

MASSACHUSETTS FAMILY VOICES

Massachusetts Family-to-Family Health Care Information & Education Center

A project of Mass Family Voices @ Federation for Children with Special Needs

**Topical Call: Tuesday, July 19, 2005
11 am - 12 noon**

Topic: Implications and Implementation of Mass General Law Chapter 171 – *An Act Providing Support to Individuals with Disabilities and Their Families*

Goal: Participants will become familiar with the contents of this Massachusetts General Law, the implications of the law (for families and for the 7 state disability agencies* named in the law), what is being done to facilitate the implementation of the law and to ensure that families have opportunities to provide “substantial consultation” to the agencies about what works, what doesn’t work and what can work better about delivery of services and flexible family supports.

***7 State Disability Agencies:**

1. MassHealth: <http://www.mass.gov/masshealth>
2. Mass Commission for the Deaf and Hard of Hearing: <http://www.mass.gov/MCDHH>
3. Mass Commission for the Blind: <http://www.mass.gov/MCB>
4. Mass Dept. of Public Health: <http://www.mass.gov/dph/>
5. Mass Dept. of Mental Health: <http://www.mass.gov/dmh>
6. Mass Dept. of Mental Retardation: <http://www.mass.gov/dmr>
7. Mass Rehabilitative Commission: <http://www.mass.gov/mrc>

Conference Call Summary:

♥ **Welcome** – *Beth Dworetzky, Mass Family Voices @ FCSN*

Mass Family Voices is project at the Federation for Children with Special Needs, and a state chapter of Family Voices, a national, grassroots organization of families, friends and professional partners who speak on behalf of children and youth with special health care needs. Mass Family Voices is also a Family-to-Family Health Care Information and Education Center, funded by the Center for Medicare and Medicaid Services. One Family-to-Family Center activity is to offer topical conference calls on subjects of interest to families of children and youth with special health care needs.

Thank you very much for taking the time to participate in today’s call about implications and implementation of Chapter 171: *An Act Providing Support to Individuals with Disabilities and their Families*. You have each received an agenda and evaluation sheet for this call. At the conclusion, please fill out the evaluation and return it to me via the e-mail or snail mail address that is on the sheet. These evaluations are really important, as the Family-to-Family Center depends on your feedback to plan future calls about subjects of interest to you and in a format that meets your needs.

Now I’m going to hand this over to Tanya Wheeler the Mass Families Organizing for Change Consultant for the Chapter 171 Implementation Grant.

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♥ **Overview of Chapter 171 - Tanya Wheeler, MFOFC Consultant for the Chapter 171 Implementation Grant**

Tanya began by asking the participants if they were familiar with Mass Families Organizing for Change (MFOFC): <http://www.mfofc.org>, which they were.

Massachusetts General Law Chapter 171 was passed in July 2002, after 11 years of advocacy. The inspiration and force behind the law came from the MFOFC Family Leadership Series. Families that attended the Leadership Series: http://www.massfamilyvoices.org/conference_Listing.htm, would talk about family supports, which at that time, consisted mostly of respite. The respite was very structured; for example, DMR (Department of Mental Retardation) would send a provider, who was a stranger to your family and child, into your home to take care of your child with a disability, and only that child, or the family could place their child in a designated childcare setting, which was not familiar to the child. This type of support, which was not flexible, was not meeting families' needs, so MFOFC began advocating for flexible family supports, which, in addition to respite, now may include, but are not limited to: coordination and facilitation of support services; counseling and information; facilitation of self-help groups; home adaptations; assistive technology devices and services and support services to facilitate full communication and language access; financial assistance; assistance in care-giving including: respite, day care, after school care and personal care or personal care surrogacy, when necessary; adaptive equipment and clothing; medical services; transportation, including vehicle modification; recreation and leisure activities; life planning; special dietary supplements and medical equipment and maintenance; mental health treatment; and advocacy training.

Guidelines for Implementation of Chapter 171 (<http://www.mfofc.org>)
Family Support Plans and "Substantial Consultation"

Seven state agencies, which all have a family support component, are named in the law. These agencies are: MassHealth, Mass Commission for the Deaf and Hard of Hearing, Mass Commission for the Blind, Mass Dept. of Public Health, Mass Dept. of Mental Health, Mass Dept. of Mental Retardation, and the Mass Rehabilitative Commission.

Each of these agencies must create an annual Family Support Plan, and the plan must be developed with "substantial consultation" from consumers (individuals with disabilities and their families who are eligible for services from that agency). MFOFC developed a template for the Family Support Plans so there would be some consistency across agencies about the information they were providing. The plans provide agency-specific background and an overview of family supports, the process for family input, and then address the focus areas of Self-Determination and Family Empowerment (current and new initiatives), Family Leadership Development Opportunities, Resources and Supports, Accessing Services and Supports, Cultural Competence and Outreach, and Interagency Collaboration (<http://www.mfofc.org>).

"Substantial consultation" can take many forms. Some agencies use paper surveys, although the return rate for surveys is very low. Others ask their existing advisory boards for input for the annual plans. Some agencies even host focus groups and meetings. This is okay, but not great, and each agency must work harder to get broader input from more individuals with disabilities and/or chronic illnesses and their families.

After each agency consults with consumers (substantial consultation), the annual Family Support Plans

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are drafted and made available to consumers for review, input and feedback, as only consumers can tell if what's in each agency's plan is what's really being offered to families. This needs to be done not less than 90 days prior to August 1st. After this review process, all the agencies submit their plans to DMR, the central coordinating agency. DMR then submits the plans (by August 1) to the Governor, the Secretary of Health and Human Services, the Joint Committee on Human Services and Elderly Affairs, the House and Senate Committees on Ways and Means, and the Legislature.

Since the Chapter 171 law was passed in July of 2002 progress has been slow towards implementation. This past year (fiscal year 2005) all 7 named agencies wrote plans. MFOFC board members reviewed all the plans to see how each agency planned to provide flexible supports in the coming year, along with how the agencies implemented their plan from the year before and how they got their "substantial consultation". Tanya also reviewed all of the plans to prepare to provide technical assistance to the agencies in writing future plans. To date, Tanya has visited 5 of the 7 agencies and provided recommendations about providing flexible family supports, about how to establish increased opportunities for substantial consultation, and ways to educate consumers about Chapter 171.

Each of these seven state disability agencies are mandated to provide flexible family support services, but these services are subject to appropriation (money that's been allocated from the state budget to provide those services). The intent of Chapter 171 is to change the way these agencies do business because the family supports they now offer are not always cost effective, flexible, or family-driven. Tanya cited an example where an agency offered only case management services and art therapy. Several families complained that their children don't like art and they wanted the money to be used for sports or music therapy instead because those activities were a better match for their children's interests. Chapter 171 states that the agency must provide services that enhance the lives of people with disabilities, so the agency needs to find a way to be flexible enough to diversify their programs to meet these children's needs.

Tanya's goal is to build a huge, informed network of families that know about Chapter 171, and who can provide substantial consultation to the agencies from which they receive services.

Families are encouraged to contact their agency liaisons (see above) to provide feedback about the family supports that are working, and also let them know what's not working and what would best meet their child's and family's needs. If you would like some mentorship about talking with or e-mailing these liaisons, Tanya (ryctanya@aol.com) will be happy to speak with you to help you understand Chapter 171 and help you state your case to your agency liaison. E-mail her to set up a time and to exchange phone numbers.

You're feedback is Important!

If you were unable to participate on this call, but would like to participate in future calls, have ideas for topics you'd like to hear about, or a "speaker" to suggest, please e-mail: massfv@fcsn.org.