# Fitting the Pilot Into the Present System:

A Review of Existing Family Support Programs in Massachusetts

ISSUES PAPER 2

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# TABLE OF CONTENTS

TOPIC	PAGE
INTRODUCTION	. 1
DESCRIPTIONS OF EXISTING SUPPORT PROGRAMS	. 2
1. (DPH) Home Health Care Services	
3. (DPW) Home Health Care for Disabled Children 4. (DPW) Voucher Day Care	
5. (OFC) Help for Children	
7. (Comm for Blind) Emergency Aid Assistance	
9. (DMR) Family Support Programs	20
10. (DSS) Respite Care Program	23 26
14. (MVR) Maintenance Program	33
COMPARATIVE ANALYSES OF EXISTING PROGRAMS	38
RETERENCES	44

### Introduction

The birth of a child with a disability or chronic illness creates a crisis for the family and all involved. Though not a frequent occurrence, numerous children in the United States have disabilities or illnesses severe enough to prompt concern for their welfare and that of their family (Hobbs & Perrin, 1985; Healy, Keesee & Smith, 1985; Ashbaugh, Spence, Lubin, Houlihan & Langer, 1985).

In response, a growing number of states are implementing programs to support family efforts, with about 20 offering cash assistance to families to offset the costs they incur. In such programs, cash is provided directly to families to offset various family expenses, including those related to care. Families either receive a periodic subsidy or stipend to pay for future expenses or are reimbursed for the costs that are incurred.

As is shown below, policy makers in Massachusetts have reacted to the needs of children with disabilities and their families by implementing a variety of programs through several state agencies. Though such programs may not yet reach all those in need, their existence and the recent emphasis placed on such initiatives by families and professionals alike reflects a growing commitment in the state to supporting family efforts. In this light, the Governor's Planning Council on Developmental Disabilities is considering the merit and feasibility of implementing a cash assistance pilot program on behalf of families.

When planning and administering the pilot, the presence of other available family supports must be taken into account. To have the greatest positive effect -- on families and the overall system -- the pilot cash program must be implemented in ways to complement, not supplant, existing support structures. That is, the cash assistance should be used to fill service gaps, accommodate unique family needs, and supplement services judged as insufficient.

In this light, the purpose of this paper, the second in a series, is to present a review of existing family or child centered programs in the state. Additionally, selected comparative analyses are offered concerning these services.

# Descriptions of Existing Programs

What follows are summary descriptions of 16 programs available in Massachusetts for special needs families and/or children with disabilities who live at home. Figure 1 lists these programs by their administrating state agency and indicates the page where its program

summary is found.

In identifying and studying these programs, project staff grew acquainted with the existing network of family supports in Massachusetts, and hoped to discover enabling policies and administrative practices that could be applied to the implementation of a DDPC cash assistance pilot program.

Each of the summary descriptions provided includes the following information:

- o Program Overview: A brief description of the program.
- o Services Offered: Those services offered through the program.
- o Eligibility Criteria: The requirements needed to participate in the program.
- o Application/Referral Process: The process of applying for admittance or being referred to the program via application or case worker.
- o Flow of Dollars: How the money is distributed from agency administering the program to the service provider.
- o Level of Consumer Choice: The choice family members have in selecting the source of the support sought.
- o Funding: The source of funding for the program.
- Number served: The number of children or families served in the past fiscal year.
- o Reference: The source for the program.

FIGURE 1: PROGRAM NAME BY	AGENCY AND PAGE REFERENCE	
Agency	Program Name	Page
Dept Public Health	1. Home Health Care Services	6
Dept Public Health	2. Adaptive Housing Program	7
Dept Public Welfare	3. Home Care for Dis Children	9
Dept Public Welfare	4. Voucher Day Care	11
Office for Children	5. Help for Children	13
Office for Children	6. Affordability Scholarship Assistance Program	14
Commission for Blind	7. Emergency Aid Assistance	17
Commission for Blind	8. Recreation Assistance	18
Dept Mental Retardation	9. Family Support Programs	19
Dept Social Services	10. Respite Care Program	21
	11. Family Support Program	22
Dept Social Services	12. Adoptive Subsidy Program	24
Dept Social Services	13. Fos Care Subsidy Progr	25
Mass Rehab Commission	14. Maintenance Program	27
	15. Transportation Program	28
	l6. Indep Living Program	30

The information that follows was obtained in two ways. First, project staff reviewed a variety of relevant documents pertaining to the programs (e.g., state statutes, agency rules or regulations, pertinent state legislation, program brochures). In this regard, the following documents were found to be particularly useful:

- o Executive Office of Human Services (1988). Mid year directory of Purchased services: Fiscal Year 1988. Boston, MA: EOHS, 1 Ashburton Place, Room 1109.
- o Massachusetts Developmental Disabilities Council (1988).

  Developmental Disabilities State Plan Fiscal Years 1988 Update.

  Boston, MA: MDDC, 600 Washington St., Room 670.
- o Department of Public Welfare (1988). Budget Narrative FY 89. Boston, MA: 180 Tremont St.

Second, staff interviewed numerous state-level persons within each of the relevant state agencies who are associated with the identified programs. A list of these persons is shown by Figure 2.

programs. A list of these persons is shown by Figure 2.

Date	Agency	Interviewee					
Reb 17, 1988	Exec Office Human Serv	Diane Mizonsin					
March 2	Dept Mental Retardation	Rick O'Meara					
March 8	Dept Social Services	Nora Etkin					
March 15	Dept Mental Retardation						
iarch 18	Dept Public Health	Barbara Abrahms					
March 18	Commission for the Blind						
farch 22	Office for Children	Polly Halfkenney					
farch 22	Dept Mental Retardation	Jo Ann Vye					
March 25	Commission for the Blind	Wendy Joselin					
larch 29	EOHS	Hans Toegel					
March 30	Mass Rehab Commission	Leo Long					
March 30	Rate Setting	Peg Keenan					
farch 30	Dept Mental Retardation	Casey Seaman					
		Susan Mullen					
		JoAnn Simons-Derr					
pril 4	Dept Public Welfare	Lorrie Ansorge					
pril 10	Mass Rehab Commission	Karen Langley					
pril 22	Exec Office Admin/Finance						

## Department of Public Health (DPH) (Two Programs)

#### 1. Home Health Care Services

Program Overview: This program provides intermittent in-home assistance to meet the medical and daily care needs of a child with multiple handicaps. Aside from accommodating the needs of the child, these services enable their families to care for their child at home.

Services Offered: In home assistance is provided in response to short-term, emergency, and ongoing support needs. Services are provided by trained home health care providers (registered and practical nurses, specialty therapists, home health aides and homemakers) who are employees of home health agencies and visiting nurse associations. These employees assist families in a great number of ways by helping with nursing, personal care and implementation of therapeutic programming.

Eligibility: Eligibility for admission to the program is confined to Massachusetts residents birth to 22 years of age who have physical disabilities with the prognosis of significant impairment of growth and development requiring substantial assistance and/or who have extensive medical/nursing needs.

Application/Referral Process: An application for service is made by a referring agency or professional currently providing medical or social service to the family. The referral includes the professional's recommendation regarding service need. A DPH inter-disciplinary team determines eligibility and amount of service to be provided.

Flow of Dollars: DPH pays for home health care after available private insurance and Medicaid funding are utilized. Payment is made by the Department of Public Health directly to the contracted provider after the service has been received by the family. An authorization for service is sent to the service provider by DPH. Authorizations are prepared to cover up to a three month period of service.

Level of Consumer Choice: Choice of the agency to provide home health services usually resides with the family, who has often had prior experience with a particular agency. If the family has no agency in mind, the department will supply the family with a list of agencies that the family chooses from. Usually choice is limited by the match between the family's need and the availability of personnel at the agency. Agencies are not limited to those which are certified by the Department of Public Health for Medicaid funding. Authorizations for service are given on a per child basis.

Source of Funding: The Federal Maternal and Child Health Block Grant (through Title V of the Social Securities Act) supports most of DPH support programs. This is supplemented with some state monies and is treated as an "07" account.

Number Served: About 210 families were served in fiscal year, 1987.

References: There is no specific Massachusetts general statute that authorizes the home health care services program. It is an internal department decision to develop this service to meet the larger mandate of providing supportive services. A DPH brochure is available for reference.

## 2. Adaptive Housing Program

**Program Overview:** The purpose of this program is to encourage the independence of children with mobility impairments by adapting or changing their home environments. It is intended to support families by facilitating care for their children with multiple handicaps at home rather than in institutions.

Services Offered: Technical assistance is provided to identify useful home modifications, and direct families to potential funding sources. Additionally in some instances, financial assistance is offered to obtain the contractor, supervise construction and evaluate the effectiveness of home modifications (e.g., ramps, widened doorways, lowered counters). Modifications cannot be made that add value to the property such as adding a room or enlarging the dimensions of the property.

Eligibility: Families having children with mobility impairments aged birth to 18 years who own their own homes or who obtain owner's permission for modifications. Families wishing financial assistance must qualify.

Application/Referral Process: Applications are made at regional DPH offices with the Adaptive Housing Program liaison. Program staff will serve as many families as possible within the limits of funding.

Flow of Dollars: DPH has a contract with a state-wide vendor who provides technical assistance to families eligible for home modification. This contractor in turn sub-contracts with local construction or other agencies to actually do the work.

Level of Consumer Choice: Often families have preferences for

specific modifications that are honored unless a less costly approach is available. Where a family has no preferences the vendor and the DPH liaison, will assist families in designing and choosing modifications. Families who require financial assistance from the program do not have choice over the particular contractor who will do the modification.

Source of Funding: Originally, funding came from the Federal Jobs Bill which provided monies for depressed industries such as construction. Presently, funding for all DPH support services comes from the federal Maternal and Child Health Services block grant. This is supplemented by state monies for a grand total of \$100,000, plus family and charitable contributions. In some cases, where a consumer is also receiving services from the Massachusetts Commission of the Blind, the cost of the modification may be shared with this second state agency. The program is treated as an 07 account.

Number Served: Since 1984, about 70 families have received this service.

References: This program is not authorized by state statute nor has it been promulgated in departmental regulations. It is internally created within DPH and supported with existing funds to fulfill the larger mandate of providing family support services. A brochure is available.

## Department of Public Welfare (Two Programs)

#### 3. Home Care For Disabled Children

Program Overview: The Department of Public Welfare created the Home Care for Disabled Children (HCDC) program to allow children with severe disabilities to receive needed services through Medicaid so that they may remain at home instead of residing in an institution. The Massachusetts Commission for the Blind (MCB) also operates a program identical to this one within its own auspices, the only difference being that the child must be legally blind. This program allows a determination of Medicaid eligibility for children who are currently living in institutional settings or are risk of such placement without regard to the financial circumstances of the parents.

Services Offered: Eligible children who live at home can receive certain home- and community-based medical services that are reimbursable under the Medicaid program. The services covered by HCDC include those provided by physicians, hospitals, nurses, physical, occupational and speech therapists, certain medical equipment, and certain medications. Some services require "prior authorization," by the Department while respite care and non-medical items, such as ramps, vans, and home modifications, are not reimbursable because of federal regulations.

Eligibility: To be eligible, a child must meet all the criteria below:

- o The child must be 18 years or younger and determined to have a disability according to the standards of the Social Security Administration (SSA).
- o The child must require a level of care equal to that of an acute or chronic hospital or pediatric nursing home.
- o The child must receive or be able to receive appropriate care outside an institutional setting.
- o The projected annual cost to Medicaid for the child's home care must not be expected to be greater than the amount Medicaid would pay in the appropriate institution.
- o The family must provide information regarding other third-party insurance coverage the child may have or for which the child may be eligible. The third-party payer will always be billed prior to Medicaid.

- o The child may not have personal income or assets that exceed the current SSI standards for a child in a medical institution (parental assets are not considered).
- o The family must either have or be in the process of obtaining a social security number for the child.

The Department performs periodic redeterminations of eligibility in which it applies the same criteria used in the initial determination. The Medicaid Division of the Welfare Department (or MCB where appropriate) reviews current clinical information and past billing records to certify that the eligibility criteria have been met and to project whether they will continue to be met.

If actual Medicaid expenditures exceed the amount that would have been spent if the child had been institutionalized, the child will be deemed ineligible.

Application/Referral Process: The application procedure begins at the family's local welfare office. Where the family completes a Medicaid application. If the child's income and/or assets do not exceed the SSI institutional standards, the local welfare office will refer the case to the HCDC program staff in Boston.

The HCDC program staff then mails an application packet to the family. The packet includes an HCDC program application and several "Release of Medical Information" forms. Completed applications are reviewed by the Welfare Department staff who eventually notify the family of the eligibility determination. The whole process may take three months to complete. In the meantime, the family may be eligible for partial assistance under regular Medicaid standards.

Flow of Dollars: Medicaid is always the "payer of last resort." All other health insurance sources must be billed first. The service provider sends a bill to the insurance company. When the family has exhausted any cap that may exist on their insurance policies, the Medicaid program pays the remaining amount if the service is reimbursable. Where the family is totally dependent on Medicaid, the bill is sent directly to the appropriate state agency. In either case, Welfare or MCB assures that the service provider is paid the amount owed.

Level of Consumer Choice: Once an application has been accepted, a social worker will visit the family to discuss the services they may need. A treatment plan is prepared based on the services needed by the child. The family is involved to a great extent in the process of determining what services are needed. To an extent, the family also may

choose what service provider will be used, though all providers must be enrolled in the Medicaid program so to receive payment through Medicaid.

Source of Funding: The Medicaid program is funded through Title XIX of the Social Security Act. Fifty percent of Medicaid expenditures are matched by the federal government. This new program was created through an amendment to the Medicaid state plan which is approved by the federal government in order to receive matching funds. This program is treated as an 07 account.

Number Served: This program is fairly new (since November, 1987), so only a few families participate in the program. Through this program, the Department of Public Welfare serves approximately 15 families and the Massachusetts Commission for the Blind has so far accepted 13 families with no denials.

References: 42USC & 139a(e)(B)(3); M.G.L.A Chapter 18, sec. 1 et seq.; Department of Public Welfare, Medical Division, Home Care for Disabled Children (HCDC) Program

# 4. Voucher Day Care

Program Overview: One of the most significant barriers to employment for participants of the Aid to Dependent Children (AFDC) program is the lack of affordable day care. The Voucher Day Care program is meant to remove this barrier by providing subsidized day care through a system of vouchers that can be used at any of 2,000 day care providers in Massachusetts. Voucher day care is the primary support service for DPW's Employment and Training (ET) program and is critical to its success.

Services Offered: Offers access to licensed day care through child care centers and family day care homes which are enrolled in the program. When an individual is scheduled to begin a training program and has chosen a day care provider, a voucher can be issued immediately, preventing delays in participation.

Eligibility: To be eligible for Voucher Day Care, recipients must be ET participants and ET graduates during their first year of employment. After this critical first year, the long-term day care needs of many ET graduates are met through the Department of Social Services extended voucher or contracted day care system.

Application/Referral Process: During the development of an employment plan, DPW staff associated with the ET Program assess the child care needs of the client and refer those who will need Voucher Day

Care while participating in ET to the Voucher Management Agency located in welfare offices. Agency staff interview clients to determine their specific day care needs and preferences, counsel them about the range of child care options available, and issue vouchers once clients choose a provider.

Flow of Dollars: Clients participating in the voucher day care program must pay a small fee toward the cost of voucher day care services. This fee is consistent with the sliding fee scale established by the Department of Social Services for the contracted day care system. The fee is paid directly to the day care provider and varies with a client's income, the type of day care arrangement, family size, and the number of children receiving care. In FY88, parents with children in voucher day care will pay and average of \$22 per month, or \$264 annually, in fee. The remaining amount of money is paid by the Department to the day care provider. In FY89, the Department projects the annual voucher day care direct service cost to be approximately \$4,095 per child.

Level of Consumer Choice: The ET client may choose any day care provider as long as the provider is known to the voucher management agency. All Voucher Day Care Programs are registered with the Office for Children. The geographic location (near work or home), ages of children served, and type of day care arrangement all influence the decision.

Source of Funding: Projected expenditures for FY88 will total some 37 million. State funds cover nearly the full cost of the program, since the amount the federal government reimburses the state for the program totals approximately \$2 million. This program is an 07 account.

Number Served: The number of children served in the voucher day care program has increased dramatically since the program was initiated in 1984. The average number of children served each month in the voucher day care program has increased by 304% from FY84 to FY88--from 2,323 to 9,388.

References: Department of Public Welfare, Budget Narrative FY89

# Office for Children (OFC) (Two Programs)

# 5. Help For Children (Individual Kid Money)

Program Overview: OFC's Help for Children (HFC) Program (aka, Individual Kid Money) is a comprehensive information, referral, and advocacy program for children. Designed to keep children from "falling through the cracks" in the system, HFC assures that every child (aged 0-18 or 0-22 years for children with special needs) receives appropriate social, health or financial support services when he or she needs them.

Services Offered: Information referral and advocacy are two primary services offered. In some cases, a family will call HFC in need of a service because cannot get service through another source. The area Child Advocate will try all available sources and if none come through with funding of services, HFC may use its Individual Kid Money (IKM) to purchase services. This is only in those emergency instances where service cannot be provided by other agencies. Services purchased range from basic needs, specialized equipment, transportation and respite care.

Eligibility: Any family with a child aged from 0-18 or 0-22 years if child has special needs is eligible for services from HFC if there is an emergency situation and no other agency can come through with funding. For example where a family cannot pay the fuel bill for the month and has exhausted all other sources of funding, the area Child Advocate presents the case to the regional office, and in most cases, the request for funds to pay the bill may then be approved.

Application/Referral Process: When area-based HFC staff are unable to find services for a child, the case is referred to the Interagency Team. Cases that require Team intervention generally involve the state's most troubled, sick or needy children. As a result of HFC and Team activities, state agencies were able to clarify their responsibility for providing particular types of treatment.

Flow of Dollars: OFC contracts with the appropriate service provider. The service provider bills the OFC who in turn pays the service provider.

Level of Consumer Choice: The services provided through OFC in emergency situations are very flexible offering families a significant amount of choice over the source of the supports in question. There is no limit to the number or type of supports that may be secured. The services provided, however, can only be offered in response to emergency situations where no other source of funding is available for the family.

Source of Funding: This is a 100% state-funded program. This program is an 07 account under individual kid money. The account is under a blanket contract where services are rate set and OFC has to follow their guidelines. Some are considered goods (i.e., fuel bills) and therefore these services are not rate set. For the most part, the program is treated as an account, although there is also an 03 account which is allotted for legal services.

Number Served: In FY86, HFC 43 area-based child specialists logged over 94,870 calls from parents, human service professionals, and children seeking information or help in locating and obtaining services. Of these initial contacts, 7,321 required the intervention of HFC staff for resolution. Just over 86% of these cases involved children, with the remainder involving families as a whole. Of all HFC advocacy cases, more than 40% involved children who needed help in obtaining special education services. Nearly three-quarters of the children served by HFC have some form of physical or psychological problem.

References: M.G.L.A. 28a, FY88 budget under field operations, line item for Help for Children.

# 6. Affordability Scholarship Assistance Program

Program Overview: The Affordability Scholarship Assistance Program (ASAP) is a one year pilot project to provide day care scholarship assistance to working families whose income falls between 71 and 100% of the state median income and who do not receive any other day care subsidies or assistance.

Services Offered: ASAP will pay a percentage of the day care provided, where:

- o The day care centers, or family day care home is licensed by the Office for Children, and;
- o The provider currently participates in or will agree to join the DSS Voucher Day Care System

Eligibility: There are eligibility standards that pertain to both parents and children. Parents must meet one or more of the following requirements:

o Working or starting a job;

- o Seeking employment (scholarships would run for 6 weeks/30 days);
- o Training to become more employable (does not include DPW E/T Program);
- o In high school full-time or a high school equivalency program;
- o Pursuing full-time vocational training to obtain a specific skill necessary to become more employable;
- Not receiving any other state day care subsidy, scholarship,
   employer -supported child care supplement: or
- o Income falls within the guidelines set by OFC.

The child must meet the following criterion:

o The child must be currently enrolled in or will be enrolled in an infant, toddler, pre-school or after-school program (day care center or family day care home) full or part-time.

Application/Referral Process: The parent completes a form for each of the children currently enrolled in or who will be enrolled in a day care program. However, there is no guarantee that the child be selected to receive a scholarship as the selection is done on a lottery basis.

Flow of Dollars: Providers receive the scholarship funds from their local Voucher Management Agency. The agency receives a check for the cost from Office for Children. The cost of day care per week is:

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$49 or less 20% is paid by scholarship ($10 per week)
$50 to $99 30% is paid by scholarship (from $15 to $30 /wk)
$100 to $159.50 40% is paid by scholarship (from $40 to $64 /wk)
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Level of Consumer Choice: The level of family choice is the same as for the Voucher Day Care. If the child is already in day care, the provider must be or agree to be registered with Office for Children and part of DSS' Voucher Day Care System. However, the family has the choice of what day care provider they want to be served by.

Source of Funding: This program is a 100% state-funded program and an 07 account.

Number Served: In the first year of this pilot program 305 families received a scholarship. Twenty-three of these families are no longer participating, leaving a total of 282 currently in the program.

References: FY87 outside section of the budget, established the Affordability Task Force.

# Commission for the Blind (MCB) (Two Programs)

# 7. Emergency Aid Assistance

**Program Overview:** The Massachusetts Commission for the Blind (MCB) is a state agency providing social and rehabilitation services to legally blind residents of all ages. Children from birth through age fourteen receive services from the Children's Service Workers. Emergency aid is offered to SSi blind recipients for special benefits.

Services Offered: The Commission may authorize payment for special benefits for SSI blind recipients. These circumstances and situations are the following pertain to either a disaster or moving:

- 1) Disaster -- The Commission may replace specific items of furniture, household equipment and supplies, food and clothing for SSI recipients when the loss of these items is the result of:
  - a) Natural disasters (i.e., flood, hurricane, tornado or earthquake);
  - b) Fire in recipient's dwelling which is beyond control of recipient The basic special benefits available in instances of disaster are:
  - a) Basic furniture (amount dependent on type of furniture)
  - b) Household equipment and supplies (amount of \$114.00 for the first eligible SSI family member and \$40.00 for an additional SSI family member, when applicable)
  - c) Food (not to exceed \$50.00)
  - d) Clothing (\$103.00 for each eligible SSI family member)
- 2) Moving -- The Commission may authorize payment for SSI recipients for moving expenses within the state, once in a twelve-month period. Payment not to exceed \$150.00 and one of the following conditions must apply:
  - a) Present living quarters has been certified to be unfit for human habitation by the local Board of Health;
  - b) Move to new living quarters is necessary due to health problems of the SSI recipient;
  - c) SSI recipient is moving into subsidized housing or housing for

elderly;

d) SSI recipient is forced to move because of fire, flood, or other natural disaster.

Eligibility: A person in the family must be legally blind and an SSI recipient to receive emergency aid from MCB.

Application/Referral Process: Authorization is ordinarily made by vendor payment but direct payment may be authorized if circumstances warrant.

Flow of Dollars: Proposals will be approved by Regional Directors/Area Supervisors. The worker will complete the necessary documentation at the time of submission of a proposal.

Level of Consumer Choice: The services provided through the MCB in emergency situations is very limited. There is a limit to the number or type of supports that may be secured. The services provided can only be offered in response to emergency situations where no other source of funding is available to the family.

Source of Funding: 100% medicaid funded. A 2040 account.

Number Served: (not known)

References: Indicated in the General Appropriations bill pertaining to MCB.

#### 8. Recreation Assistance

Program Overview: Limited funding is available for recreation to encourage participation in social activities. Recreation assistance is offered to families who have a legally blind family member and meet the income criteria.

Services Offered: Services received through recreation assistance may be an objective in the individual service plane. The recreation of supports sought may vary greatly depending on what seems appropriate for the individual. Besides recreational assistance, there is also a free after-school recreation program for legally blind children aged 3-12 in Boston. This program functions two days a week and free transportation is provided.

Eligibility: There is an income eligibility criteria in order to receive funding for recreational services. If a family is found eligible, they can make a selection of several different kinds of recreation.

Application/Referral Process: Recreation assistance is an objective in the individual service plan for the individual. An individual must apply and meet the income eligibility criteria.

Flow of Dollars: MCB will write a check to the service provider for those families deemed eligible for recreational services.

Level of Consumer Choice: There is a limited amount of choice in that the services offered are only for recreational purposes. Within recreation, however, there is a great degree of flexibility. The family can choose from a wide variety of recreation service (i.e. camperships, after-school programs, karate classes, Y memberships...).

Source of Funding: A mix of federal and state dollars under the social services block grant. A 2040 account.

Number Served: (not known)

References: Indicated in the General Appropriations bill pertaining to MCB.

# Department of Mental Retardation (DMR) (One Program Type)

# 9. Family Support Programs

Program Overview: DMR has established several family support programs around the state through contracted vendors. The purpose of these programs is to support the unique needs of families with a member (child or adult) with mental retardation or autism. The overall goal is to reduce family stress, provide supports through a wide range of services to families who have family member with mental retardation at home, and to prevent unnecessary out of home placement.

Services Offered: Vendors holding contracts with DMR may prioritize several services from a wide range of permissible services. Service priorities are based on assessments of local family needs and are reviewed by a parent advisory committee. For example services may include: transportation, respite care, adaptive equipment, or home health care. Services may be provided directly by the vendor, may be brokered from another state sponsored service, or may be obtained by the vendor through some private sector source. In all cases vendors are encouraged to utilize existing, local services and to facilitate family access to local generic facilities. Where no services exist locally the vendor can opt to deliver the service directly.

Eligibility: Any family who provide care at home to a person with mental retardation or autism may apply.

Application/Referral Process: Families request services directly to the area family support service vendor.

Level of Consumer Choice: Vendors are being encouraged to survey families in their region and to design services to meet the most pressing needs. Families are also represented in the parent advisory group which reviews service priorities. In this way parents have a substantial voice in service design and delivery, although parents do not always have full control over choosing the service provider. Vendors will attempt to meet all needs either through direct source provision or through use of generic services, vendors may not be able to provide 100% of the services requested by all families.

Flow of Dollars: Private non-profit vendors have contracts with DMR to provide family support services for a given area. Vendors can use their money to secure services for families and/or if necessary to provide services directly. Vendors have struggled with whether their contract is sufficiently flexible to deliver cash to families. The acceptability of such a practice is unclear.

Number Served: As the family support program is newly implemented the number of families who are served at this time is unknown. At the end of the year a count will be available.

Source of Funding: In the DMR budget, approved by the Massachusetts legislature, there is new funding allocated to family support services. The money is coming from general state revenue. Although there is no other specific statute pertaining to family support, the budget narrative describing family support has the power of a legislative act.

References: DMR budget appropriation statement.

## Department of Social Services

### 10. Respite Services

Program Overview: Respite services are designed to allow families time apart from the caretaking responsibilities of their family member with developmental disabilities in order to enhance family functioning. The program is presently administered by DSS but will be transferred to the Department of Mental Retardation in July, 1988.

Services Offered: Respite care is provided by a trained worker to families caring for individuals with developmental disabilities, in or out of person's home or in a respite care facility. The Department can provide up to 10 days of respite every six months. In some cases additional respite for a family may be approved.

Eligibility: Respite is available to all families caring for an individual with developmental disabilities as defined by federal legislation.

Application/Referral Process: There are 50-70 private non-profit respite vendors who have contracts with DSS to provide respite services. Vendors are available across the state and do not serve particular catchment areas. A family can apply for respite at any of these vendors. The vendor makes eligibility determinations.

Flow of Dollars: Regional DSS offices have contracts with local respite vendors to provide respite services. The amount of the contract is based on historical usage of the agency by families. The aim is to provide services to all families who are eligible and request services. Sometimes that is not possible, and the contract that the state has with a vendor is insufficient to cover all family requests. In other cases the vendor may only be able to offer a portion of the 10 days the family is eligible for, and/or the family may be referred to another vendor who has more "room".

Level of Consumer Choice: Families arrange with respite vendors the terms of the respite such as, when the days will be requested, how much advance notice is required, and whether out of home respite is necessary. Families can choose from any the contracted DSS respite vendors, however, they cannot arrange for their own independent respite workers.

Source of Funding: Most of the funding comes from general state revenue to the Department of Social Services. This program is treated as an 07 account.

Number Served: 4,200 individuals with developmental disabilities in FY-1986.

References: There is no state statute authorizing the respite program. DSS regulation 110 CMR sec. 7.50 pertains to the respite program.

## 11. Family Support Services

Program Overview: Family Support Services is a spectrum of services that supports the maintenance of the family unit and enables adults and/or children to meet the goals of the DSS service plan. Family Support Services are used to help strengthen the family unit, to decrease or eliminate the need for the placement of children into substitute care, and at times, to assist the family while a child is served in a transition home or through substitute care. The decision to use Family Support Services is made with consideration for the overall goals of the treatment plan.

Services Offered: Family Support Services include the purchase of items or services that provide social and developmental opportunities for a family and/or individual family members. In most instances, the services and/or items identified as Family Support Services will differ from those services/items which the Department already is able to purchase through established contracts or purchase agreements with provider agencies. Family Support Services does not include those services/items which already are accessible to clients through other state or community agencies or through other means (e.g., family's financial resources).

The following four categories provide a general description of the kinds of services/items which can be authorized through Family Support Services. The examples included under each category heading are not intended to represent an exhaustive list.

### Category I: Educational/Developmental and Skill Building

Family camping accommodations;
Music and dance lessons and instrument/equipment rental;
Diet and other health or skill improvement classes;
Trips and admissions to cultural, scientific, educational and recreational events/displays; and
Similar opportunities which promote enhanced family functioning.

### Category II: Membership Fees and Dues

Clubs (e.g. YWCA; YMCA; school teams);
Uniforms or equipment required for participation
(e.g. Scouts and scout uniforms); and
Church or community groups.

## Category III: Emergency/Crisis Services

Any service or item (not available to the client through other state or community agencies or other means) which is necessary to ameliorate a family crisis. For example, in the event of a housing catastrophe which represents a services need that does not fall within another agency's responsibility (e.g., DPW is responsible for eviction assistance), authorization for short-term use of an alternative family setting may reduce disruption and eliminate the need to place children in substitute care.

# Category IV: Community Services

Outward Bound, Parenting Partners, transportation, MBTA passes, "Substitute Care for Parents", or other services families which fall within the limits outlined above.

Family Support Services are provided on usually a one-time basis and authorized only after the specific service/item and the purpose or goal which it is intended to accomplish have been clearly defined in the service plan.

Eligibility: Any family who is receiving ongoing DSS case management services is eligible for Family Support Services if, in the judgement of the Department:

- o Family Support Services will strengthen the family unit and decrease or eliminate the need for placement of children into substitute care.
- o The family is able to demonstrate a willingness to participate in goal setting and achievement. The family is able to effectively use the services offered for problem resolution, as determined by the Social Worker.

Family Support Services are used to support the family's effort to accomplish service plan goals and the specific service (or item to be purchased), reasons/goals and parameters for use must be stated in the family's service plan. Family Support Services can be authorized only after having been directly identified in the existing service plan. They should be made available to as large a portion of the area's service population as will benefit from them within available resources.

Application/Referral Process: The local DSS social worker, together with the client identifies the specific service/item to be provided. A statement is prepared for the service plan regarding the specific service/item, reasons/goals and parameters for use. An application and the service plan is forwarded to the Area Director and then to the Regional Director for approval. There are procedures for emergency/verbal authorization of payment.

Flow of Dollars: Once the application is approved the Regional Operations Managers authorizes payment and issues the check and tracks all payments. All authorizations are made prior to the purchase of the service/item. In all cases the check is issued in the name of the person/agency who is providing the service/item. Where that is not possible the check is made payable to the Area Director/designee who will assist the Social Worker in accomplishing the purchase of the designated service/item. In no case is payment for the purchase of a service/item authorized in the name of a client or social worker.

Level of Consumer Choice: Family members work with their family case manager to design a service plan which specifies how the family support money will be used. Services can be widely interpreted and are not limited to pre-approved vendors of service or types of service. Services are designed to achieve specific goals. Money used for ongoing needs or to enhance family financial status would not be considered appropriate.

Source of Funding: Under further study, but is treated as an 07 account.

Number Served: (not known)

References: DSS policy paper #86-013 has been issued regarding the Family Support Services program. This program has been created internally in DSS and is not specifically authorized in state statutes. It is specifically appropriated in the budget.

## 12. Adoption subsidies

Program Overview: The purpose of the adoption subsidy is to encourage families to adopt special needs children, or to enable families to achieve permanent situations for children who would not otherwise receive appropriate adoptive placement.

Services Offered: Monthly cash subsidies are given directly to families who have adopted children with special needs. The subsidy varies by the needs of the child but cannot be greater than the foster

care payment. The Subsidy is given to aid the general support of the child. A quarterly clothing subsidy is also available to some families in addition to the subsidy.

Eligibility: All families who are providing substitute care for children under age 18 with special needs through DSS are eligible for the subsidy if adoption is the legal plan for the child and once adoption is legally consummated. Family income is not taken into consideration. Special needs of the child may include: physical, mental, or emotional disability; significant ties to foster parents that would adversely affect child's development if not adopted by them; twelve years of age; racial or ethnic factors. The size of subsidies vary by the specific needs of the child and the family's circumstances. When this specific need is no longer present the subsidy may be discontinued. Subsidies are reevaluated every year. For some families it is understood that the needs will be on-going. Families are not required to show receipts or otherwise account for how they have spent the money. Though it must be clear that the child's needs are being met. At the time of reevaluation, the family must document the child's on-going special need.

Application/Referral Process: Families apply for adoption subsidy directly with assistance from their DSS worker. The social worker will complete a general diagnostic report describing in part the child's special needs and current condition. The report and application is submitted to the Regional Director for final approved.

Flow of Dollars: Checks are administered through the central office of DSS and are mailed directly to families.

Level of Consumer Choice: There is no departmental oversight as to the particular service provider or goods the family may purchase to meet the service and regular care needs of the child.

Source of Funding: Funding comes from a combination of state (+ 90%) and federal (+ 10%) dollars. The federal support derives from P.L. 96-272 "Adoption" Assistance and Child Welfare Act of 1980." The program is treated as an 07 account.

Number Served: There are currently 2,385 subsidized adoptions in Massachusetts.

References: GCL chapter 188 sec.21. Department regulation 110:CMR Section 7.209.

### 13. Foster Care Subsidies

See sections 13a. and 13b. for a description of supplemental reimbursement programs providing cash payments above and beyond the basic foster care payments described below.

**Program Overview:** Foster care payments are made to the families who provide foster care services to children who are in the care and/or custody of the Department of Social Services.

Services Offered: Monthly cash payments are made to families based on the child's age. Recent increases in the foster care rate incorporate the cost of general recreation and transportation. Payments provide for the food, shelter and other needs of the foster child. The foster care rates are based upon the standards set by the U.S. Department of Agriculture for the cost of child rearing in the Northeast.

Eligibility: Families who are interested in becoming foster families must participate in a comprehensive evaluation and training program.

Applications/referral process: Once a child is placed in the approved foster home, the social worker completes the Authorization form to generate payment. The Department utilizes an automated payment system.

Flow of Dollars: Monthly checks are administered through the D.S.S. central office and sent directly to the foster parents.

Level of Consumer Choice: The foster family has complete discretion over of the use of the cash payment. D.S.S. conducts annual foster family re-evaluations in addition to the on-going support and monitoring provided by the area office social work staff.

Source of Funding: State general revenues -- 07 account.

Number Served: There were 6,953 children (ages 0 tol8) in foster care placement in July, 1988.

References: D.S.S. Monthly Report -- June/July, 1988.

## 13A. Extraordinary Out of Pocket Expenses

Program Overview: In addition to their regular payments, foster

parents may be reimbursed for exceptional yet essential out of pocket costs incurred on behalf of their foster child or children.

Services Provided: Examples of extraordinary yet essential expenses are: 1) medical expenses not covered by Medicaid; 2) additional laundry expenses for an enuretic child; 3) extraordinary transportation expenses; 4) fees for after-school recreational programs.

Eligibility: All foster parents who incur extraordinary yet essential expenses as a result of their foster child's or children's needs are eligible. Determination of need is based on the specific needs of the child as stated by his/her service plan.

Applications/referral process: Requests for payment must be preapproved and are typically determined in advance by the foster parents and social worker. All claims for reimbursement must be accompanied by a receipt or other verification. All requests require Central Office/Commissioner's approval and are submitted through D.S.S.'s authorization system. This system can review and approve or deny requests and issue payments directly to foster parents.

Flow of dollars: Reimbursements are administered through D.S.S. central office and are paid directly to foster parents.

Level of consumer choice: The requirement of preapproval and definition of expenses as extraordinary yet essential dictate a limited level of consumer choice. Again, all reimbursable costs are determined by the needs of the child.

Source of Funding: This program is funded under the D.S.S. Foster Care budget and is an O7 account.

Numbers Served: Approximately 437 children were served in this program in the month of July 1988. There is some variation in service demand from month to month.

References: D.S.S. Guidelines for Supplemental Reimbursement.

13b. PACT

**Program Overview:** Hourly reimbursement of \$7.50, beyond regular foster payments, is provided to foster parents who provide planned, specialized services designed to address identified needs and defined goals in their foster child's service plan.

Services Offered: Examples of PACT services for which parents may be reimbursed include: 1) teaching an adolescent mother independent living skills and the basics of child care/parenting skills; 2) supervision of visitation between foster children and their biological family; 3) the provision of physician prescribed care by a medically trained foster parent -- physical therapy/range of motion exercises, feeding through a gastro-intestinal tube, suctioning.

Eligibility: Participation in the program is determined by the needs of the child as indicated in his/her service plan and the foster parent's ability to provide the special services to address those needs.

Application/referral process: The PACT team comprised of the child's social worker, foster parent and family resource worker review the child's needs as indicated in his/her service plan and determine the specialized PACT services to be provided. All PACT requests must be approved by the Area Director. PACT services of more than 7 hours per week must also be approved by the Regional Director. PACT services of more than 20 hours per week must be approved by the Deputy Commissioner.

Flow of Dollars: Through the D.S.S. authorization system described in section 13a., payments are made directly to parents.

Level of Consumer Choice: Foster parent reimbursement is made for the specialized services provided. The child's needs as identified in the service plan determine the services required. The PACT team works together to develop the PACT plan.

Source of Funding: The program is funded through the D.S.S. foster care budget and is an 07 account.

Number Served: In the month of July 1988, 377 children were served in the PACT program. There is some month to month variation in the demand for service.

References: D.S.S. Guidelines for Supplemental Reimbursement.

#### Massachusetts Rehabilitation Commission

## 14. Maintenance Program

Program Overview: Maintenance is a supportive rehabilitation service provided to enable an individual to participate in, and derive the full benefit of, other needed vocational rehabilitation services. Payments are provided at any time from the date of initiation of vocational rehabilitation services through the provision of postemployment services. This is a limited service for use when the circumstances of providing a vocational rehabilitation program service require assistance to the client in meeting the extra costs of food, shelter, clothing or subsistence. It is not a service intended to reduce or eliminate poverty or to upgrade an individual's living conditions.

Services Offered: Maintenance may be provided in amounts not to exceed the estimated costs to the clients for subsistence which will be caused by the client's involvement in the rehabilitation process. Maintenance may be paid when the benefit of the needed vocational rehabilitation service would be lost or severely reduced without this support. The maximum amount an individual may receive is \$100.00 for maintenance.

Eligibility: An individual must be 16 years old or over. In order to receive maintenance services as part of a vocational rehabilitation plan, an individual must be found eligible for such services pursuant to the Commission's economic need criteria. However, whenever maintenance is provided because it is needed in order to enable a client to participate in a diagnostic and evaluative service, these economic need criteria do not apply. The following criteria must be met in order to receive maintenance services:

- o The vocational rehabilitation program increases the cost of subsistence for the client.
- o Similar benefit resources have been considered and are not available.
- o The value of the rehabilitation services would be lost or reduced without the support of maintenance.
- o The Individualized Written Rehabilitation Program (IWRP) describes the required maintenance in terms of its purpose, costs, and the period of time during which it will be needed.

Application/Referral Process: Maintenance is a service, along with other services, provided only after consideration of financial need. To determine the financial need of an individual, a client will fill out an application on financial need. Included is: medical coverage, assets, weekly resources, weekly financial requirements, and determination of MRC financial participation.

Flow of Dollars: Depending on the circumstances, maintenance may be paid directly to the individual, to the parent or legal guardian of the individual, or to a facility, institution or agency providing maintenance services to the individual.

Level of Consumer Choice: Maintenance can be used for those expenses that are increased due to the participation in a vocational rehabilitation program. Payments are provided to cover an individual's basic living expenses, such as food, shelter, clothing, and other subsistence expenses. Therefore, there is a limited amount of choice in how maintenance is to be used.

Source of Funding: The federal share of revenue for vocational rehabilitation services is 80% and the state matches with 20% of the funding. In FY86 \$460,000 was appropriated for Maintenance. This is a 00 (4120 0020) federal account.

Number Served: 471 clients in FY87.

References: 107 CMR 24.00 - Maintenance Services; Massachusetts General Laws, Chapter 6, Section 75.

# 15. Transportation Services:

**Program Overview:** Transportation is a supportive service which contributes to the individual's ability to receive the benefits of other vocational rehabilitation services. Transportation services may be furnished in connection with any rehabilitation service during the rehabilitation process from diagnostic evaluation through postemployment services.

Services Offered: Transportation costs may include:

o Fares or travel costs associated with using public or private vehicles for an individual to participate in a rehabilitation program.

- o Transportation costs for escorts, if necessary.
  - o Relocation and moving expenses.

In selecting the mode of transportation to use, the counselor should consider the individual's capacities to function independently, and the availability and costs of the transportation.

Eligibility: An individual must be 16 years old or over. In order to receive paid transportation services an individual must be found eligible for such services pursuant to the Commission's financial need criteria. Whenever transportation services are provided because they are necessary to enable an individual to participate in a diagnostic and evaluative service, a counseling and guidance service, or a placement service, these financial need criteria do not apply. Transportation services may be provided only when the following criteria have been met:

- o The vocational rehabilitation program increases the cost of transportation for the individual.
- o The value of the rehabilitation services would be lost or reduced without the support of transportation services.
- o Similar benefit resources have been considered and are not available.
- o The case record describes the required transportation in terms of its purpose, costs, and duration.

Application/Referral Process: Maintenance is a service, along with other services, provided only after consideration of financial need. To determine the financial need of an individual, a client will fill out an application on financial need. Included is: medical coverage, assets, weekly resources, weekly financial requirements, and determination of MRC financial participation.

Flow of Dollars: Transportation may be paid directly to the individual, to the parent or legal guardian, or to a private vendor or other person providing transportation services.

Level of Consumer Choice: There is a choice as to what kind of transportation services may be used to the individual. Public transportation is often the least expensive type of transportation and should be used whenever available and appropriate.

Source of Funding: The federal share of revenue for vocational rehabilitation services is 80% and the state matches with 20% of the funding. In FY86 \$1,003,000 was appropriated for Transportation. This is a 00 (41200020) federal account.

Number Served: 2,734 clients in FY87.

References: 107 CMR 25.00 - Maintenance Services; Massachusetts General Laws, Chapter 6, Section 75.

### 16. Emergency Small Cash Loans within Independent Living

**Program Overview:** Emergency cash loans through independent living are provided to individuals with disabilities to help lead independent and productive lives in the community.

Services Offered: In some cases there are no available funds for a needed service. A "team advocate" will try all available sources and if none come through with funding, the independent living center may help the individual. For example, an emergency loan may be offered if the individual locates an apartment but does not have the first month rent. The independent living center will lend the money as to enable the individual to rent the apartment. In other cases, the Independent Living Center will give a small cash grant to the individual where there is no payment due.

Eligibility: An individual must have a disability and be 16 years old or over. Such individuals, who demonstrate the need, motivation, and capability to live more independently, are eligible for independent living services. To further qualify for emergency cash assistance, an individual must have a need for a service where funding is not available through any other sources.

Application/Referral Process: If an individual with disabilities needs financial assistance in order to receive some service, an advocate will work with the individual to try to get funding from other agencies, community resources, or religious organizations. If none available, the Independent Living Center may assist the individual with a cash loan.

Flow of Dollars: Where there is a cash loan, the money is given directly to the individual. The Independent Living Center prepares some type of payment agreement with the individual.

Level of Consumer Choice: Consumers may exert a great amount of discretion over the selection of a service provider.

Source of Funding: In the rate setting form 600B, there is a line item which each Independent Living Center can appropriate money for emergency cash loans. This is optional and does not have to be done. The Boston Independent Living Center seems to be doing this the most out of all Massachusetts centers. The amount that is appropriated is small, approximately \$500.00.

Number Served: In the Boston Independent Living Center, there were approximately 15-20 persons who were given cash loans in FY87.

References: Center for Independent Living Brochure.

# Selected Comparative Analyses

In this section, two figures are presented. Figure 3 displays each of the previously described 16 programs and the essential elements of each. Upon review, the following observations are made:

- o There is a great amount of variance in program design and implementation. For instance, eligibility criteria vary so that taken together most disabilities and age groups are covered, but most programs accommodate only certain disabilities or ages. Thus it is likely that some families in need of a particular program may not qualify for admittance or the programs for which they do qualify may not offer the specific services needed.
- o The flow of dollars generally moves from the state agency to the service provider (not necessarily a state contracted vendor). There are, however, instances where the dollars flow directly from the state to consumers, who in turn, pay the provider.
- o The level of choice accorded consumers in choosing the service provider is typically restricted in that the consumer must choose among previously approved providers. There are, however, exceptions where the consumer is free to solicit and obtain the services of a provider of their own preference.
- o Nearly all the programs are listed as "07" accounts. These include programs where goods (as opposed to services) may be purchased without following previously set rates.
- o Much of the funding for these programs stems from state revenue only, though several incorporate federal revenue as well.

Overall, however, the most striking observation pertains to the great variance in program design and practice. It appears that, pending approval by the legislature through statute or the budget appropriations process, decision makers at the state's human service agencies have great latitude in how they seek to fulfill their mandate. For instance, there is frequent precedence for meeting unique family or child related needs that cannot be accommodated through the existing service system by paying community providers directly. In such instances, the rate setting provisions applicable to a great number of services is often bypassed. Likewise, the level of choice accorded consumers in choosing a service provider also varies by program, though there seems to be an emerging emphasis on encouraging consumer choice to the extent possible.

FIGURE 3: 16 PROGRAMS AND THEIR ESSENTIAL ELEMENTS

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FIGURE 3 (CONTINUED)

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Figure 4 lists the 16 programs and the supports made available within each. Taken together, there is a great range of services available, but:

- o a family may not be provided the service it needs because it is not offered by the particular program in which it is participating, or is not available altogether,
- o the services received by individual families, may be restricted due to limits placed on the amount of service permissible (e.g., respite, housing adaptations) or the providers that may be used, and
- o relatively few programs are designed to accommodate unique needs, with most focusing on a few pre-set services.

Again, this figure suggests that in several cases decision makers can exercise discretion over the supports made available. More importantly, however, the variance among programs shown here and in Figure 3 above suggest that, given cash, families may be hard pressed to negotiate the system wisely on their own. With so many programs offering "a piece of support" based on varying eligibility criteria and administrative practices, families could well profit from a specialized "family agent" to help them make greatest use of both those supports already available and whatever cash they receive.

FIGURE 4: 16 PROGRAMS AND THE SERVICES OFFERED BY EACH

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- 1. HOME HEALTH CARE SERVICES
- 2. ADAPTIVE HOUSING PROGRAM
- 3. HOME CARE FOR DISABLED CHILDREN
- 4. VOUCHER DAY CARE
- 5. HELP FOR CHILDREN
- 6. AFFORDABILITY SCHOLARSHIP ASSISTANCE PROGRAM 14. MAINTENANCE PROGRAM
- 7. EMERGENCY AID ASSISTANCE
- 8. RECREATION ASSISTANCE

- 9. FAMILY SUPPORT PROGRAMS
- 10. RESPITE CARE PROGRAM
- 11. FAMILY SUPPORT PROGRAM
- 12. ADOPTIVE SUBSIDY PROGRAM
- 13. FOSTER CARE SUBSIDY PROGRAM
- 15. TRANSPORTATION PROGRAM
- 16. INDEPENDENT LIVING PROGRAM

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