MFOFC Celebrates a Decade of Organizing and Action at its 10th Annual Meeting

Massachusetts Families Organizing for Change (MFOFC) celebrated the accomplishments of a decade of principled advocacy on behalf of individuals with disabilities and their families at its annual breakfast meeting in Milford, MA last November. Members and friends of the organization joined together to reflect on 10 years of achievement and challenges in pursuing MFOFC’s mission of empowering people with disabilities and their families to have a genuine place at the table where so many critical decisions are made about the supports and services that affect their lives.

After a brief welcome from Board of Directors member Chris Pelletier, Western Regional Coordinator Dana Danseureau presided over the election of a new slate of officers for the organization. With a few energetic newcomers joining many returning veterans of the Board, MFOFC will be equipped to provide dynamic and creative leadership for the organization’s statewide activities in the coming year.

MFOFC Treasurer Lou Nisenbaum then did double duty as he first provided a year-end fiscal report for the organization, and then presented a moving tribute to the late Gunnar Dybwad, one of the founders and preeminent mentors of the disability movement.

MFOFC Board Chairperson Emily Murgo Nisenbaum followed with a retrospective of the organization’s accomplishments since its founding in 1991. She noted that the grassroots family organization which began with 30 family members had now grown to have connections with more than 2,000—without losing its focus on family leadership and advocacy for quality services.

MFOFC has been active in the campaign to develop flexible family support services, in the effort to promote culturally competent supports across the service delivery system, and in the imperative to close our state’s institutional facilities. MFOFC has also gained national and international recognition for its groundbreaking work and expertise with family governed systems of support. Emily concluded that, despite this menu of achievement, much more needs to be done to develop high quality family driven supports across the service spectrum, and that the mission of MFOFC remains relevant as the organization begins its second decade.

MFOFC Board member Kathi Hackett then introduced keynote speaker Val Bradley of the Human Service Research Institute (HSRI), who presented a historical perspective on the development of family support services nationwide. Val also discussed “best practices” in family supports, challenges to the current system and an agenda for change that will continue the process of putting more control in the hands of individuals with disabilities and their families. At the end of her presentation, Val and Marianne Taylor from HSRI were honored for their roles over the last ten years in the growth and development of MFOFC. Lou Nisenbaum was also honored in a moving tribute for his ten years of consistent and dedicated leadership for the organization.

As we face the next decade, many challenges remain to be addressed and overcome so that people with disabilities and their families can take their rightful place and be valued as contributing members of our communities. Massachusetts Families Organizing for Change is committed to continuing the necessary work of advocating for quality, flexible and consumer directed supports and services that empower people to take charge of their own lives.

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Central

As 2001 came to a close, I spent time reflecting on the progress that Central Massachusetts Families Organizing for Change (CMFOC) and the statewide organization, MFOFC, has made over the past year. Our Steering Committee met many challenges early in 2001, but we've transformed ourselves into a collaborative, effective and goal-oriented group focused on assisting families in Central Massachusetts to become and remain successful.

Over the past year, CMFOC has developed several initiatives to support our mission. Families Assisting Families, a collaboration with our regional Department of Mental Retardation (DMR) office, is becoming a viable resource for families. CMFOC volunteers collaborate with the DMR to make community resources available to families.

Our Family Leadership Series remains strong with over 30 participants involved in the year's training. The Mentoring Program continues to complement the Leadership Series with past participants guiding current family members participating in the series and assisting them with project development.

We've organized several other events for families. Parent's Night Out was one activity in which 24 children were matched up with a Shriver Job Corps volunteer and parents were able to enjoy a few hours to go out to dinner, catch a movie or do whatever else they wanted! We also sponsored an activity last December in which Central Mass. Families boarded a tour bus and enjoyed Bright Nights in Springfield.

We've spent many hours advocating with legislators and encouraging families to support the Individual and Family Support Bill. We've also begun to establish relationships with the Department of Mental Health and with the National Association for the Mentally Ill in hopes that we can collaborate with all families within Central Massachusetts, regardless of disability.

As the year 2002 unfolds, we feel energized and confident that CMFOC will continue to meet the changing needs of families within our region.

Submitted by C.J. McGregor

Southeast

The Southeast chapter of MFOFC began its 11th Family Leadership Series on October 26th. There are 46 family members participating in this series—by far our largest group! The series started off really well with the active and enthusiastic participation of all attendees. The group was wonderfully diverse and we provided simultaneous translation in Spanish, Crioli and a Nigerian dialect. We are looking forward to the start of the second session on January 26th.

The Southeast region continues to reach out to families through our Area Coordinators. Dianne Clemence-Shriner represents the Cape and Islands, Dianne Huggon works in the Taunton/Attleboro

Western

Thirty family members gathered on a beautiful Friday morning in October to start our region's 10th Family Leadership Series. After having taken last year off to celebrate a 10-year reunion, it was exciting to see many new faces join together again in search of information, ideas and support offered through the series. The weekend started with a session in which participants introduced themselves to the group and talked about their families and why they had come—it's always so fascinating to watch the hesitancy and nervousness wash from people's faces as they discover that everybody else there has a family just like theirs! Leadership was the theme for the weekend as participants explored their leadership style, discussed various forms of personal leadership and ended the weekend with an afternoon session with the ever-popular Lynn Williams-Tonkin who discussed "Leadership in Your Own Backyard." The families left on Saturday expressing lots of appreciation and anticipation for the second weekend scheduled for the middle of January.

Our region has also been involved over the last few years with a grant from the federal Administrating Agency on Developmental Disabilities. MFOFC, The Institute for Community Inclusion, Arc Massachusetts, the Federation for Children with Special Needs, and the Department of Mental Retardation are partnered together to develop better support services for unserved and underserved groups in the Springfield and Athol areas.

Submitted by Dana Dansereau
Northwest

The Northeast began its ninth Family Leadership Series in September with a diverse and interactive group of parents. We started on Friday with a packed agenda that included leadership and communication skill building. Saturday’s activities featured a panel of past Family Leadership Series participants and their unique styles of making a difference in the lives of people with disabilities. The panel included a former Mrs. Massachusetts Pageant participant who had disability awareness as her platform, a person involved with the Autism Awareness quilt project and some unbelievable community organizers and PAC board members standing strong in the face of adversity and working hard to promote wonderful lives for people with disabilities. Our current participants were so inspired by them! When they were asked what they enjoyed, appreciated or learned, typical comments went like this, “I enjoyed everything— the speakers were terrific as were the handouts.” and “I appreciated that the presentations were by actual parents of children with disabilities.” Lots of positive feedback and we’re looking forward to our next session scheduled in February.

Our region sponsored a Summit for the Family Council, which involved networking and sharing information on how each council works—and dinner! This was an extremely successful evening and we plan on having another summit in the spring to reconnect.

We have been active on the Planning Committee for the Federation for Children with Special Needs’ Creating a World of Opportunity Conference on February 9. It promises to be an exciting event with over 30 educational workshops, free resources and a new strand involving assistive technology. Scholarships to the conference are available in each of the regions, as well as a bus for people attending from western Mass. If you get this newsletter in time and would like a scholarship or need more info—just give your regional coordinator a call!

Submitted by Susan Nadworny

Southeast

During the last year, the Southeast chapter of MFOFC helped coordinate a multi-part series on housing called "Home is Where the Heart Is" and an evening for family members with Tom Kohler on Citizen Advocacy.

Submitted by Emily Murgo Nisenbaum

Boston-Metro

It's been a while since we've sent out a newsletter or held a meeting, so I'm glad for this opportunity to give you an update. I've been out of the picture for a while, but I'm back now, still working with Tom Taranto and Wayne Hines and I appreciate the support of family members who want to renew our group as we plan for another Family Leadership Series.

There have been a few changes in our region of the Department of Mental Retardation (DMR), including the appointment of an acting Regional Director and consolidation of offices in several areas of the region. Suzanna Chan, the Family Services Coordinator, met with us last summer and recently contacted us regarding plans for soliciting "Requests for Proposals" from service providers this spring. This gives us a chance to share our plan for a Family Leadership Series in our region, and determine what level of support DMR might provide. In addition, Ms. Chan has indicated that she will continue to support family members from the Boston-Metro region who attend Family Leadership Series in other regions.

Starting in January, we plan to meet at least once a month with a dual focus of planning a Family Leadership Series and discussing the changes in Special Education. I plan to get a speaker from the Boston Special Needs Parent Advisory Council to give us an update on current issues and their efforts to remain strong despite funding cuts.

If you would like to help us with planning the next Family Leadership Series or want to attend monthly meetings for Special Education updates, please see the front page of this newsletter for how to contact me.

Submitted by Jean Palmateer
Operation House Call

Operation House Call is a collaborative program between Greater Boston Arc, Boston University School of Medicine and volunteer families. We are looking for families of children with disabilities who would be willing to host third-year medical students for a two-hour home visit. This is a win-win situation for everyone involved! Families participating in this program have a unique opportunity to share their knowledge about raising a child with disabilities and provide future doctors with a long lasting and enlightening experience that will serve them well throughout their careers.

If you live in or near Boston, Norwood, Framingham, Brockton or the North Shore and wish to become involved with Operation House Call or need more info, call Susan Nadworny at 781-665-5179 or email snadw@aol.com. You can make a difference without even leaving home!

IMPACT — Individual Members Planning and Assessing Choices Together

Are you confused about your benefits or benefits for a family member? Well, here is something that may help! The Social Security Administration has awarded grants to two Massachusetts organizations with the main objective of providing benefit planning, assistance and outreach for persons with disabilities over the age of eighteen (18) who are interested in working or returning to work. In the eastern part of the state, the Massachusetts Rehabilitation Commission (MRC) will administer the grant, and in western Massachusetts an organization called BenePLAN will be responsible for implementing the grant.

The grants will allow individuals with disabilities, their families, professionals and significant others to access accurate and understandable information regarding benefits and planning. The benefits specialists can assist you with questions and information on Medical benefits, Social Security, Public Housing and other public benefits. They can work with you to develop a confidential and personalized benefits plan, offer counsel and support on issues concerning benefits, deal with the Social Security Administration and provide assistance with work incentives.

Take advantage of this great service—for a referral form, please call MFOFC at 1-800-406-3632. Be sure to leave your name, address, telephone number and the county you live in.

Tools for Tomorrow

Massachusetts Families Organizing for Change is embarking on another exciting grant which we are calling Tools for Tomorrow. The main objective of the grant is to support individuals with disabilities and their families in evaluating the quality of the supports that they receive. We're collaborating on this grant with some great partners—Arc Massachusetts, Mass Advocates Standing Strong and the Massachusetts Development Disabilities Council—so you can be sure the grant will remain focused on individuals and families.

The first year of the grant will center on selecting the evaluation tool and preparing the curriculum to provide training for individuals and families. In year two, the formal training sessions will be provided in both the Springfield and Boston areas. Collection and dissemination of information will also begin in year two, and continue into the third year and beyond. Families and individuals who are interested in participating can watch for information in future newsletters or on MFOFC's website.
Update on Senate 2188/House 3118—The Individual and Family Support Bill
From Lou Nisenbaum & Dana Dansereau, Legislative Committee Co-Chairs

All of your phone calls and letters to your Senators to move Senate 686, the Individual and Family Support Bill, out of the Senate Ways and Means Committee have borne fruit! After what seemed like forever, our bill passed the Senate on January 8 with a 33 to 0 vote. Senator Mark Montigny of New Bedford and Chairperson of the Senate Ways and Means Committee presented the bill to his Senate colleagues who were very affirming of our legislation and of Massachusetts Families Organizing For Change.

Now that our bill has cleared the Senate, our next major hurdle is the House Ways and Means Committee. We are fortunate this year to have a great group of House sponsors, led by Representative William Strauss of Mattapoisett. In the very near future, we will be initiating our campaign in the House of Representatives, so we ask all of you to get ready—we’ll need each of you and your families and friends to work the bill.

As you are probably aware, we have our work cut out for us to pass the House version of the legislation, since this is where the bill has stalled in the past. We’ll need to capture and harness the momentum generated from passage of Senate 686 to move H3118 out of the House Ways and Means Committee and onto the floor of the House of Representatives. We’ve been unable to clear this hurdle in the past, but we’ve never been so organized as we are this year—nor have all of you done as much as you already have. But we’ll all have to do a little more as we lift the bill on our shoulders and carry it through the House for passage!

Our sincere thanks to all of you who have made contacts in support of the bill, and kudos to MFOFC’s Legislative Committee for their hard work! Together we can get this done—this is our year!

We’d like to quote a few paragraphs from a press release announcing passage of the bill:

Senator Mark Montigny (D-New Bedford) and Massachusetts Families Organizing for Change, a group that advocates for improved services for individuals with disabilities and their families, announced that the Massachusetts Senate passed, by unanimous vote, legislation requiring better coordination between the departments serving individuals with disabilities. The legislation also requires that individuals with disabilities and their families be given a voice in how these services are delivered. Sponsored by Senator Montigny, Senate Bill 2188, An Act to Support Individuals with Disabilities and their Families, would require all of the state departments that serve individuals with disabilities to prepare an annual report detailing the department’s plan to coordinate, enhance and expand services to people with disabilities. These reports would also describe the department’s efforts to provide services that are more flexible and creative in addressing families’ needs. Most importantly, the departments must develop their plans to improve services through substantial consultation with individuals with disabilities and their families.

The legislation, supported by Republicans as well as Democrats, is not expected to cost the Commonwealth any money. It does not require a new program or mandate any additional services. It is intended as a planning tool that may save the Commonwealth money by enabling individuals to live at home in the care of their families with appropriate support services from the state.

The bill will now go to the House of Representatives, where supporters hope it be acted upon quickly. Representative William Strauss (D-Mattapoisett) has also filed a companion bill, H3118, in the House, which has been in House Ways and Means awaiting action since June 11th.

Check out our website at www.communitygateway.org/mfofc for the latest information on our legislative campaign.
The Heart of the MATTERS

We Hope we Can Appeal to You!

Dear Friend of Massachusetts Families Organizing for Change,

We hope you're enjoying reading this issue of Family Matters! For quite some time, Massachusetts Families Organizing for Change (MFOFC) has been trying to publish this newsletter on a consistent basis, but as so often happens in our busy lives, something always gets in the way—little things like time, energy and money! That's part of why we're writing this appeal...we need your help!

As you know, we are a grassroots, statewide coalition of individuals with disabilities and/or chronic illness and their families. We believe that supports for individuals and families can be more comprehensive, more flexible and better designed to respond to the actual needs people have. Since we started organizing back in 1991, we have written legislation to create statewide policy and practice for individual and family support. Through the efforts of MFOFC, the design and implementation of family support in Massachusetts has changed from the one dimensional "respite" that was inaccessible to most families, to a full array of services and supports that are available today and that value the whole family.

When MFOFC incorporated as a private, non-profit organization several years ago, identifying sources of funding became crucial to our group's effectiveness and survival. We need a reliable and stable base of funding so that we can continue our work organizing and strengthening families in order to create positive change and ensure better futures for our family members who have disabilities. We'd like to ask that you give serious consideration to making a contribution to MFOFC. Thank you for kindly considering this request and we're grateful for any support, large or small, you can offer to enable us to continue our mission—and to continue publishing this newsletter! On behalf of each member of MFOFC, please know that we value and appreciate the everyday contributions you make in the lives of individuals with disabilities and their families. We'd also like to take this time to extend our best wishes for the New Year to you and your family.

Sincerely,

Jean Palmateer, Boston-Metro Region Coordinator
Susan Nadworny, Northeast Region Coordinator
Emily Muzio Nisenbaum, Southeast Region Coordinator
CJ McGregor, Central Region Coordinator
Dana Danseveau, Western Region Coordinator

Thank You For Your Support!

Your contribution is tax deductible - please let us know if you would like a receipt

Please make your check payable to: Massachusetts Families Organizing for Change

Mail to: P.O. Box 61
        Raynham, MA 02768
MATTERS of Opinion

MFOFC Position Statement

Massachusetts Families Organizing for Change (MFOFC) advocates for policies and practices that enable children with disabilities/chronic illness and their families to live together in their communities and that reflect the principles and practice of self-determination for adults with disabilities/chronic illness. The continued use of Massachusetts state institutions and developmental centers is antithetical to this mission.

Members of MFOFC care deeply about the rights of ALL people to enjoy community life with family, friends and neighbors. We strongly believe that Massachusetts state institutions and regional developmental centers must close to enable people living in these facilities to claim their rightful place in our neighborhoods, towns and cities. Until this occurs, we shall honor these people and their rights by remaining consistent with our mission and conducting our affairs in the communities where we live, work and play.

The Board of Directors of Massachusetts Families Organizing for Change has adopted the following position concerning participation in meetings:

Individual board members of MFOFC, when acting in the capacity of a board member and thereby representing MFOFC, will request that meetings he or she is asked to attend be held at locations other than the state institutions or regional developmental centers (Dever, Fernald, Glavin, Hogan, Templeton, Wrentham and Monson). Whenever feasible, MFOFC board members should assist in locating mutually convenient alternative sites. In those situations where an alternate meeting location is refused and barring significant unforeseen or mitigating circumstances, MFOFC board members will decline the invitation to attend such meetings.

Adopted 9/26/01 by MFOFC Board of Directors

MATTERS of Interest

March 12 ~ MDDC/Arc Massachusetts Legislative Reception

Come out to the State House on March 12th from 10:30 am until noon at the bottom of the Grand Staircase for the 24th Annual Legislative Reception sponsored by the Massachusetts Developmental Disabilities Council and Arc Massachusetts. For more information, call Arc Massachusetts at (781) 891-6270.

March 27 ~ Department of Mental Retardation (DMR) State House Reception

The DMR is planning a number of events throughout the month to honor the accomplishments of people with developmental disabilities. As in previous years, the month will culminate with a State House reception in the Great Hall on Wednesday, March 27, 2002, to honor individuals and/or groups from each region for their work on behalf of people with disabilities. The Dybwad Leadership Award will also be presented at this ceremony.

For more information on MR/DD month, contact Gerry Ryan, Director of Communications at (617) 624-7710.

Spring 2002 ~ Transition with A Vision

A Conference on Transition to Adulthood

Come hear:
- other parents talk about how they developed their vision and made their plans become a reality!
- professionals outline the steps you can take right now to begin your planning!

For more information, contact Liz Hopkinson at Minute Man Arc, 978-371-1543 Ext. 37 or lhopkinson@minutemanarc.org.
Our Web Site **MATTERS**

Check it out! Besides learning more about who we are and what we do, you can find links to many other important web sites where you can learn the latest about upcoming trainings, conferences and other events and items of interest.

The MFOFC site provides the latest info on the progress of the *Individual and Family Support Bill*—the legislative section will also tell you what you can do to help out. We’ve provided sample phone scripts and letters to make it easier to contact your legislators. We invite your comments and suggestions to make our site even more helpful! Visit us at www.communitygateway.org/mfofc.

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Subscription to Family **MATTERS** is free! If you did not receive this newsletter in the mail and would like to be placed on our mailing list, please use our address, phone number, fax number or e-mail address listed in this box and give us the following information:

Name
City/State/Zip
Street Address or PO Box #
Phone Number

Please feel free to refer us to another family member or friend!

About Massachusetts Families Organizing for Change...

We are a statewide, grassroots coalition of families with children and adults who have disabilities and/or chronic illness. We are actively organizing our talents and our experiences with the conviction that family and individual support can be comprehensive and flexible.