

MASSACHUSETTS COMMISSION FOR THE BLIND
Annual Flexible Family Support Plan
State Fiscal Year 2006

BACKGROUND:

The Massachusetts Commission for the Blind (MCB) was founded as the Division for the Blind in 1906. There has been a long history of the consumer having personal choice. This is a dynamic and ongoing process.

The Commission for the Blind has two mandates:

- To ameliorate the conditions that, are the result of legal blindness. There is no age limit of any kind.
- To keep a register of all legally blind persons in the Commonwealth. If a person is legally blind, eye care professionals are mandated under Chapter 6 Section 136 to report this in writing to MCB.

At any given time, there are around 35,000 (Thirty-five Thousand) registrants. The ages range from infants including newborns, to those who have passed the century mark of life.

A legally blind person has different needs at various times in his or her lifespan. What is needed to ameliorate the conditions related to blindness is very individual-specific. Obviously, a child will have different needs than a middle-aged, gainfully employed person or an elderly person. A person who has no vision or only light perception will have different needs than a person who has residual vision. A person who has been legally blind since childhood has different needs than a newly blinded person who is an adult.

MCB which is often characterized as a one-stop agency designed to meet all of its consumer's needs, considers Flexible Family Support another approach to serve our consumers. It has provided MCB counselors the opportunity to think outside the box when working with the consumer to find a solution, a possibility; to find a way.

The blind community in the Commonwealth, as well as, nationwide, has a history of strong advocacy. An example of this effective advocacy is the fact that legally blind persons are allowed higher income limits for SSI Blind eligibility and receive a higher benefit than other persons with other disabilities.

MCB has always sought, and received strong input from the blind community and has been very responsive to the suggestions, recommendations and counsel that

have been made over the century. MCB has a long-established and active network of both regional (local) and statewide Advisory Councils, that, serve as the primary consumer-led forums for MCB to regularly engage with blind persons of various ages and aspirations, as the agency seeks to creatively and successfully meet its consumers goals and aspirations, as well as its basic needs.

The formal advisory boards and the informal input from blind consumers have supported the idea of Flexible Family Supports. However, the most enthusiastic supporters of Flexible Family support have come from families of young registrants. These families of young children have made their need and support for Flexible Family support known to their child's MCB Children's Services Social Worker. Some families had, in the past, received Flexible Family support from other agencies such as DPH and DMR; others were aware of the program through information they got from other parents who have children with disabilities.

Most of MCB's registrants are elderly. Less than 5% of the registrants are children. Legal blindness is a low incidence disability for children. Approximately 40 % of the children who are registrants have additional disabilities; many are very medically fragile; many (approximately 12 %) require skilled intrusive nursing procedures on a daily basis, e.g. are on some sort of life support system (vent dependent, on respirators, require oxygen, are G-tube fed).

One of the first things that the Children's Service Social Workers try to do for the family, is to arrange regular in-home supports through the MassHealth program. Some of the children receive regular MassHealth because of their SSI eligibility; others, who are over-income for SSI eligibility and regular MassHealth, are eligible for and receive MassHealth through the Kaileigh Mulligan Program. Still others, who are less involved, can receive MassHealth through the sliding fee program, CommonHealth.

MCB has, historically, provided these families with respite, in addition, to their in-home supports funded by MassHealth. These children cannot be left with their grandparents, neighbors, or family friends because they need specialized care. Due, in part to, the nursing shortage, many families of these children are really limited in their ability to participate in family, community, church or temple activities and in being able to maintain their jobs. MCB continues to have traditional respite as a service for families.

This coming year we are hoping to redouble our efforts to reach out to these harried families and assist them so that they may participate in the regional and statewide regional boards. Their input has always been sought by their MCB

counselors, but the participation of these families on an advisory board has generally been lacking due, mostly to the reasons just cited.

When MCB has been able to get parents to participate, their attendance usually lessens over time. The advisory boards represent the full range of consumers that MCB serves. Most (95 %) have adult issues and concerns related to jobs, technology, transportation and housing, for example. Most of the adults, who have been blind since birth or childhood, have not had experience with the very medically involved kids that MCB has served for the past few decades. Their experience and knowledge base comes from their own experiences and those of their legally blind friends as children growing up. Their perspective is that of a person who is "just blind". The blind community, MCB consumers are not a monolithic group, being able to remain in their homes, but all these issues are magnified and complicated.

FAMILY EMPOWERMENT:

MCB consumers live in a variety of families, some are a family of one, perhaps elderly and living alone, perhaps a young adult just starting out on their own; some are a family of two; others have children and grandchildren to care for; others who are young, live with their parents. Some who are adults who, are Deaf-Blind or have additional disabilities may live in group homes in the community.

MCB consumers have different ages, different races, different ethnic background, different religions, different cultures, different income levels, communicate in different languages (spoken, American Sign Language and Tactile sign language), have different educational levels, different cognitive levels, different health status, different levels of functional vision, different additional disabilities. The only thing they have in common is that, at some point in their life, they have been determined to be legally blind.

MCB provides direct services to its consumers in a variety of ways. All registrants are offered case management services from MCB counselors. Those who are of working age can receive Vocational Rehabilitation Services. Those who want to continue either to continue to work in their homes as mothers, fathers, homemakers can receive Rehabilitation Teaching from MCB Rehabilitation Teachers. Those who want to be able to travel safely getting to and from work, around their communities can receive O & M (Orientation and Mobility) from MCB Orientation and Mobility Instructors. Those who wish to learn to use the new technologies that will enable to continue to do their outside the home jobs are served by MCB Counselors, technology department and

Rehabilitation Teachers. MCB has a relationship with its consumers who choose to have services from MCB.

MCB is going to institute a series coffee get-togethers for parents of legally blind children throughout the state. At these coffees, which will held in each of MCB's six regional offices, the parents will get to meet and talk with various MCB staff and administrators. As always, there will continue to a dialogue between MCB and its consumers.

FAMILY LEADERSHIP:

MCB will continue to seek consultation from the regional and statewide advisory boards. We will try to increase participation of parents of legally blind children on these boards; to develop opportunities for families as a group to consult with MCB via coffees at regional offices. Hopefully, the natural flow, and give and take, of these activities will result in the development of evolving Family Leadership. And just as importantly, MCB will continue its ongoing dialogue with consumers. We will continue encourage each consumer to be empowered to make his or her own choices and decisions wisely.

FAMILY SUPPORT AND FUNDING

MCB consumers and the MCB advisory boards, recommended that any consumer who receives Flexible Family supports from MCB be able to receive funding only once a year. This is based on the relatively small amount of funds available and the large number of potential consumers that MCB serves.

The advisory boards and individual consumers have made it clear that they prefer that Flexible Family Support be there as needed, rather than an entitlement to receive every year. Most of the funding for MCB for social services comes from Title XX funding. Title XX has income eligibility criteria that must be applied for any purchased services. There are some exceptions that can be authorized by the Deputy Commissioner for Services; but in practice this occurs only in extraordinary circumstances.

MCB has a small amount of federal money that it receives from a grant for Independent Living housing and vehicle modifications. This money does not have income eligibility criteria.

For the past two years, MCB has striven to meet the needs of those they serve by providing funds through Flexible Family Support for those identified needs which are not part of the available services provided by MCB through the usual funding stream.

Based on consultation with MCB consumers, Flexible Family Support has been provided to as many consumers (and their families) as resources allow. Receiving Flexible Family Support is an option, but not a guarantee. The consumers who have received Flexible Family Supports have been quite pleased and relieved to have the assistance that helps most to remain in their homes happily and safely. Our goal is to continue to provide Flexible Family Supports to as many of our consumers as possible.

We have found that having the Independent Living money in Flexible Family Supports has allowed MCB and consumers and family members to avoid the state bidding process that is so costly and timely. We have been able to serve more people in need of housing or vehicle modifications with the same amount of money. Families are empowered to seek the information on the product or modification that they need, to get the best price and to hire whom they want to.

ACCESSING SERVICES AND SUPPORTS

Any legally blind person who is registered with MCB is eligible for case management services, which includes:

- Support Counseling
- Advocacy
- Talking Books
- HP Placards
- Consumer ID and Travel Pass

Additionally, there are specialized programs for children(Children's Services), adults who wish to be employed (Vocational Rehabilitation), adults who wish to learn how to care for themselves and their homes (Rehabilitation Teaching), adults who wish to learn to travel safely (Orientation and Mobility), those who wish to learn how to utilize the technologies that are increasing available to legally blind persons (Technology Department and Rehabilitation Teaching), Deaf-Blind, Deaf-Blind Retarded (A Deaf-Blind Unit) and elderly(Social Rehabilitation Counselors) and a small Independent Living Program.

As, legally blind persons age and have different needs that can be met by a different program responsibilities are transferred internally to the appropriate program.

Any one who is registered, and has an open case in any of the MCB programs is eligible for Flexible Family Supports. MCB counselors really get to know the consumers they serve. The consumers really get to know the agency and their counselors. Service Plans are developed and modified as needed. Flexible Family Supports is one of the services that MCB can provide.

CULTURALLY COMPETENT OUTREACH AND SUPPORT

For more than 10 years MCB has had a person responsible for reaching out to the various diverse communities in the Commonwealth. MCB supports diversity in its hiring practices. MCB has contracts with Catholic Charities for Language Interpreters to assist MCB counselors communicate with those that do not speak American English; contracts for American Sign Language Interpreters and counselors have access to the AT & T Language Line to communicate with consumers. Additionally, MCB's training unit contracts to train staff to become more culturally competent.

INTERAGENCY COLLABORATION

A requirement in the process that MCB counselors must follow when requesting Flexible Family Supports is that other funding sources be explored. With other state agencies, "cost-share" informal agreements have helped provide funds for families that meet eligibility criteria for two agencies (sometimes three). Additionally, funding sources such as community service clubs such as the Lions, Rotary, Knight of Columbus, Kiwanis are sought with the family's permission.

MCB is pleased to have a Flexible Family Supports program to offer to its consumers. We believe that we have a close one-to-one relationship with many of our consumers and that suggestions, requests, recommendations flow both ways in the communication between consumer and counselor. We have several regional and statewide advisory boards and we will redouble our efforts getting parents to participate.

We will be reaching out to families of legally blind children, by way of having coffees at our regional offices, where families can meet with various MCB staff and administrators and express their ideas and needs and to provide ongoing input as to how we can better serve them.