care or custody, DSS is primary. If in custody of DYS, DYS is primary. DMH may also assign case managers in these situations.	Key for eligibility is diagnosis with need for treatment, and treatment not available through another source
3. Department of Mental Retardation (DMR)	В	18	Significant/complex medical needs	Significant delays (DMR eligible)	State	-	None	Intensive case management is provided for families in need of "stabilization, crisis management, resource access and skill building"
4. Department of Public Health (DPH)	В	22	Substantial physical disability expected to last >1 year or terminally ill	-	State	-	Within primary target population of another agency	There is a separate, small HIV case manager program
5. Early Intervention (EI)	В	3	Known disabling physical or mental condition	Delay or risk criteria	State	-		
6. Department of Social Services (DSS)	В	21	Complex medical management on regular basis for prolonged period	-	Boston- metro area with plans to expand statewide	-	Children must meet certain clinical criteria for enrollment	Must have need for complex medical management and must be in care and custody of DSS, living in foster care. Child may remain in the program up to one year after return to biological home or adoption.

Table 2: Eligibility Criteria

	Lower age	Upper age	Medical	Develop- mental	Geography	Finances	Exclusions	Other
7. Mass. Commission for the Deaf & Hard of Hearing (MCDHH)	В	None	Deaf or hard of hearing	-	State	-	None	Discretion of program administrators
8. Mass. Commission for Blind (MCB)	В	14	Legally blind	-	State	Considered for purchased services only	None	Age 14 legally blind children are transitioned to other MCB programs such as vocational rehabilitation or MCB's deaf/blind/handicapped unit
9. Mass. Rehabilitation Commission (MRC)	Grad. from 766 program		Severe physical disability with mobility impairment	-	State	-	If receiving DMR, DMH, MCB, or SHIP services	Must be graduating from 766 program; must be eligible for chapter 688 and have a 688 transition plan which includes supported living services.
10. Division of Medical Assistance (DMA) Primary Care Clinician Plan/Behavioral Health Program	-	-	-	-	State	-	DSS residential care	Must have acute care service in the last year and/or clinical risk factor according to established criteria; must be enrolled in PCC Plan's Behavioral Health Program
11. State Head Injury Program (SHIP)	-	-	Externally caused traumatic brain injury	-	State	Family income considered for sliding fee scale	None	Must also be able to benefit from community based services

Table 3: Referral Sources

	Primary Care Doctor	Self- referral	Active Outreach	Diagnosis-based Automatic Referral	Comments
1. Division of Medical Assistance (DMA)	Yes	Yes	Yes	No	Word of mouth, hospital discharge inquiry, prior authorization requests
2. Department of Mental Health (DMH)	Yes	Yes	No	No	Programs and facilities can also file applications on behalf of patients
3. Department of Mental Retardation (DMR)	Yes	Yes	Yes	No	The area children's coordinator handles referrals. This person may receive requests from family, school, EI, medical providers, etc.
4. Department of Public Health (DPH)	Yes	Yes	Yes	No	Outreach letter sent to all families deemed SSI eligible; outreach to agencies by regional staff; referrals through hospitals and EI are common
5. Early Intervention (EI)	Yes	Yes	Yes	No	
6. Department of Social Services (DSS)	Yes	No	Yes	No	Potential applicants are identified by DSS agency staff, hospital staff, referrals from foster parents, and other state agencies involved in serving children with special health care needs.
7. Mass. Commission for the Deaf & Hard of Hearing (MCDHH)	Yes	Yes	Yes	No	Agencies often refer patients

Table 3: Referral Sources

	Primary Care Doctor	Self- referral	Active Outreach	Diagnosis-based Automatic Referral	Comments
8. Mass. Commission for Blind (MCB)	Yes	Yes	Yes	Yes*	"All new registrants are contacted and offered a home visit services are explained and offered."
9. Mass. Rehabilitation Commission (MRC)	No	Yes	Yes	No	MRC staff meet parents at IEP meetings and often have substantial contact with families after the individual has moved into an independent apartment in the community.
10. Division of Medical Assistance (DMA) Primary Care Clinician Plan/ Behavioral Health Program	Yes	Yes	Yes	No	Inpatient and outpatient units can refer patients. The vendor's clinical staff also make referrals. Vendor accepts referrals from any source.
11. State Head Injury Program (SHIP)	Yes	Yes	Yes	No	

^{*}Legally blind as defined in M.G.L chapter 6, Section 136. Institutions, physicians, oculists and optometrists are required to report within 30 days all cases of legal blindness: 1) All cases where vision with correction is 20/200 or less in the better eye. 2) All cases regardless of visual acuity, if the visual field is reduced to the radius of 10 degrees or less with a 6 mm. white test object.

Table 4: Program Capacity

	Families Served at Time of Survey	Number of Families Receiving Services Annually	Waiting List?	Comments
1. Division of Medical Assistance (DMA)			No	The pilot program began 12/99.
2. Department of Mental Health (DMH)	1,433 children as of 1/24/00	1,612 during FY 1999	Yes: 1,938 children	
3. Department of Mental Retardation (DMR)		80 served in 1999	Yes	
4. Department of Public Health (DPH)		1,200	No	
5. Early Intervention (EI)	10,000	20,000	No	
6. Department of Social Services (DSS)	16	Projected 100-150	No	This is expected number. The pilot program was initiated in 1999.
7. Mass. Commission for the Deaf & Hard of Hearing (MCDHH)		2,150 (includes adults and information & referral)	Yes: 15/month	
8. Mass. Commission for Blind (MCB)	750	750-900	No	All MCB services are voluntary. Not all of the families of the approximately 1,500 legally blind children want or need MCB case management at any given point in time. Most who do tend to have ongoing needs.
9. Mass. Rehabilitation Commission (MRC)	?	?	No	

Table 4: Program Capacity

	Families Served at Time of Survey		Waiting List?	Comments
10.				
Division of Medical Assistance (DMA)				
Primary Care Clinician Plan/ Behavioral Health Program		138 children	No	
11. State Head Injury Program (SHIP)	20	20	-	

Table 5: Staff Capacity

	Number of Case Managers	Do case managers primarily serve children?	General Background of Case Managers	Required Credentials	Approximate Case Manager: Client Ratio
1. Division of Medical Assistance (DMA)	8	No	Home and hospital clinical experience	RN	
2. Department of Mental Health (DMH)	71.75 case managers, 24 supervisors, 3 directors	Mostly	Aim for MSW's who have experience or other MH professionals	Work experience in human services, BA or Master's Degree can be substituted for some experience	1:20
3. Department of Mental Retardation (DMR)	5	Yes	Parents of medically involved children		1:5
4. Department of Public Health (DPH)	18	Yes	Masters in education and a few licensed social workers	3 years human service experience	
5. Early Intervention (EI)	1,400	Yes	Certified EI specialist & may be in one of several disciplines	Credentials vary depending on discipline	Difficult to estimate
6. Department of Social Services (DSS)		Yes	Nurse practitioner	Nurse practitioner	1:15-20
7. Mass. Commission for the Deaf & Hard of Hearing (MCDHH)	3	Yes	Usually social work or rehab counselor background	Master's degree preferred	1:30
8. Mass. Commission for Blind (MCB)	6	Yes	Human service degree and experience working with families	Bachelor's degree	1:100-1:116 varies from region to region
9. Mass. Rehabilitation Commission (MRC)	17	No	Most have some college background		

Table 5: Staff Capacity

	Number of Case Managers	Do case managers primarily serve children?	General Background of Case Managers	Required Credentials	Approximate Case Manager: Client Ratio	
10. Division of Medical Assistance (DMA) Primary Care Clinician Plan/ Behavioral Health Program	7 for kids, 8 for adults	Yes	Mental health experience with children	Master's level licensed clinicians	1:40	
11. State Head Injury Program (SHIP)	6 employed and 32 through contracts	No	Advanced degrees in social work, rehab counseling and/or nursing	Bachelor's degree with a minimum of 1 year experience + 2 years working with head injury patients	1:40	

Table 6: Services Provided

- a) Initiate contact with primary care doctors
- b) Initiate contact with El
- c) Transportation to MD's office
- d) Schedule doctor appointments
- e) Accompany families to meetings, school, etc.
- f) Explain what services are available under health insurance
- g) Help families obtain services within health insurance

- h) Explain what services are available in other programs (not insurance)
- i) Help families obtain services available in other programs (not insurance)
- j) Help coordinate care between school and clinicians
- k) Help families appeal denials of care
- I) Determine eligibility for certain services

	a)	b)	c)	d)	e)	f)	g)	h)	i)	j)	k)	I)	Comments
1. Division of Medical Assistance (DMA)	Х					Х	Х	Х		Х	Х	Х	Coordination of DMA funded services, some discharge planning
2. Department of Mental Health (DMH)	Х	Х		Х	Х	Х	Х	Х	Х	Х	Х		Key role is comprehensive assessment and service plan
3. Department of Mental Retardation (DMR)	Х	Х	Х	Х	Х	Х	Х	Х	Х	Х	х	Х	See annual report available from DMR
3. Department of Public Health (DPH)		Х	Х		Х	Х	Х	Х	Х		Х	Х	Access to SSI, assistance with insurance, school placement, other needs
5. Early Intervention	Х			Χ	Х		Х	Х	Х		Х		
6. Department of Social Services (DSS)	Х	Х	Х	Х	Х	Х	Х	Х	Х	Х		Х	Access via NHP to durable medical equipment and supplies for foster home
7. Mass. Commission for the Deaf & Hard of Hearing (MCDHH)	Х	Х			Х	Х	Х	Х	х	Х	х	Х	Also train other state agency workers on communication access
8. Mass. Commission for Blind (MCB)	Х	Х	Х	Х	Х	Х	Х	Х	Х	Х	Х	Х	See sample service plan available from MCB
9. Mass. Rehab. Commission (MRC)	Х			х	х			х	х	х	х	х	Case managers also help with PCA, adaptive equipment, social/recreation, transportation/mobility and financial management.
10. DMA - Primary Care Clinician Plan/ Behavioral Health Program	Х	Х	Х	Х	Х	Х	Х	Х	Х	Х		х	These services are not all provided directly by the ICM clinician. Many are provided by the community support workers, which the ICM client is eligible for through the ICM program.
11. State Head Injury Program (SHIP)	Х	Х			Х	Х	Х	Х	Х				Limited to advocating for support under 766 and child welfare programs

Table 7: Miscellaneous Questions

	Service Limits?	Written Plan?	Do your case managers coordinate with others?	Source of Funding	How many years in operation?	Are all children being served?
1. Division of Medical Assistance (DMA)		Being developed	It is a goal	State and federal	<1	No. Just starting program
2. Department of Mental Health (DMH)	No	Yes	Yes	DMH + federal Medicaid dollars	>15	No. Long waiting list
3. Department of Mental Retardation (DMR)	No	Yes	Yes	DMR family support	3	No. The demand exceeds our resources.
4. Department of Public Health (DPH)	No	Yes	Yes	Federal MCH Block Grant, State Family Health Services line item	20	No. By limiting outreach fewer children are identified. Key gap in outreach is via primary care doctors.
5. Early Intervention (EI)	No	Yes	Yes	State and federal	17	No. There are hard to reach populations.
6. Department of Social Services (DSS)	Services are provided through the MCO to enrolled children based on the DMA contract with the MCO.	Yes	Yes	Contract with DMA	<1	No. Pilot program began 12/99
7. Mass. Commission for the Deaf & Hard of Hearing (MCDHH)	No	Yes	Yes	State budget	13	No. Many children who are deaf or hard of hearing are not identified.
8. Mass. Commission for Blind (MCB)	No (purchased services are subject to appropriation)	Yes	Yes	State and federal (Social Services Block Grant)	"Decades"	Yes, because of mandated registration of legally blind children by physicians; our services are voluntary.

Table 7: Miscellaneous Questions

	Service Limits?	Written Plan?	Do your case managers coordinate with others?	Source of Funding	How many years in operation?	Are all children being served?
9. Mass. Rehabilitation Commission (MRC)	No	Yes	Yes	State budget	9	No. There are young people who could utilize independent living and supported living services throughout Massachusetts.
10. Division of Medical Assistance (DMA) Primary Care Clinician Plan/ Behavioral Health Program	No	Yes	Yes	Contract with DMA	5	Yes - If referred children meet eligibility criteria and ICM clinicians have openings in their caseloads.
11. State Head Injury Program (SHIP)	Yes short term only	No	Yes (not required)	100% state funded	14	No. We do not have enough staff to do active recruitment.

Table 8: Other Comments					
	Other Comments				
1. Division of Medical Assistance (DMA)					
2. Department of Mental Health (DMH)	Many aspects of case coordination are provided by vendors, especially residential treatment programs. This questionnaire was answered in terms of what we at DMH call case management a service provided by state employees.				
3. Department of Mental Retardation (DMR)	Medically fragile is only one service provided by DMR. We also provide children's coordination, autism support, educational advocacy, intensive behavioral management, flexible family support as well as additional area based initiatives. There is also an available resource for families seeking information and support to participate in regional family advisory councils/coalitions of families with medically fragile children. The majority of families that we serve receive supports via our family support agencies.				
4. Department of Public Health (DPH)					
5. Early Intervention (EI)					
6. Department of Social Services (DSS)	We would like to see this pilot expanded to children who have complex medical conditions but who do not meet the medical criteria for this program.				
7. Mass. Commission for the Deaf & Hard of Hearing (MCDHH)	Behaviorally oriented children are often only served by this department, not DMH (because they do not meet the criteria for DMH).				
8. Mass. Commission for Blind (MCB)					
9. Mass. Rehabilitation Commission (MRC)	Most of our consumers would not be living successfully in the community without case coordination supports. Many need help with problem solving landlord and housing issues, balancing checkbooks, paying bills, budgeting, managing PCA's, etc.				
10.					
Division of Medical Assistance (DMA)					
Primary Care Clinician Plan/ Behavioral Health Program					
11. State Head Injury Program (SHIP)					