“Celebrating Families: Many Voices, Many Choices”

DMR held an event at the State House on March 25, Celebrating Families: Many Voices, Many Choices, to culminate the Department’s observance of Mental Retardation and Developmental Disabilities Awareness Month. The theme of this year’s event was family support and numerous families from around the state were recognized for their outstanding achievements for being both creative and resilient in their role of supporting a family member with developmental disabilities.

Emily Murgo Nisenbaum, former chairperson of MFOFC, received the Gunnar Dybwad Award from DMR at the ceremony. The award is given in honor of the late Professor Dybwad, who, with his wife Rosemary, was an internationally renowned researcher and a tireless advocate for securing human rights for people with mental retardation and other disabilities.

Gerry Morrissey, the Commissioner of the Department of Mental Retardation, presented the Award to Emily. “Emily is a giant,” he said. “Her ideas, her energy, her organizing ability and her commitment to families are all ‘super sized’.

She is a passionate and strong believer in the capacities of families and she has been a tireless advocate for inclusive communities and for supports that are more flexible and responsive to the actual needs of individuals and families.” “Emily has been a bridge builder and collaborator,” commissioner Morrissey said. “She was a founding member of the Massachusetts Families Organizing for Change and served as their chairperson for 13 years. In this role she helped build an organization that provides essential information, leadership training and support to families all across the state. Families who have had the opportunity to participate in leadership training will comment that it was a ‘life changing event’ that provided them with inspiration and a sense of mutual support. She very much represents the legacy Gunnar has left behind.”

In acceptance of her award, Emily cited her daughter Amy as the key person in her life who gave her the courage and the strength to do what she does in her work. She also recognized her husband Louis, who has been there with her in support and who himself is a leader in the field of mental retardation services in the state.

Thank you Emily for all that you do for individuals and families all across Massachusetts and for your dedication and devotion to promoting positive public policy through your work with Massachusetts Families Organizing for Change.
Chapter 171 of the Acts of 2002

An Act Providing Support to Individuals with Disabilities and Their Families

After almost 11 years of advocacy by members of Massachusetts Families Organizing for Change (MFOFC), Chapter 171 of the Acts of 2002, An Act Providing Support to Individuals with Disabilities and Their Families, was passed into law on July 26, 2002.

Chapter 171 is not just about respite care! It’s about giving individuals with disabilities and their families a voice in crucial decisions being made about their lives. It’s about providing a variety of flexible home and community supports that help families stay together and help people with disabilities or chronic illnesses live outside of institutions.

The main components of Chapter 171:

- Agencies need to provide flexible supports – flexible supports are supports that are individualized for each individual and family’s needs and should not be pre-determined or decided upon without input from individuals and families.

- Agencies need to obtain substantial consultation – substantial consultation should be a combination of outreach to individuals, families and representative groups – to give the agencies input on needed supports and services as well as a review of proposed annual agency family support plans. Individuals and families should have opportunities throughout the year to give input.

- Agencies need to develop an Annual Individual and Family Support Plan after substantial consultation has been obtained. The plan needs to address how the agency will provide flexible supports for families and individuals. The plan needs to include goals on how the agencies will coordinate with other agencies to enhance and expand individual and family supports during the fiscal year. Each agency shall seek creative and innovative ways, within its existing authority and mandate for serving individuals with disabilities and chronic illnesses, to provide flexible support.

Once the plans are written by each agency they are submitted to the Governor, the Secretary of Health and Human Services, the legislative committee overseeing disability services, and the House and Senate Ways and Means Committees for review.

There is a timeline for obtaining substantial consultation and completing the plans. The date for final submission for the plans is August 1 of each year.
Massachusetts Families Organizing for Change
The Development of Chapter 171

Massachusetts Families Organizing for Change (MFOFC) is a grassroots advocacy organization comprised of people with disabilities and their families, allies, and supporters. MFOFC’s purpose is to engage in a wide array of activities designed to promote responsive, high quality, flexible and individualized community supports and services that are family or person centered. MFOFC’s objective is to lead in the ongoing process of positive systems change for people with disabilities and their families. This objective is being accomplished through Family Leadership training, along with technical assistance to state systems, alliances with other disability organizations and targeted legislative advocacy.

The premise for the development of the Individual and Family Support bill was information obtained from family members participating in the first SE Massachusetts Family Leadership Training. They were asked the question “If family support was truly supportive what would it look like?” and “Can you imagine better supports?” Families’ responses to these questions led to the development of what today is Chapter 171.

- Families responded to the questions with a variety of answers but the main ideas were:
  - Families want real choices for the supports they receive, they want a voice in what is offered.
  - Families want to be respected, do not need to be fixed – but do need support;
  - Families have the right to make decisions involving services provided to their families.
  - Family support needs to be for the whole family.
  - Family support needs to be available before a crisis arises.
  - Families want to live ordinary lives, receive natural supports, and have access to community resources.

This information and the motivation of families led to the development of MFOFC. MFOFC’s first action step was to develop a legislative agenda and draft a bill that would ensure responsive individual and family supports from all Massachusetts human service agencies serving people with disabilities. Collaboration with organizations that had similar goals was sought and the first bill was drafted and submitted to the legislature in 1992. After many revisions and much advocacy by families who were Leadership Series graduates and other interested parties, legislators finally passed the Individual and Family Support bill that was signed into law in July 2002.
What is Family Support?

Family support means different things to different families. Since the early 1980’s, an increasing number of states have begun to off at least some services to families of people with disabilities. And now, more progressive states deliver a wide array of supports and services that are:

- **Family driven:** Each family leads the decision-making process concerning the type and amount of support they receive;
- **Easy to use:** Families are not overwhelmed by paperwork and red tape; and
- **Flexible:** Families can choose supports and services based on their individual needs and preferences.

These family support programs make use of structures, services and supports, as well as informal or natural supports in the community. The idea is to provide *whatever it takes* for families of people with disabilities so that they can live as much like other families as possible. The supports that families receive need to be determined by the individual family based on their culture, values, preferences, and specific needs at any given time.

Providing useful support can involve any number of types of services and support. These supports might be aimed not only at the person with a disability, but at other family members as well. Also, it is important to remember that *it is not just what is offered to families, but how it is offered.*

The main goals of family support are:

- To keep families together until the person with a disability chooses to live independently;
- To enhance a family’s ability to meet the many needs of their family member with a disability;
- To improve the quality of supports to families while minimizing the need and the cost of out-of-home placement;
- To allow the family to participate in integrated leisure, recreational, and social activities; and
- To make a positive difference in the life of the person with a disability as well as the lives of all family members.
Quality family support programs should:

- Focus on the entire family;
- Change as the family’s needs, roles, and ages change;
- Encourage families to express their own needs and decide how their needs will be met;
- Treat people with disabilities and their families with dignity by respecting their individual choices and preferences;
- Respect cultural, economic, social, and spiritual differences;
- Encourage families to use the natural community resources; and
- Provide supports and services that are easy to find and easy to use

Potential Family Supports

*Centered Around the Person with Disabilities:*
- Diagnosis and assessment
- Therapeutic services
- Medical/dental services
- Home health care
- Recreational opportunities
- Special clothing and diets
- Transportation
- Adaptive equipment
- Housing adaptations
- Adequate health insurance

*Centered Around Family Members:*
- Information and referral
- Service coordination
- Temporary relief/respite
- Family counseling
- Parent/sibling education
- Day or family member care
- Financial assistance
- Future financial planning
- Mutual support groups
- Housing modifications
Massachusetts Developmental Disabilities Council
Chapter 171 Implementation Grant

After many years of hard work by board members of MFOFC, families and allies, Chapter 171 finally became law. After celebrating the successful passing of the law, MFOFC had to continue working to make sure the law was understood by all of the involved parties and implementation of the law was begun. With the support of MFOFC board members, a grant proposal was written and submitted to the Massachusetts Developmental Disabilities Council (MDDC). The grant was written with the following goals in mind:

- To collaborate with the Executive Office of Health and Human Service (EOHHS) agencies to develop supportive relationships with the staff responsible for implementing Chapter 171. This is to be done by providing consultation and technical support to help the staff understand flexible supports and assist in their efforts to outreach to individuals and families to ensure broad representation in the development of the Agency Support Plans.

- To build a coalition that will provide effective outreach and training at the grassroots level in order to raise awareness of Chapter 171 across the disability spectrum and to spread the word about the benefits of Chapter 171 to increase the availability of flexible supports.

- To ensure systems change by developing and implementing strategies to educate policy makers, providers, and the general public about Chapter 171 and the benefits of flexible supports. To work in partnership with other organizations to solidify the Commonwealth’s long-term commitment to flexible individual and family supports.

The grant was written with the expectation that this would be a multi-year project with progressive goals each year working towards the ultimate goal: To insure the proper implementation of Chapter 171 and to work toward the broader understanding, acceptance and utilization of flexible supports.

Make Chapter 171 Work For You and Your Family!

There are many ways to get involved with the implementation of Chapter 171.

- Contact the agency that provides services to you or your family member and request a copy of their Family Support Plan, review the plan and give feedback to the agency.

- Educate yourself on flexible supports and what they are so you know what you are able to request.

- Get involved legislatively; set up a meeting with your legislators, introduce yourself, let them know what challenges you face as an individuals with a disability or special health care needs or as a family member of a person with a disability or special health care needs.

- Contact MFOFC for more information on Chapter 171 and other current advocacy efforts.
While the Metro/Boston Region of MFOFC officers have continually and arduously worked towards the positive goals of MFOFC large, two conspicuously missing elements caused Metro/Boston a little out of sync with their co-regions: a consistently run Family Leadership Series, and a permanent part time regional coordinator. We’re glad to say both issues have been addressed in ways that greatly benefits the Metro/Boston region, and thus MFOFC as a whole.

In mid-March Anastasia Coulianos Mulvoy joined the team as a permanent part time Metro/Boston Coordinator, being the first to formally hold the “official title”, but very much the beneficiary of the tremendous amount of work and commitment that held MFOFC Metro/Boston together for so well and so long. Plenty of hard and dedicated work had been taking place in the long beforehand, mainly the planning of a new Family Leadership Series which well underway by hard work of Jean Palmateer, Tom Toranto and Cathe Carpenter. It was their determination and devotion that make reviving Metro/Boston region possible. The first weekend of the series was held on May 14-15, 2005 at the Westin Waltham Hotel.

The first weekend of May 14-15 focused on “Advocacy”. Participants learned more about the history and makeup MFOFC and Family Support by a presentation made by Jean Palmateer. The parents then went around the room and introduced themselves, telling as much of their story as they felt comfortable telling, but always enough to form a bond of recognition with someone in the room. They then had the change to hear a panelists of family members who had already gone through the leadership training, and were either receiving or were familiar with Flexible Family Supports. It was encouraging to see so many questions being asked -- everyone was thirsty for information. On the second day of the weekend, Deborah Reidy (a well-known private consultant on leadership issues at many levels), presented a workshop on “What it Means to Be a Leader”. This was a hands-on workshop with participants coming away with a better understanding of what makes a leader, the different forms of leadership ability, and the importance of having strong leaders in our community.

Judging by the evaluation forms fill out prior to participants’ departure on Sunday afternoon, the weekend was a success. The group was highly positive and passionate in the belief the Family Leadership Series can be a very useful tool in community. There were a few suggestions of what might be better in terms of logistics, but all appreciated what was gained that weekend. We’re sure our families’ enthusiasm will remain high during the next two weekends of the series, currently scheduled for September 17-18, and November 5-6. We are firming up last minute speaker details, but we do know Lyn Tonkin will be delivering an all-day workshop on Saturday, September 17th to designed to help participants develop a vision for themselves and their loved ones On Sunday, November 6 Mary Lou Maloney will join us in the afternoon for an informative and useful workshop on “Tools for Working with the Legislature.” As we continue to work to finding complementary speakers to enhance the weekend, we’re certain we are giving the families at the Leadership Series the very information and strength they’ve been seeking.

At the close of the weekend, several parents expressed an eagerness to jump right into the second workshop, and suggested proving them with an e-mail/phone list so they could be in contact one another before the next weekend. This is perhaps our biggest endorsement pointing to a successful workshop.
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