MASSACHUSETTS CONSORTIUM
for Children with Special Health Care Needs

The Implementation of Chapter 171

A Report by the Community-Based Systems of Care Work Group of the Massachusetts
Consortium for Children with Special Health Care Needs
To the
Massachusetts Family to Family Health Information Center

Executive Summary

Chapter 171 of the Massachusetts legislature's Acts of 2002 creates a new mandate for seven state agencies that provide services to adults and children with disabilities. It requires each agency to obtain “substantial consultation” from consumers about the support needs of individuals with disabilities and their families, and to create a yearly Individual and Family Support plan for the allocation of agency consumer support funds reflecting that input. Goals of the law include increased access to services, cross-agency coordination of resources and referrals, pooling of funds to improve support for people with multiple conditions, and provision of technical assistance, training and outreach to consumers and community providers about family support.

Objectives of the law, designed to promote achievement of its goals, include:

- Increased family and/or consumer input into and oversight of support programs and policies;
- Agency accountability around achievement of short and long-term objectives;
- Improved identification of supports based on family needs;
- Increased community participation for individuals with disabilities and their families;
- Increased community capacity to serve individuals with disabilities and their families; and
- Consumer and family empowerment.

This document summarizes a set of interviews conducted between February and April, 2008 with representatives of agencies covered by Chapter 171. It reports good faith, energetic efforts by several agencies to implement the law, but substantial differences across agencies in regard to:

- Methods for obtaining imput,
- Target groups for solicitation of input,
- Numbers of families or individuals targeted to give input,
- And diversity of families and individuals from whom input was sought.

There is no available outcome data related to Chapter 171: we do not know whether consumers and families perceive the supports they receive from any agency to be better or worse based on the 171 process. We cannot, therefore, identify any set of strategies as optimal. What our interviews <u>do</u> clearly indicate is that the current approach, which involves 1) isolated effort on the part of each of participant agency, 2) lack of oversight of the process across agencies, and 3) lack of a systematic mechanism for review of the

process and of agency findings by consumers within or across agencies, falls short of the intent of the law. Recommendations, provided at the end of the report, focus on improved practice by individual agencies but also call for greater consistency and coherence among agencies, better oversight, and increased opportunity for consumer response to the process as a whole.

Our most important recommendation calls for the establishment of a single family advisory group to the Executive Office of Health and Human Services. This group should include families served by each of the mandated agencies, families served by several of those agencies, and families caring for children or adults with disabilities who receive no state services. It is this group that we would empower to oversee and review the 171 process as a whole, assuring not only good work on the part of each agency, but also reduction in the duplication and fragmentation across agencies and the gaps in care between agencies, that currently confront families dealing with disability in Massachusetts. Such a group would provide an important mechanism for achieving the primary goals of the law, specifically, cross-agency coordination of resources and referrals and increased access to services.

This project was designed and this report developed by the Community Based Systems of Care (CBSC) Work Group of the Massachusetts Consortium for Children with Special Health Care needs in collaboration with the state's Family-to-Family Health Information Center. The project also, however, reflects the good will and commitment of agency staff who gave their time to be interviewed: the report reflects broad commitment to collaboration and especially to consumer involvement, among agencies in this state.

Background and rationale for the project

The Massachusetts Family-to-Family Health Information Center (MA F2F HIC) was established in 2004 with funding from the federal Centers for Medicare and Medicaid Services. Since June 2007, a grant from the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Division of Services for Children with Special Needs has funded Center services and activities. These include promotion of the six Healthy People 2010 objectives for children with special health care needs. Two of those objectives: 1) promoting family/professional partnerships at all levels of decision-making and being satisfied with services, and 2) services that are organized and easy to access, coincide most closely with the goals of Chapter 171, although the overall aims of the F2F HIC and Chapter 171 overlap considerably.

Chapter 171 represents this state's most explicit commitment to consumer participation in disability policy and to a responsive, integrated, system of consumer services. Effective implementation of Chapter 171 would provide opportunities to promote achievement of specific F2FHIC goals. The MA F2F HIC seeks to enable families to make informed choices about services; Chapter 171 calls for more openness on the part of state agencies, enabling families to get a clearer sense of what is and is not available and to whom. Similarly, the MA F2F HIC is a clearinghouse for information on public benefits and services in MA. Chapter 171 objectives related to input, accountability and interagency collaboration would facilitate the organization and dissemination aspects of the Center's clearinghouse role.

This report reflects a collaborative effort of the Community Based Systems of Care Work Group of the Massachusetts Consortium for Children with Special Health Care Needs (the Consortium) and the MA F2F HIC. The MA F2F HIC collects information about and identifies issues of concern to families with children and youth with special health care needs. The Consortium, a subcontractor to the F2FHIC, analyzes systemic issues that arise in the context of F2FHIC work and proposes policy level interventions to address them.

The MA F2FHIC provides a variety of services aimed at enhancing consumer knowledge of and access to optimal health services through operation of an 800 number hotline and other means. While consumers have not directly discussed Chapter 171 implementation in their calls to the Center, they have raised lack of agency transparency and system fragmentation as challenges faced by each family obliged to construct a unique system of care for a particular child. Given that experience, the MA F2FHIC consulted with parent leaders at Massachusetts Families Organizing for Change (MFOFC), a grassroots coalition of families dedicated to individual and family support. This organization led the fight for passage of Chapter 171; they enthusiastically supported this collaboration as they too wanted to know how the seven mandated agencies were going about implementation of the law. After some discussion, it was agreed that the Work Group's first collaboration with the MA F2F HIC would be to assess agency practices related to Chapter 171 and identify opportunities to use the law as a framework for responding to concerns about system transparency and coherence. That agreement was reached in January, 2008.

Methodology

At the suggestion of the MA F2F HIC, the CBSC Work Group decided to create a survey and conduct key informant interviews with Chapter 171 liaisons at each of the seven participating state agencies. The mandated agencies are the state's:

- Rehabilitation Commission
- Department of Mental Health
- Department of Mental Retardation
- Department of Public Health
- Commission for the Blind
- Commission for the Deaf and Hard of Hearing
- and, Medicaid program.

As a first step, work group members identified a Chapter 171 contact at each of these agencies. Step 2 was the development of a questionnaire to guide CBSC Work Group interviews with agency liaisons. Several drafts of the questionnaire were developed by the Work Group with MA F2F HIC staff until a final version, broad enough to reflect varied agency strategies but targeted enough to reveal patterns across agencies, was reached. Work group volunteers were each assigned an agency to contact. Interviews were conducted by phone between February and April 2008. One agency never responded to requests for an interview; after approximately 20 attempts (phone and email) and several promises to respond, that agency was presumed to have opted out of participation.

Findings

Considerable variability was found across agencies in regard to Chapter 171 implementation, which was apparent as soon as the interview process began. Some agency contacts were quick to respond and quite clear about agency implementation efforts and findings; others were slower to respond and in some cases, less able to describe agency efforts with certainty.

Once contacted, agencies also reported very different approaches to implementation. Three agencies, which we identify as Agencies 1, 2 and 3, reported development of new consumer outreach efforts specifically to gather "substantial consultation" for Chapter 171 purposes. Other agencies reported that they rely on pre-existing consumer links to gather consumer input.

Table 1 presents a summary display of activities conducted by each of the seven mandated agencies. A few additional details fill out the picture agency by agency:

Agency 1

Agency 1 developed a statewide Family Support Council in response to Chapter 171, striving to assure diversity within the 15 person group, in terms of geography, age and diagnosis of the child or adult receiving care from family members, race/ethnicity and culture. Agency 1 also offers an on-line survey to families, offering them a chance to comment on the extent and nature of family supports and interagency collaboration. While clearly relevant to Chapter 171, the survey does not explicitly mention the law. Beyond the council and this survey, Agency 1 gets input from an estimated 1,000 client families through a variety of ongoing channels.

Agency 2

Agency 2 conducts Chapter 171-specific focus groups with families throughout the state to solicit information on support needs. Additional information gathering strategies include an on-line survey, which is publicized to families at conferences, meetings and other presentations, and via outreach to caregivers who call the agency's statewide information and referral line. Agency 2 care coordinators are also instructed to invite client families to complete their survey. These 171-specific channels are supplemented with information from agency staff. In FY 08, approximately 1,000 families were reached through these strategies; 464 responded to requests for input. Surveys were distributed to Spanish, Portuguese, and Haitian Creole, as well as English-speaking, families; 10% of responses were in languages other than English.

Agency 3

Agency 3 conducted Chapter 171-specific focus groups immediately following passage of the law. Since then, it has relied on ongoing channels for family involvement to elicit information on support needs. These include 40 parent coordinators employed directly by the agency and the central office and field office of a statewide, parent run organization that has regular and frequent contact with the agency.

Agency 4

Agency 4's primary consumer base is adults, rather than children and families. To meet its mandate under Chapter 171, the agency has gleaned information related to children and families from general, ongoing information gathering efforts. The agency's contact person for 171 queries staff of programs that serve youth to gather this information. These programs include a regionalized Transition Program and the Independent Living, Assistance Technology Center and head injury programs. Research staff who conduct regular consumer surveys are queried as well. No specific estimate of number of consumer contacts was available.

Agency 5

Agency 5 identified multiple ongoing mechanisms for staff contact with consumer families which are used for Chapter 171 planning. These include statewide and regional advisory groups that include parent members, staff conversations with individual families, annual town meetings in two regions of the state and insights gleaned from families who call an information and referral line. One of the advisory groups on which Agency 5 relies is actually a joint venture with a separate state agency (which is not mandated to participate in Chapter 171, but does have a stake in family support needs). Agency 5 reported particular efforts to identify needs of immigrant families, and of families raising children with special needs in foster care. No specific estimate of number of consumer contacts was available.

Agency 6

Agency 6 uses an ongoing family advisory group as a source of Chapter 171 input. In addition, staff people ask all client families about support needs; these reports are then synthesized into the Individual and Family Support Plan as it is developed.

Agency 7

Agency 7 did not respond to the survey.

Table 1. Agency strategies for consumer input under Chapter 171[1]

Agency	Consumer focus groups[2]	Advisory group consults	Client Interviews[1]	Staff/Vendor report of client surveys, intakes and contacts	Review of staff/vendor perceptions	Consumer surveys	Consumer town meetings
Agency 1	X	X			X	X	
Agency 2	X		X		X	X	
Agency 3	X[3]			X			
Agency 4					X		
Agency 5		X	X	X	X	X	X
Agency 6		X	X	X			
Agency 7							

[1] Shading indicates an activity designed specifically for 171 process; "X" indicates an affirmative response.
[2] "Consumer" refers to any individual who is a caregiver of a child, youth or adults with special health care needs or a disability. "Client" refers to a caregiver of a child with special health care needs or a youth or adult with special health care needs or disability who received services from the agency in question directly or through a vendor.
[3] Last focus group conducted two years ago.

In addition to asking about strategies to comply with the "substantial input" provision of the law, the survey asked agencies to report on the ways they use their support plans; whether and how they distribute the plan to consumers, vendors, agencies, professional organizations, or state agencies, and whether the plan is posted on agency websites. The Work Group saw this as a critical question, since it speaks to goals of the law that have to do with improving accountability, once input is gathered.

All agencies reported sharing their Individual and Family Support Plans with other state agencies as required by the language of Chapter 171. All reported using the plan to influence policy and to inform staff and consumer education programs. The survey did not reveal clearly, however, the extent to which information gleaned through the Chapter 171 input process was directly linked to the development of policy and in education, or whether respondents were speaking in more general terms about congruence between Individual and Family Support Plans and agency activities. There was variability, as reflected in Table 2, in the extent to which the plan was targeted to audiences other than state agencies. The question of posting results on agency websites may be particularly valuable as an indicator of outreach efforts, since it is objectively verifiable. Two agencies reported posting family support plans on their websites. Examination of each agency's website indicated that a third does as well. In addition, each agency support plan, for the years 2004 – 2008, is posted to the Massachusetts Families Organizing for Change website at www.mfofc.org.

Table 2: Agency dissemination and use of family support plans

Agency	**Dissemination Audience**					**Other uses of Plan**	
	Consumers/ Families/	**Staff**	**Vendors**	**State Agencies**	**Web**	**Policies**	**Education**
Agency 1	Planned			X	X	X	X
Agency 2	X	X	X	X	X	X	X
Agency 3		X		X	In progress	X	
Agency 4		X		X			
Agency 5		X		X		X	X
Agency 6		X		X		X	X
Agency 7							

Finally, agency respondents were asked to comment on the effectiveness and efficiency of their methods to gather information. These questions, designed to learn what agencies might identify as best or promising practices for obtaining "substantial consultation," also yielded mixed replies. All but two responding agencies rated their own strategies for gathering input effective. Agency 4 said frankly that current input strategies were inadequate. Agency 1 addressed the overall process: the Agency 1 contact indicated that while input activities were effective, the resultant plan was not used adequately as a guide for agency activities.

Three agencies rated their own activities "fair," in terms of efficiency. Agency 2 characterized the process as resource intensive, requiring some funds and considerable staff time.

Discussion

We are limited in our ability to identify best practices related to Chapter 171; however, it is possible to make some observations about the extent to which different practices reflect the intent and goals of Chapter 171. From that perspective, we would identify as "promising" strategies those which:

- **Are clearly defined as efforts to gather input**: When information is collected as a side product of some activity that has another purpose, families may not be systematic about gathering their thoughts, reflecting on their experiences and offering clear-cut guidance. Certainly agencies should take advantage of all opportunities to glean input from families. But the language of Chapter 171, which calls for "substantial consultation," implies opportunities for families to provide explicit responses to well-defined questions. Agencies which engaged families in extensive needs assessment and program evaluation prior to passage of the law may already be providing such opportunities. They may, however, find value in identifying the agency's Family Support Plan as one use for input.

- **Use multiple methods to gather input**: Families differ in their comfort in different settings and with different forms of communication. One or two strategies for gathering input may be enough to get "substantial input" from a few families or families in a limited set of circumstances, but on a broader level, substantial family input calls for a multifaceted approach.

- **Target disenfranchised groups**: Emphasis on particularly vulnerable or disenfranchised groups is consistent with the spirit of Chapter 171. Agencies may become complacent if they hear only from people in groups they are most accustomed to serving. And some groups, like children in foster care, are likely to be missed entirely by standard agency outreach methods. Given that disenfranchised groups may also have higher levels of baseline risk, it is doubly important to proactively seek their input on family support needs.

- **End with broad dissemination of Individual and Family Support Plans**. Dissemination should be targeted both to vendors and staff, who need to understand their own roles in responding to family needs, and to families, who can assess the extent to which plans reflect their input and address their real needs. Obvious placement on agency websites is one easy route to widespread availability of the plan, but active dissemination strategies are important as well.

Recommendations

The Community-Based Systems of Care Work Group, in collaboration with the MA F2F HIC, offers the following recommendations to enhance implementation of Chapter 171.

These recommendations are directed first at the seven agencies covered by the law. In some cases agencies already act as the recommendations suggest – the call here is for standardized implementation of these practices across agencies. And several recommendations would require leadership from the Executive Office of Health and Human Services, the cabinet-level agency to which the seven covered agencies report. And all suggest an agenda which might be pursued by consumer and advocacy agencies seeking more responsive government agencies and improved systems of care. These recommendations fall into six domains, which we define in terms of the objectives of the law:

A. **Increased consumer/family input into and oversight of support programs and policies**
   1. All mandated agencies should commit to, and EOHHS require, some outreach activities that are explicitly identified to families as opportunities for "substantial input' on their family support plans.

B. **Agency accountability around achievement of short and long-term objectives**
   1. Agencies should commit to, and EOHHS require, a process for presenting annual plans and reporting past year accomplishments to a defined group of current and potential consumer families;
   2. Agencies should be required to display annual support plans on their websites as well as share with other parent advocacy groups within the state, such as MFOFC and the MA F2F HIC, among others.
   3. Annual agency plans should include, and EOHHS should require, clear, measurable annual objectives and an analysis of achievement of past year objectives.

C. **Improved identification of supports based on family needs**
   1. EOHHS should identify specific vulnerable groups whose input should be sought to assure that identified needs reflect the full spectrum of consumer experience;
      a. These groups should include, but not be limited to, immigrant and non-English speaking families, biological and foster families of children in state custody, families of children with multiple, complex needs, and families of children who receive the bulk of their services from schools (which are not covered by Chapter 171);
   2. Agencies should commit to, and EOHHS require, a process to broaden consumer awareness of support options;
      a. This might include education of consumer families engaged in the group referred to in B.1., above;
      b. Options for family support should be understood to include strategies used by one agency but not others; options in place in other states;
   3. Recommendation A.1. is also relevant here: only if consumers are aware that their input is being sought under the provisions of Chapter 171 will they be able to take full advantage of the opportunity.

D. **Increased community participation for individuals with disabilities and their families**
   1. Agencies should commit to, and EOHHS require, some outreach activities that engage consumers in group (rather than individual) settings;

   2. EOHHS should identify some opportunities for standardization of the Chapter 171 process across agencies in order to promote community among consumers and families served by different agencies and promote cross-agency strategies to meet needs;
      a. This might include use of some standard questions in surveys used by different agencies to collect input.

E. **Increased community capacity to serve individuals with disabilities and their families**
   1. Agencies should commit to, and EOHHS should require, dissemination of family support plans to staff and vendors;
   2. Agencies should commit to, and EOHHS should require, incorporation of language reflecting family and consumer input into staff purchase of service activities;
   3. Agencies should commit to, and EOHHS require, incorporation of content reflecting family and consumer input into staff orientation and staff and vendor training activities (ad hoc or ongoing).

F. **Consumer and family empowerment**
   1. EOHHS should establish a statewide family advisory committee, including consumers and families of children served by or eligible for services of each of the mandated agencies. This group should also include consumers and families whose children are served by, or eligible for services from multiple agencies. This group should have a broad oversight role, including:
      a. Review of agency family support plans
      b. Review of annual progress in meeting agency objectives
      c. Review of agency adherence to the recommendations outlined above
      d. Identification of target groups or needs that do not fall clearly within any one agency's purview
      e. Identification of services that are not currently available to families in the state
      f. Opportunities to converse with EOHHS and agency leaders
      g. Opportunities to interact with legislators concerning the overall adequacy of state services to consumers and families of children with special health care needs and disabilities.

Massachusetts families have identified fragmentation across agencies as a major barrier to finding the services they need. At meetings, and in needs assessments they report difficulty sorting out what services exist, what services do not exist, and which of the services that exist are available to them. The search for services is a continuing burden to families already dealing with unique challenges. These recommendations, derived from the gap between the requirements of Chapter 171 and current practice, would address that burden. Most important among them, in our view, is the last: only through cross-agency review will a clear picture of what the state does and does not provide emerge, and optimal use of resources to eliminate gaps and fragmentation be possible.