

MINUTES

November 8, 2007

Marlboro, Massachusetts

Members Present: Robin Adair, Zulmira Allcock, Pat Cameron, Darleen Corbett, Jen DerBogossian, Peggy Freedman, Leslie Gaffney, Jen Greco, Jack Harris, Karin Lifter, Margaret Mahoney, Anne Marsh, Neal Michaels, Barbara Popper for Sara Miranda, Judith Nest-Pasierb, Kimber O'Connell, Nancy Phillips, Kathie Rose, Ronna Schaffer, Arlene Tannenbaum, Joanne Williams, Amy Young.

Members Absent: Kim Amato, Richard Breault, Sandra Daly, Pam Kuechler, Peggy Lee, Anita Moeller, Therese Murphy-Miller, Nancy Schwartz, Pam Wildnauer.

Non-Voting Committee Chairs in Attendance: Rena Ginsberg, Tom Miller, Alden Wood, Peter Woodbury.

1. Welcome: Co-Chairperson Amy Young welcomed the group and introduced Leslie Gaffney, newly appointed MetroWest Parent Representative to the ICC. Amy also reviewed a list of ICC committee accomplishments of the past year, and commented on the ICC Retreat held October 3 and 4, 2007. On the first day of the Retreat, the Program Planning Committee presented a morning panel and discussion on infant mental health. In the afternoon, working groups generated ideas that Steering Committee will use in revising the ICC's Strategic Plan. On the second day, a panel that included Sally Fogerty, Monica Valdez-Lupi, Mary Ann Mulligan and State Representative Thomas Conroy addressed opportunities and challenges the Massachusetts Early Intervention system is currently facing. The Retreat ended with a policy and data update by Department of Public Health Staff.

Approval of Minutes: The Minutes of the ICC meeting held June 14, 2007, were approved as written.

2. Director's Report – Ron Benham: Ron thanked the ICC for hosting the Listening session that will take place later in the meeting today. Recalling Charles Dickens' *A Tale of Two Cities*, he commented that the ongoing struggle to procure adequate funding for Early Intervention makes these "...the best of times...the worst of time;" And quoted Bruce Springsteen: "It's time to get on up, get on up, get on up, get on up, yah!" Ron then discussed the following items:

Two weeks ago, The Department of Public Health completed re-organization. Sally Fogerty is continues as Director of the renamed Bureau of Family Health and Nutrition, which includes the Nutrition Division and the Perinatal, Early Childhood and Special Health Needs Division.

After the annual December 1 child count, it takes at least 8 months before the data becomes available. According to the point-in-time count on 12/1/06, 6.41% of all children under three in Massachusetts were receiving EI services. This compares to the US baseline of 2.4%. Only Hawaii serves more than Massachusetts, but their criteria for counting at risk children differs from ours. By doubling our 6.41% to roughly 13%, one could obtain an approximate dynamic count for the full year. In Massachusetts, we counted 3.12% of children under one year of age, whereas the US average is 1.06%.

It will be challenging to hold Massachusetts EI within budget in the current year, Fiscal 2008. State FY 05 was the first year of negative growth in numbers of Massachusetts children served. That corresponded with going to a flat 25% delay eligibility criteria. By FY 07, growth had taken off again. Because of the way the budget process works, DPH has to project FY 09 numbers even before accounting for FY 07 is complete; this means revisions are always necessary. The Department has been told that it can submit a supplementary budget request for FY 08.

EI will face a multi-million dollar shortfall for FY 09 unless there is a substantial increase in state appropriation. This projection is based on several factors:

- Growth in regular EI continues at 4.5-5% per year.
- Participation in MassHealth has steadily increased over the last 4-5 years.
- There is concurrent growth in the proportion of EI staff who are developmental specialists.
- More employers are moving to self-insured plans that are not obligated to cover EI.

The Department will be talking with MassHealth about accepting a different level of financial responsibility for EI services. We can still tweak program elements a little bit; raising eligibility is a last resort. However, there is an overlay of challenges. One example is the American Academy of Pediatrics' recent recommendation that all children be screened at 18 months and again at age two for features of autism spectrum disorder. Undoubtedly more children will be identified who will need services. Yet, while there is some money flowing for advocacy and research, no one is asking for more service dollars.

3. DPH Update – Competency Review Process – Holly Newman: States participating in Part C of IDEA are required to maintain CSPD – a Comprehensive System of Personnel Development – to oversee personnel, training and credentialing. Holly is the CSPD Coordinator at DPH. She distributed a handout dated November, 2007 and explained that the task for the coming two years involves reviewing the 69 competencies that are part of the certification process for EI personnel in Massachusetts. This will be a community-wide process to examine competency indicators. Holly stressed that this is not a review of the portfolio review process; that comes later. Six work groups will be formed: Infant and Toddler Development; Evaluation and Assessment; Intervention Strategies; Family Centered Services and Team Collaboration; Service Coordination and IFSP; Policies, Procedures, and Professionalism. Information and application forms for people interested in participating in work groups were recently mailed to programs. Committees formed in January and February will receive training. Workgroups will be ongoing, with review of products by summer, 2008. **Discussion:** Suzanne Gottlieb stated that DPH is seeking family members to participate in this process. Karin Lifter stressed the importance of the competency review process to higher education programs that prepare EI personnel; this work guides curriculum development and revision.

4. Presentation by the Center for Public Representation on the Rosie D. vs. Romney litigation, “Transforming the Medicaid Children’s Mental Health System.” The presenter, Steven J. Schwartz, is Executive Director of CPR, a non-profit public interest law firm providing mental health and disability law services. A handout of power point slides was distributed. The lawsuit known as Rosie D. was a class action suit filed in 2001 that “sought to compel provision of intensive mental health treatment to Medicaid-eligible children in their homes and communities, thus avoiding unnecessary hospitalization or extended out-of-home placement.” Steven explained that the case was brought on behalf of 9 children who had serious emotional disturbance. Most of the caregivers were single mothers or grandmothers; all were receiving public assistance. Only one child had received EI services; his mother described to the judge her own journey. Her child had wraparound services –

though not called that – and lost the service when he turned three. The outcome of the suit was that the court found Massachusetts in violation of EPSDT provisions and ordered the state to develop in-home services including comprehensive assessments, case management, behavior supports, and mobile crisis services. Implementation timelines stretch from Nov. 2007 through June 2009, at which time the service delivery system must be operational and home-based services are to be available to children who have Medicaid. There are significant challenges to implementation: Workforce shortages, provider capacity, ongoing training and education, outcome measurement, network development, and overall resources. Steven stated that EI providers have the experience to be helpful in this process.

Discussion: The following points were discussed:

- The capacity to do this work will have to be developed because almost everything needed will be in addition to what already exists. While some Family Stabilization Teams do exist, integration and consolidation of emergency services will be necessary, and mobile crisis teams will be new for them.
- Beginning 1/1/08, every primary care pediatrician is obligated to screen for autism, and if findings are positive they are required to refer for evaluation in order to be paid by Medicaid. Service capacity will initially fall short; however, there will be problems initially, the basic judgment is in place and will not change.
- Robin Adair, physician representative to the ICC, commented that she is involved in training physicians to do the screening.
- Additional information is available at www.centerforpublicrepresentation.org and at www.rosied.org.

5. Committee Reports:

- **Personnel Preparation Committee – Rena Ginsberg:** The committee will be meeting again soon with representatives of the higher education community in an effort to keep communication flowing. A survey has been sent to programs asking for input about their training and supervision needs for part time and fee-for-service staff.
- **Program Planning Committee – Joanne Williams:** The committee wishes to thank the ICC for the opportunity to focus at length on social emotional development and related service needs at the recent ICC Retreat.
- **Specialty Services Committee – Tom Miller:** The committee is reviewing its strategic planning goals for FY 08. Discussion of the ICC Retreat led to the recommendation that an Autism Forum should be formed.
- **Fiscal Committee – Peter Woodbury:** The committee continues to discuss potential budget shortfalls for FY 08 and FY 09. It is also tracking the progress of the College Cost Reduction Act through Congress. This bill may make amounts of up to \$5,000 per year available for loan repayment in areas of national need, including early childhood, nursing, and speech-language pathology.

LISTENING SESSION - November 8, 2007

Department of Public Health staff convened a **Listening Session** as the final segment of the regular ICC meeting held November 8, 2007, at Marlboro, Massachusetts. Sally Fogerty, Ron Benham and several other Early Intervention staff of the Department were present. Many members of the provider community joined ICC members. The goal was to listen to concerns of providers and parents as the Early Intervention system in Massachusetts faces challenges brought about by growth in numbers of children served along with growing fiscal challenges.

Sally Fogerty thanked the ICC for providing this opportunity for an exchange of ideas about the challenges we collectively face. She also thanked Peter Woodbury, Chair of the Fiscal Committee, for urging that this meeting take place early in the decision making process while there is still time for collaborative planning. Sally stated that EI in Massachusetts is an incredibly strong, high quality service system that is seen as a national model. No other state has our broad system of payers. We also have an exceptionally dedicated workforce.

Ron Benham commented on the recent American Academy of Pediatrics statement that all children be screened for autism in their primary care setting two times by the age of two. Additional children will most certainly be referred to EI and this will exacerbate a revenue problem that already exists. The Department does continuous data runs and knows more than ever before about who is being served. We are proud that accessibility to services, for lower income and multi-risk families, is steadily improving. Advocacy efforts are strong.

A serious challenge to the system is that EI in Massachusetts operates as a quasi-entitlement without secure funding. There is continuing significant growth in numbers of children served. It is no longer possible to attract, hire and retain sufficient staff to do the work. In the Massachusetts child count on December 1, 2006, 6.41% of all 0-3-year-olds were being served at that point in time, compared to the national average of 2.435. the cumulative count is roughly double that. Yet we receive progressively less federal money because Massachusetts births are declining when compared with other states.

In the current FY 08, we face a \$3 million shortfall and will be allowed to submit a supplementary budget request. Systemically, there are double digit increases in numbers of children who have MassHealth and in developmental specialists working in the system. In addition, an increasing number of employers are using self insurance plans that give them the *choice* of whether or not to cover EI services. Insurance deductibles and co-payments have quadrupled; even a small increase, multiplied across such large numbers, causes a significant shortfall.

There could be a multi-million dollar funding gap in FY 09. The big question is how to address growth and also address the need for a rate increase in order to begin to deal with workforce issues. Can we tweak the system any more without harming the quality of services to families?

Mary Ann Mulligan, Legislative Analyst for the Massachusetts Early Intervention Consortium, made the following statement about how to frame discussion. The system needs to move on two fronts: caseload numbers and service provided; and workforce challenges. It's important to stop splitting these topics and acknowledge that, collectively, we have a serious problem. The system cannot be restructured on a broken base. EI needs to think and act like an emergency room where triage takes place. Put staffing up front because children and families are waiting for the service. We need to *frame, prioritize, triage (create 30-day and 60-day timelines, for example), and change our culture.*

Peter Woodbury described six issues facing the system and requested the Commissioner 's direct involvement in exploring possible solutions: 1) Ask Medicaid to assume responsibility for all costs for eligible children. 2) Obtain a Medicaid waiver to directly pay autism specialty providers. 3) Convene insurance industry leaders and challenge them to pay for all services to children with the medical diagnosis of autism. 4) Re-examine the current coverage of co-pays and deductibles for EI services, which relieves insurers of much of their responsibility. 5) Explore all the potential pockets of funding that may exist within other agencies in EOHHS. 6) Convene a blue ribbon committee of all players to determine best practice and discuss what an informed society can do to achieve it.

In the discussion that followed, Department staff heard the following ideas and concerns from parents and providers. For coherence, they have been grouped here under several headings:

Alternative sources of funding:

Provide a list of grants that are available to help get resources to families.

Look at the Rosie D litigation for possible sources of further support for EI.

Could children with multiple complex needs be a revenue-generating group of children?

Eligibility:

- Change the duration of the IFSP to six months so that programs are not locked into serving children who are no longer eligible.
- Leave eligibility at 25% but re-look at the list of diagnoses that make a child immediately eligible, and require a delay in addition to the diagnosis where appropriate. Consider the severity of problems.
- If eligibility guidelines are made more strict, there will be some children who become eligible for special education services at age three who did not qualify for or benefit from EI services.
- The greatest increase in numbers of children served is in children with speech and language delays. Most have one delay of less than 30%, and many of these do not go on to need special education. However, for some children, early intervention potentially has maximum impact on later school success, making an excellent return on investment. Other things can go wrong if children with benign speech delay are not treated early enough.

Definition of the scope of Early Intervention; changes to Operational Standards

- More clearly define EI; it is not meant to provide five days a week of multiple therapies.
- Combine intake and assessment hours so that programs can be reimbursed when developmental specialists are doing intake. Bear in mind that six hours is the average of assessment time being used, and that 25% (more than 8,000 children) with any billable event do not go on to receive IFSP services.
- Consider making service coordination, including phone calls, a separate billable service. Bear in mind that the rate for treatment services would probably be reduced if this happens.
- Currently we define eligibility in broad categories and for long periods of time. Experiment with time-limited treatment designs.
- Eliminate clinical judgment.
- If it becomes necessary to go to 30% delay, numbers served would drop and then recover, and children who need more intensive services would be able to receive them.
- Look at alternative ways to offer services to children with mild to moderate speech delay and no associated problems.

Parent participation fees

Participation fees should not be further increased.

Service system for children on the autism spectrum

- Reconsider the provision of up to 30 hours of services per week to children with autism diagnoses. Bear in mind that 10-15 hours of specialty services is the system average at this time and that the rate paid to specialty providers goes down as the number of hours per week goes up.
- Consider center-based regionally organized services for children with autism.

Medicaid payment for services

- Expect Medicaid to pay for behavioral services for covered children.
- Medicaid is concerned about setting a precedent by paying for developmental specialists; reimbursement through FFP circumvents that concern.

Workforce issues and staffing patterns

- Reconsider whether Certified OT and PT Assistants should be made billable. Bear in mind that the reimbursement rate is the same as for registered therapist as long as 20% of their time is directly supervised and a supervisor signs off on the work; but also that salaries paid to these assistants may already exceed what EI rates would allow programs to pay them.
- Some programs provide special training and mentorship to help developmental specialists become billable as speech therapy assistants.
- When programs hire more part time and fee-for-service therapists, they also must assign developmental specialists as service coordinators for the same families that are receiving therapy services.
- Work with the Board of Higher Education to address the intersection between supply and demand; brainstorm solutions and fast track them.

Program viability

- Programs have exhausted all possible adjustments to the way they do business. There is an increasingly urgent need to pay fair wages to staff and obtain reimbursement for escalating operating expenses.
- Put reimbursement rate and numbers served on the same table at the same time, and confront the fact that increasing the rate could require limitation in numbers served and/or scope of services.