

A Brief Overview on the History of Chapter 171

The creation of Massachusetts Families Organizing for Change (MFOFC) and Chapter 171 were preceded by two events of consequence. One event was the establishment of the Family Leadership Series in Southeastern MA in 1991 followed in short order by a series in Western MA. The second event was the support of the Human Service Research Institute (HSRI) through a federal technical assistance grant that allowed HSRI to assist family driven advocacy groups to develop within certain states.

The first family leadership training brought family members together to network and start thinking about more effective support for families. At this training families were asked the question, “If family support were truly supportive, what would it look like?” and “Can you imagine better supports?” Families’ responses to these questions were:

Families want real choices. *Real choices would include control over the supports received and having agencies “Ask us how family support money can best be spent”.*

Families should be treated with respect. To understand what this means agencies need to understand that *families do not need to be “fixed”.* Families need access to information. Families should have the right to make decisions involving services provided to their family. Professionals should consult with families; families should not feel that they are consulting with “professionals”. Supports should be available for families to access but they should not be imposed on families.

Family support needs to be for the whole family. *Supports need to be available before a crisis arises rather than in response to a crisis.* Families need to be provided the opportunity to network with other families. These network opportunities need to be both formal and informal. For some families, the best form of family support may be cash assistance.

Families want to live ordinary lives. *Supports need to be more natural in form rather than only specialized service supports.* Families want access and use of community resources.

Two key philosophies of any family support program are that every family is different and no two people with disabilities are exactly alike. Support services that work for one family may not be what another family needs or wants. Family support services require flexibility and should be delivered so as to enable families and people with disabilities to meet their specific and unique needs.

The Individual and Family Support Bill (later to become Chapter 171) was created by MFOFC, a statewide, grassroots coalition of families with children and adults who have disabilities and/or chronic illness. The mission of MFOFC is to provide sustained advocacy and leadership training in pursuit of high quality, individualized community support and service options, including family support, for people with disabilities and their families.

There were problems along the way to the eventual passing of the Individual and Family Support Bill into Chapter 171 law. When the initial bill was being drafted in 1991, it addressed the 0-22 years of age population. As the development of the bill expanded, it was quickly realized that adults as well as children were in need of this legislative protection and therefore all individuals and their families were included in the draft.

During the 1992 legislative year, some lobby groups, educators (e.g.: residential schools), and unions were leery of the bill. With three powerful groups afraid of the legislation, MFOFC discussed the need to change it back to a “child” bill. Some felt that if this were done the bill would be easier to pass. The bill would be more easily understood and would eliminate some of the opposition that had been generated. The families decided to take a closer look at the opposition to determine what the barriers were and what could be addressed to overcome some of these barriers. The families did not want to compromise their beliefs for the sake of advice given by Special Action Committees that did not have the local voice at heart. Within the group there was friction and differing philosophies. In the end, MFOFC decided that this was the time to unite, to stay on track with their values, keep focused, build toward the future and not compromise the needs of adults for the sake of getting the legislation passed. Once MFOFC was united in philosophy they decided to meet with the various constituency groups to see if there was a feasible way to structure an adult and child bill.

As time passed, the law was rewritten and each time it was resubmitted the pressure to remove the “individual” component from the bill continued. MFOFC stayed firm and refused to make that change. When the bill eventually became law in June 2002, Chapter 171 included individuals; believing that every individual with disabilities and/or chronic illness and their family should receive the flexible supports they choose to enhance their lives. As stated in the law, *“Each department shall seek creative and innovative ways, within its existing authority and mandate for serving individuals with disabilities and chronic illnesses, to provide flexible supports.”* The goal of MFOFC to pass legislation that would encourage and facilitate the development of flexible and responsive supports for both families and individuals was achieved. Obviously, **the work ahead is for families and individuals to see this law implemented so that it does what it’s meant to do.**