Welcome!

Welcome to the inaugural edition of the Massachusetts Families Organizing for Change statewide newsletter. In this edition you will find compelling, life changing articles, news, upcoming events as well as a history of MFOC.

Families Organizing for Change has grown tremendously since those early days back in 1991. At that time it was easy to stay in touch with all members with just a phone call or greeting card. Well, bow times have changed! With well over 1500 families and individuals on our mailing list, a phone call just is not practical.

That is why we created your MFOC Statewide Newsletter. We say this is your newsletter because you are the families and individuals who make MFOC so powerful. This is our way of staying in touch with you, while also giving you a forum to express your views.

If you are not familiar with Families Organizing for Change please read our mission statement and take a look at our goals. If your vision is one of individual and family empowerment and flexible, responsive, family support then please take a moment to complete the enclosed address form and you will be added to our mailing list.

If you want to find out more about our Family Leadership Series, legislative advocacy initiatives, or attending our meetings, please call you local Regional Coordinator or our toll free Statewide number (800 824-6946).

Our Mission

Our mission is the creation of a statewide policy and practice for individual and family support that listens to persons with disabilities and their families, values individuals with disabilities and their families, treats families and individuals with respect, and promotes attitudes and supports that maintain the dignity of families and individuals.

Our vision for individual and family support is one of empowerment that includes planning, choices and decision making.

Who We Are

We are a statewide, grassroots coalition of individuals with disabilities and/or chronic illnesses and their families. We believe that supports for individuals and families can be more responsive, comprehensive, and flexible and designed to respond to the actual needs people have.

We are actively organizing families to use the power of our numbers to effect the change.

We are the people who understand most deeply how effective services can assist in helping individuals with disabilities to achieve the best within themselves.

We also understand how inclusive community benefits us all. It is our goal to join together and Organize for Change.
and discuss their questions and concerns. We have taken these into consideration and have re-worked the legislation reflecting our responses to their comments while maintaining the integrity and content of the legislation.

The areas of clarification are as follows:

A clearer definition of “Individual and Family Support Plan” and “flexible supports” as called for in the legislation has been included. Also, clarification of the role of the individual and the role of the family when the individual is an adult. This makes it clear that adults with disabilities will make their own decisions unless they have a court appointed guardian.

The addition of language in several places that says that “Individual and Family Supports” are subject to appropriation and are not entitlements. It also clarifies that family support will come from “available family support allocations.”

A definition of “generic community services” was added.

Language has been added that “such plan will be guided by each agency’s mandate” in several sections to address the specific mandates and capabilities of each agency.

A recommendation that “following the original submission of a Family Support Plan, the plan will be UPDATED in the following years.”

The re-filed legislation has been expanded in scope to include the following: Massachusetts Commission for the Blind, Massachusetts Commission for the Deaf and Hard of Hearing, Massachusetts Department of Mental Retardation, Massachusetts Department of Mental Health, Massachusetts Department of Public Health, Massachusetts Department of Social Services, Massachusetts Department of Medical Assistance and the Massachusetts Rehabilitation Commission. It is our hope that the Commissioners of these Departments will indicate their support of this legislation to the Legislature thus removing one more hurdle to the passage of this vital legislation.

The legislation says that the Departments of Mental Retardation and Public Health must submit their initial plans within 150 days of the passage of this legislation. All the other state agencies named above have one year from the passage of this legislation to prepare to submit their plans.

MFOFC is currently developing strategies for the passage of “An Act to Support Citizens with Disabilities and Their Families.” One of these strategies is to continue to educate legislators about the importance of a mandate for Family Support. Another is to meet with the sponsors of the legislation and other key legislators to ask for their commitment to making this legislative session the one for passage. A third strategy, as mentioned earlier in this article, is to obtain a firm commitment from the Commissioners of the EOHHS agencies for their support of the legislation.

Copies of the re-filed legislation and further information can be obtained from the Regional Coordinators for MFOFC. You can also call your Regional Coordinator to ask how you can help with the passage of this important legislation.

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**Our Goals**

Members of Massachusetts Families Organizing for Change have written legislation to create statewide policy and practice for individual and family support. We have held conferences to inform and educate individuals, families and community members about advocacy, services, and local, state and federal resources.

Families Organizing for Change provides information and assistance to families; provides leadership training; and has regular regional meetings for families and individuals. Each Region of Massachusetts has representation at the statewide Steering Committee. We welcome all people who are interested in the issues we pursue and encourage new members to join with us.

- To secure the passage of legislation calling for more flexible home and community based supports
- To create an awareness of and to educate the members of our communities about the contributions of Individuals with disabilities and their families and the kinds of support they need
- To continue training for individuals and families in leadership and to develop a process toward empowerment for families and individuals throughout the state of Massachusetts to strengthen our ability to create change in the way support is provided to individuals and their families.

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"In the Beginning"

by Marianne Taylor

The late Elizabeth Monroe Boggs, a parent and an extraordinary leader in the field of developmental disabilities, reminds us of the importance of telling our shared history when she wrote: "A creature who lives only 6 hours can die believing that the sun always shines." To help us avoid the ignorant fate of this creature, I will take a moment on this rainy Sunday to trace the history of the Massachusetts Families Organizing for Change and attempt to anchor it within the broader history of supports for people with developmental disabilities in this country.

For me the story of family support begins with a personal reflection. I remember my parents daily struggle to manage a household of 4 children including my sister who was like a tornado (I have many memories from my childhood but an orderly household is not among them). Patrice was the youngest of our brood, and only escaped institutionalization (this was the mid 50's) because her metabolic disorder was not discovered until she was one-year-old and a treasured member of our family. Because I loved her so much, I like to think that my parents would have said "no" to an out-of-home placement even if they were aware on the first day of her life of her severe disabilities. But who knows? It was routine in those days for doctors to recommend institutionalization, and common for concerned and loving parents to accept this "expert" advice.

I remember my mother's strength and persistence in banding together with some other parents to pool their resources and pay for a special education teacher for their children (public schools did not yet provide the educational benefits secured under PL 94-142). Those early memories of the day-to-day challenges that are shared and solved through fellowship with other families have taught me the power of the family support movement. My parents and many others were pioneers in a tradition of change and mutual support that is the central organizing vision of Massachusetts Families Organizing for Change. Each generation takes up a new challenge, making it better for those who come after.

Most pioneers went west and so it was with the Massachusetts Families Organizing for change. In the early days (1991-92), we met in the distinguished meeting rooms of the "Budgetel Hotel" in Auburn, Massachusetts to shape our early agenda for policy reform. Families came together for many different purposes and reasons but everyone agreed that public resources for people with disabilities did not offer the kind of help people need in their homes. For example, at that time more than half of the budget of the Department of Mental Retardation was spent on supporting a small number of people in institutions. Almost a decade later, thanks to MFOFC and other advocacy groups including the Massachusetts ARC, this picture is changing.

Guiding the architecture of needed reform is the consensus vision articulated by the early leaders of the MFOFC and captured in the MFOFC Family Support principles that call for a "flexible array of supports to ensure that people with disabilities and chronic illness are able to live on their own or with their families in their community." This and other principles guiding our activities, demand a fundamental shift in how individuals with disabilities and their families are supported and provides an important centerpiece to the various family support bills MFOFC has worked to pass in the last 8 years.

Principle-based policy and legislative reform has been one of the primary contributions of MFOFC and other family groups across the nation. The kinds of legislation that families wrote and many states passed (Come on, Massachusetts!) is extraordinary for making its heartfelt philosophy explicit and binding! What families understood instinctively is that the failure to heed the heart, voice and spirit of families and individuals with disabilities led to the tragedy of institutionalization as the only systemic response for people in desperate need of help. So we raise our voices and our ideas in clearly defined principles to teach others what is important, indeed, to bind public action to be more responsive to the choices and dreams of people with disabilities and their families - as it should be!

Early support for MFOFC came from the Human Services Research Institute (HSRI) and the Massachusetts Developmental Disabilities Council (MDDC). Through a grant from the federal Administration on Developmental Disabilities (ADD), HSRI had funds to support the growth of grassroots family organizations throughout the United States. It was an

continued next page
Help to Sponsor John Nadworny in his Support of Family to Family

A Letter from John Nadworny

In 1998, through the efforts of families and concerned citizens, over 400 families were removed from the Department of Mental Retardation waiting list and are now receiving services. This year, we continue to share stories of families waiting for services and update you on the progress of Family to Family.

Funded through a three-year grant from the Joseph P Kennedy Jr. Foundation, Family to Family will end in June of 1999 without additional monies. Because this project has been so successful, dramatic steps must be taken to keep it alive. I will be taking on the challenge of participating in the Ironman USA, a triathlon consisting of a 2.4-mile swim, a 112-mile bike ride and a 26.2-mile run. This event will take place on August 15, 1999 in Lake Placid, New York.

Since the Ironman is considered the toughest multi-sport event, it is symbolic to use the challenge to seek pledges and corporate support. The event itself reflects the resilience and endurance exhibited by the families on the waiting list. However, there is a quantum difference between the two. There is a start and a finish to this one -day event. The Ironman will be conquered by following a regimented training plan and a never quit attitude. For families on the waiting list, no plan exists for their destiny and quitting is not an option.

It is our goal to provide these families the comfort of knowing that their family member will have a secure home in the community and a meaningful life. I hope you can become part of the effort in achieving our goal.

Please make your check payable to:
Family to Family
c/o Arc Massachusetts
217 South Street
Waltham, Massachusetts 02453

Your Support is Greatly Appreciated!

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...exciting time with families finding their voice and becoming a powerful tool for reform as many family groups passed groundbreaking family support legislation in other states. HSRI approached the MDDC to match the ADD funds and encourage the unification and growth of family leadership groups in Western Massachusetts, Uniting Families for Change and in the Family Leadership Network of Southeastern Massachusetts.

Since that time, MFOFC has gathered strength through a combination of extraordinary leaders, and with much instrumental support from key agencies that enables MFOFC to bring families together in Family Leadership training to become knowledgeable advocates for their family members and each other.

A key rallying force in our organization is our effort to ensure the continuity of the progress we have achieved by permanently embedding family supports in social policy through legislation. In this way, we can be sure that we provide a legacy to other families that will endure the shifts in leadership and philosophy that accompany political and governmental life that affects our families so deeply. Elected and appointed officials come and go, but families are forever. Let’s be strong and give the next generation the support they need to live fully and happily in their communities.

Editors note: people interested in a detailed overview of the family support movement nationally may want to consult the End of the Decade Status Report published by HSR.
Family Leadership Series

By Joanne Spencer

Nancy Reagan once said, “A woman is like a tea bag; you never know how strong she is until she gets in hot water.” Six years ago I became a tea bag, and my hot water was known as the Family Leadership Series. I was a single mom, bringing up three teenage boys. Two of my sons have disabilities, which made our lives a little more complicated than expected, but basically I thought we were doing okay. I went to the boys’ schools for their Team meetings, took them to a multitude of Doctor’s appointments each year, and attended my Parent Advisory Council meetings. I knew there was a much broader world out there, but wasn’t sure how to find my place in it.

I spent three weekends in 1993 with people like Michael Kendrick, Emily and Lou Nisenbaum, Jim Ross, and a group of the most wonderful, knowledgeable families I have ever met. I don’t even know who referred my name to the Series but I owe them a heartfelt thank you. By the end of my first weekend, this teabag was brewing!! I went home with my head spinning, I was ready to take on the world. By the end of my Series, people at home were starting to look at me strangely. Who was this woman and when did she start calling her legislators? The kids’ doctors and teachers began to look at me warily when I walked in, as if to say, “what idea does she want to share today?” It may sound to most people like the Leadership Series had created a monster, but in truth, it had given my children a stronger advocate, and given me a new sense of self-assurance and a renewed vision for my family.

Family Leadership has brought so many gifts to our lives. It has given me a support network of families all over the state that I turn to with my doubts, my fears and my successes. I no longer feel like I have to “fight the battles” alone; however, I know now that I CAN fight those battles if need be. The series gave me advocacy and negotiating skills, and showed me the way to use those skills effectively, without anger, but with conviction.

I work as a parent coordinator for the Family TIES program, which is a statewide support and information network for families of children with special needs. In my job, I talk to families every day. I think one of the greatest gifts I have been able to pass on to these parents is to teach them how to access services and supports by themselves. The empowerment this gives to families is so rewarding, and it gives me such pleasure to know that I can pass on what was given to me at the Leadership Series.

In my personal life, I use the skills I have learned constantly. For example, two years ago, my oldest son David turned twenty-two and was transitioning out of Chapter 766. David is a wonderful young man with an engaging smile and a great sense of humor. Dave also has autism. His transition year was probably one of the most difficult years of my life. Going from adolescent to adult services was so scary and nothing was going right. My Family Leadership family rallied around us, and gave us the support and the courage we needed to advocate for David to have the life he dreamed of. I can tell you that two years later my son is happier than he has ever been in his life. He has his own apartment, a wonderful supporting agency, and a part time job in a jewelry packaging firm that he absolutely loves. He has become part of his community—people greet him at the local restaurant and video store by his first name. A few months ago I was given the opportunity to come back to the Leadership Series and talk about what it had done for my life. I asked David if there was anything he would like me to tell the families I would be meeting about his new life. He grabbed his computer, gave me a quick smile and typed, “Tell them I’m happy, Mom.” No one has ever enjoyed a cup of tea as much as this mother has.
MFOFC Annual Meeting

by Michelle Harris & Dana Dansereau

Families and friends from across the Commonwealth joined together on Sunday, November 1 for the Massachusetts Families Organizing for Change (MFOFC) Annual Meeting and Brunch. The gathering was held at the Holiday Inn in Marlboro, and families representing all five regional chapters were in attendance. MFOFC President Emily Murgo Nisenbaum, Treasurer Lou Nisenbaum and Clerk Jim Ross gave their annual reports. Each shared some of their reflections on the humble origins of MFOFC, back when meetings were held at kitchen tables and the operating budget came from the pockets of families.

Highlighting the event was the keynote address “Family Empowerment as a National Trend” by Margaret J. Gould, who is the President and CEO of the Visions Center for Creative Management located in Catorah, New York. She also works with the Geraldo Rivera/Wall Street Group Philanthropy, which has recently awarded MFOFC a grant to continue and strengthen our “Family Leadership” activities, achieve policy and statutory reforms that will give relief to our families, and reach out to minority families and assist them in making a difference in the lives of their own families. Margaret spoke on the subject of family empowerment with a primary focus on how families are becoming the “decision makers” in selecting the support options that they want within their communities. She was very upbeat, positive and inspiring in sharing her vision of the future for families and their relationships with the agencies that provide support for them. She encouraged both families and agencies to look beyond traditional boundaries for support. To illustrate, she spoke of her relationship with the stockbrokers on the board of the organization that awarded the grant to MFOFC. Here are men and women who control and make millions of dollars in a fast-paced and stressful environment, yet are genuinely concerned about individuals with disabilities and their families. They are forward thinking in their vision and values and have stepped “out of the box” to provide support.

Margaret senses that there are many people and organizations who care and are willing to help, but they don’t know where to begin or whom to connect with. We family members need to raise our hands and shout, “Here we are!”

Elections were also held for the MFOFC Board of Directors, with nine new members joining the thirteen members who are currently serving. There are still two openings for representatives from Central Massachusetts and one from the Boston region. Call your regional coordinator or MFOFC’s office at 800-406-3632 if you are interested!

The meeting closed with Special Recognition awards presented to the Massachusetts Developmental Disabilities Council for their tremendous support to MFOFC over the years, and to Representative Patrick Guerriero of Melrose for his efforts on behalf of the “Individual and Family Support Bill” that MFOFC has filed.

Cove Human Services of Boston was given Special Thanks for allowing MFOFC free meeting space for Board meetings.

Everyone left the Holiday Inn feeling inspired and motivated to continue working to achieve the goals and objectives of Massachusetts Families Organizing For Change!

Networthy

Federation for Children with Special Needs
www.fcsn.org/
A powerful sight that is filled with information concerning all aspects of special education specific to Massachusetts. John Sullivan does an excellent job maintaining this informative site while Executive Director Rich Robison ensures quality of content. This site also contains links to the Massachusetts Legislature.

ADA website (U.S. Dept of Justice)
www.usdoj.gov/crt/ada/adahom1.htm
Find out what your rights are concerning the Americans with Disabilities Act. Gain access to the latest court rulings that effect this important legislation.

Family Village
www.familyvillage.wisc.edu/
A nice little community of informational resources on specific diagnoses, communication connections, adaptive products and technology, adaptive recreational activities, education, worship, health issues, and disability-related media and literature.

ICI Net
www.childrenshospital.org/ici/icinet
An online resource network of the Institute for Community Inclusion. This site has numerous Massachusetts and National links, Legislative links and a host of informative educational links. This is one local Internet site that really shines.

If you have any comments or suggestions concerning networthy please email Rich Bissell at networthy@twinsaneteryrisac.com □
Noteworthy

The Executive Office of Health and Human Services (EOHHS), established in 1971, is Massachusetts' cabinet-level agency in charge of all health and human service programs in the Commonwealth. EOHHS is the largest secretariat in state government overseeing a total budget of $8 billion and employing 23,000 people. EOHHS manages every aspect of policy development and service delivery that takes place among the 15 state agencies that comprise EOHHS. The Secretary of Health and Human Services is William D. O'Leary and he is the Governor's chief policy advisor on all health and human service issues. We have listed just a few of the EOHSS agencies that we believe would be helpful to you. We also give a brief synopsis of each agency.

**Department of Mental Retardation**

*Gerald Morrissey, Commissioner*

(617) 727-5608

The Department of Mental Retardation (DMR) is responsible for providing services and supports to Massachusetts' citizens with mental retardation. Everyday, DMR provides a wide variety of services to more than 24,000 individuals. Their level of disability may require assistance in job placement, transportation, residential services, or intense levels of treatment, monitoring and care. DMR also provides assistance to people with severe disabilities. They provide these services through state-operated programs and by contracting with more than 370 private provider agencies across the state.

**Department of Mental Health**

*Mary Lou Sudders, Commissioner*

(617) 727-5600

The primary mission of the Department of Mental Health (DMH) is to provide services to citizens with long-term or serious mental illness, early and ongoing treatment for mental illness, and research into the causes of mental illness. The Department of Mental Health also provides emergency, evaluation and short-term treatment for any child, adolescent or adult who is experiencing an acute mental health crisis and requests assistance.

**Division of Medical Assistance**

*Bruce Bullen, Commissioner*

(617) 210-5500

The Division of Medical Assistance (DMA) was created in July 1993 to manage health care benefit plans in Massachusetts. As of September 30, 1998, over 800,000 residents of the Commonwealth received assistance from DMA's MassHealth program (Medicaid). If you have a question about eligibility requirements call 617-210-5500.

**Massachusetts Commission for the Blind**

*David Govostes, Acting Commissioner*

(617) 727-5550

Provides financial and technical assistance for children who are blind and legally blind. The following programs are available for children whom they service. Children's Social Services. Provides case management and technical assistance for children who are blind. Call 800-392-6450 for more information. Medical Assistance. Can determine Medicaid eligibility of and coverage for children who are blind. Call 800-392-6450 for more information.

**Department of Public Health**

*Dr. Howard Kyongju Koh, Commissioner*

(617) 624-5700

The Department of Public Health (DPH) promotes and ensures conditions that improve and protect the health of Massachusetts residents. DPH focuses on community-based approaches, fosters continuous improvements in the health status of individuals and communities, supports programs that prevent and treat disease and disability, and intervenes to reduce threats to the public's health. DPH's focus includes the health status of all Massachusetts residents and communities, with particular emphasis on those at highest risk and in greatest need.

**Department of Social Services**

*Linda Carlisle, Commissioner*

(617) 727-0900

The primary mission of the Department of Social Services (DSS) is to protect children who have been abused or neglected in a family setting. Additionally, DSS will provide a range of preventive services to support for families with children at risk of abuse or neglect.

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Noteworthy (continued)

Massachusetts Rehabilitation Commission
Elmer Bartels, Commissioner
(617) 204-3600
The Massachusetts Rehabilitation Commission (MRC) is committed to increasing the independence of disabled citizens of the Commonwealth through services that result in competitive work and/or reduce reliance on benefit programs. The degree of independence achieved is based on individual ability, desire, professional intervention and commitment.

Massachusetts Commission For Deaf and Hard of Hearing
Barbara Jean Wood, Commissioner
(617) 695-7500 (617) 695-7600 (TTY)
The Massachusetts Commission for Deaf and Hard of Hearing (MCDHH) serves as the principal agency in the state on behalf of deaf and hard of hearing individuals. They provide statewide interpreter referral service, case management, technical assistance and other related services. MCDHH also provides Contracted and Independent Living Programs (DHILS programs) for deaf and hard of hearing people at ten regional sights throughout the state.

Office of Child Care Services
Ardith Wieworka, Commissioner
(617) 626-2000
The Office of Child Care Services (OCCS) is responsible for fostering the well-being of children enrolled in childcare by establishing and enforcing health and safety standards. OCCS staff provides training for childcare staff and coordinates educational programs for teachers and children on child abuse prevention. The agency also provides information and referrals for parents seeking childcare. OCCS serves children up to age 18 (to age 22 with special needs) and their families.

If you have any comments or suggestions concerning noteworthy please email Rich Bissell at noteworthy@twintenterprises.com

What's in a Name?
We need your help in naming this newsletter. Send in your suggestions! Every entry will be considered. The winning entry will win a $30.00 gift certificate to a restaurant in your area.

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