MEETING SUMMARY

Massachusetts CSHCN Invitational Meeting

Identifying Top Priorities for Investment to Improve the System of Care for Children with Special Health Care Needs and their Families

December 16, 2008

PURPOSE OF MEETING: To solicit ideas and guidance about priorities regarding CSHCN and their families, and about where DPH and the Consortium can most effectively focus their efforts.

HOSTS: Massachusetts Department of Public Health; Massachusetts Consortium for Children with Special Health Care Needs

PARTICIPANTS: Approximately two dozen stakeholders in leadership positions across the system of care.

SUMMARY OF PANEL'S POLICY PRIORITIES

Moderator: Nancy Turnbull, Harvard University School of Public Health

Panelist #1: Meg Comeau, The Catalyst Center: Improving Financing of Care for CYSHCN (BUSPH) and parent of a young adult with special health care needs.

- **Underinsurance and medical debt.** Citing National Survey of CSHCN (from pre-health care reform): 32.9% of MA families of CSHCN did not have enough coverage to meet their needs; 15% had financial problems because of their child's health. Uninsurance is not the only issue; we need to consider not only breadth of coverage but depth of coverage.
- **Electronic health care records.** Electronic records are important for safety issues, care coordination, and medical home; work in this area would need to address privacy issues. There is a role for the Consortium here.
- **The process for obtaining durable medical equipment (DME).** The current system overburdens families and wastes dollars. The Consortium has begun work in this area, but there is more work to be done. There is a possible role for DPH in quality improvement and contract oversight with payers
- **What MA is doing right:** Our Early Intervention system is a model for the nation. We have a high degree of collaboration, communication among diverse stakeholders. In our current budget crisis and the general economic crisis, we face tough choices; the worst thing to do would be to retreat back into our silos and stop talking to one another.

Panelist #2: Barry Zallen, Blue Cross Blue Shield of MA

- **Measurement to identify the needs and the quality of care of CSHCN:** Without measurement of what's going on with CSHCN we don't know what needs are, what good quality is, where gaps are. Hampers our ability to tell the story to anyone else to get money, support, resources. Measurement for kids more challenging than for adults: smaller numbers, variations in conditions .
- **Coordination of care and access to care, whether through medical home or other models.** Medical home is one possible solution but may not be the only one. Various models possible to achieve coordination: physical medical homes, virtual medical homes, others.
    - From payer perspective, reimbursement influences how care is delivered. Ex. Alternative Care Contract is move to paying for quality, efficiency, safety and care for populations, rather than for quantity and complexity.
    - Any effort to pay for high quality coordinated care means taking money from somewhere else. To support pediatric medical home probably means taking from adult specialty care, lots of overuse there.
    - CMS/Medicare would be the ones who would have to make that happen; they overpay for some specialties, procedures, etc. and underpay for others. What they pay influences what docs do. But Medicare not a big player for peds. Medicaid and private payers can influence for kids. National work on medical home focuses on adults; when that takes off, kids will then benefit in slipstream.
- **Respite and parent support.** Promote through online social networks. Measurement really comes into play here, no one knows what numbers are.

Panelist #3: Judith Palfrey, Children's Hospital Boston

- **Medical home.** It's time for the Medical Home in MA because: 1) National moment of opportunity, 2) we know what to do, and 3) MA should be taking a leadership role.
    - Momentum: Medical home is on radar in Washington. Patient Centered Primary Care Collaborative (PCPCC), includes Fortune 500 employers, unhappy with what they're getting, they want medical home. "We want quality, we want IT. we want Medical Home." Like Guido in Breaking Away, we can latch on, benefit from the slipstream.
    - Medical home started out in 1960's meaning medical record: all info about child in one place. Current definition, continuous, comprehensive, coordinated, etc., financing isn't on the list, but it's a central component.
    - All those other things – transition, coordination, recreation etc. are all wrapped up together in medical home.
    - PACC (Pediatric Alliance for Coordinated Care) experiment: 6 practices with $15K per year for medical home, cut hospitalizations, got parents back to work, increased family satisfaction.
    - Other states are leading the way: Washington, Minnesota, Oklahoma, Illinois, Louisiana, Alabama, North Carolina has dreamiest medical home system (they're doing it and saving money), Pennsylvania, Connecticut and Rhode Island. Alabama and Rhode Island are saving substantial money on kids. Re measurement: does MA have to show cost savings of medical home for kids?
- **Priorities for this group:**
    - At national level, we need to participate with PCPCC. Make sure Medicaid is part of the conversation along with private insurance and Medicare. Advocate for

parity of Medicaid with Medicare. Medicaid pays 66% what Medicare pays, kids vs. adults. Need to work with NCQA and other quality initiatives.

- At state level, useful to think about PCPCC and possibility of going for Medicaid pilots for kids to advocate for Medicaid parity and create an all-payer system for medical home. What if the Consortium acted as the PCPCC, bringing in head of Medicaid, all payers, and some employers. Need to align with power brokers, they want medical home.

Panelist #4: Deborah Klein Walker, Abt Associates, Inc.

- Development of a clear platform for reform: Need to develop a platform leading with **medical home**, to be able to go to government, Medicaid and other payers. Really spell out clearly what we want. Supports what all panelists said, but this is what we need to make it happen.
  - See NES's platform for reform from 1986. We got CommonHealth but everything else in that platform we haven't gotten.
  - Nation looking at MA as a model re health care reform, but much was left out. Look at those things out we left out: Medical home, care coordination system across all state agencies, family support system. Prevention and wellness -- the other big thing in the adult world.
  - Note on medical home: needs to include mental health and developmental disability.
- **Advocacy and education to promote the platform**: Needed to promote the platform, like 1988 Platform. May not be a role for the Consortium but a subgroup. "Friends of CYSHCN." Strong advocacy, spelling out clearly what we want, so Consortium is the "Go To" place.
  - We've made a lot of tools, etc, but where are we? Need to raise it another level.
  - We need to get on everyone's agenda – including prevention and wellness.

THEMATIC SUMMARY OF DISCUSSION

Facilitator: Deborah Allen, Boston Public Health Commission

Policy areas are listed in alphabetical order; discussion summaries include paraphrased comments made by panelists and participants.

1. Constituency-Building in Support of a Platform for Reform
2. Durable Medical Equipment (DME)
3. Electronic Health Care Records
4. Family Support Programs/Respite Care
5. Medical Home
6. Quality Care Measurement
7. Systems Integration, Coordination of and Access to Care
8. Underinsurance and Medical Debt

1. Constituency-Building in Support of a Platform for Reform

Developing a Platform for Reform
A clear platform will enable us to go to the government, to Medicaid and other payers to ask for what is needed. The platform should include:

- Things that were included in New England SERVE's 1986 platform for reform that still haven't happened.

- Things that were left out of Massachusetts health care reform: medical home, care coordination, family support, prevention and wellness.
- Families' real world problems/needs; these should be the starting point for policy.
- Precise language about medical home and care coordination: service components, payment structure, how it differs for kids vs. adults. *See also Medical Home.*

Advocacy and Education to Promote the Platform

We need to build an informed constituency to promote the platform:

- Advocate to make sure kids are included in what is already happening both in and out of MA – medical home training, defining Medicaid procurement for MCO's, etc.
- Measurement will be extremely important to promoting the platform. *See also Quality Care Measurement.*
- Promote it through online social networks.
- May not be a role for the Consortium but a subgroup
- Care coordination for kids with disabilities is an active discussion now with MassHealth, MCO's. Looking at disabilities across lifespan, also medical home and care coordination across agencies. The Consortium could play a role in advising on kids' needs, the ways kids and adults are the same and different in terms of provider mix, financing mechanisms, service components.
- Is there anything in Obama's stimulus package that could benefit us? Consider roles people could play ex. labor force training PCA's, care support personnel.

2. Durable Medical Equipment (DME)

The current system for obtaining DME overburdens families and wastes dollars. The Consortium has begun work in this area but there is more work to be done. There is a possible role for DPH re quality improvement and contract oversight with payers.

3. Electronic Health Care Records

Electronic health care records are important for CSHCN in terms of safety issues, care coordination. Role for Consortium here. Need to address privacy issues.

4. Family Support Programs/Respite Care

The Need is Great, and Growing

- Families are primary providers of care. In times of economic crisis a lot more responsibility will be shifted to families; their role is not on the balance sheet. We need to make the case for the role families play, and there needs to be a complementary role on the professional side.
- This is related to the need for health literacy.
- Family support has to be a priority, not just in terms of families' roles, but in that families define the needs. *See also Constituency-Building in Support of a Platform for Reform.*
- Families are looking for coordination between school and medical care. *See also Systems Integration, Coordination of and Access to Care*
- Some families are approved for home nursing but can't find nurses. This is not only a respite issue but an issue of infrastructure, and some kids go into long term care because of that. Need flexible family supports.
- *See also DME, Medical Home, Underinsurance and Medical Debt.*

5. Medical Home

It's time for the Medical Home in MA because: 1) there is a national moment of opportunity, 2) we know what to do, and 3) MA should be taking a leadership role.

National Moment of Opportunity

- The work of the Patient Centered Primary Care Collaborative (PCPCC) demonstrates current national momentum; medical home is "on the radar" in Washington. Fortune 500 employers want it.
- The medical home model that the AAP created has gotten co-opted by adult world, and patient-centered medical home will be implemented at the adult level in 2009. The pediatric world can benefit from the slipstream.
- The nation is looking to Massachusetts since health care reform; we should be taking a leadership role in medical home, as other states are – Washington, Minnesota, Oklahoma, Illinois, Louisiana, Alabama, North Carolina, Pennsylvania, Connecticut and Rhode Island.
- Other priorities – transition services, care coordination, family support, etc. – are all wrapped up together in medical home.
- Family-centered medical home takes care of families, not just kids.

Defining Medical Home More Precisely

- Medical home started out in 1960's meaning medical record: all the information about a child in one place. The current definition – continuous, comprehensive, coordinated, etc. – does not include financing on that list of adjectives, but it's a central component.
- We will need to define pediatric medical home more precisely, including how it differs from adult medical home in terms of provider mix, financing mechanisms, needs, and service components.
    - If we add precision to the language about medical home and care coordination, they could become shared concepts – we should not assume that they are shared now.
    - We need to make sure it includes mental health and developmental disabilities.
    - The package of services from the adult side is really chronic condition management. That's where money is being spent. In pediatrics, Medical Home is much broader than chronic condition management, there are thousands of different conditions, many more than adults.
    - Pediatric care coordination [in a medical home] includes things that don't go to the payer, like help with school supports, IEP's, family supports, optimal achievement, nothing to do with current reimbursement.
    - We'll need to go beyond what constitutes medical home and get clear about services and outcomes. Outcomes are not just health indicators, but also things like family stabilization.
    - Have diversified financing mechanisms, but in kid world EI then school and health care. Waivers for adults – HCBS waiver for adults and some kids. Not just stabilizing health outcomes, not just nursing home or not, goes to point about measurement.
    - *See also Systems Integration, Coordination of and Access to Care.*

Demonstrating Cost Savings

Will we need to demonstrate that medical home for kids will provide cost savings?

- Alabama and Rhode Island are saving substantial money on kids with medical home.
- The PACC (Pediatric Alliance for Coordinated Care) experiment gave 6 practices $15K per year for medical home. They cut hospitalizations, got parents back to work, increased family satisfaction.
- States that have shown savings have defined SHCN very narrowly, i.e., the most expensive kids. It's easy to show savings for adults, because if you move them from a nursing home to the community, there's a big savings. But many of the most expensive CSHCN are already in the community. Parents are providing care but are not paid, so savings are hard to show.
- No one has proved cost savings of medical home even in the adult world, so why hold to kids to a different standard? We couldn't show it anyway for a long time. Showing improved outcomes will be enough.

6. Quality Care Measurement

- Without measurement of what's going on with CSHCN we don't know what the needs are, what good quality is, where the gaps are. That hampers our ability to tell the story to anyone else to get money, support, resources.
- Measurement for kids is more challenging than for adults: smaller numbers, greater variations in conditions.
- Quality measurement is important to kids because of prevention.
- Measurement is needed for every one of these policy priorities.

7. Systems Integration, Coordination of and Access to Care

Care Coordination, Access, and Reimbursement

Coordination of care and access to care are the important goals; medical home is one possible way to get those things but it may not be the only one. Various models are possible to achieve coordination: physical medical homes, virtual medical homes, others.

- From a payer perspective, reimbursement influences how care is delivered. Example: the Alternative Care Contract is a move to paying for quality, efficiency, safety and care for populations, rather than for quantity and complexity.
- Any effort to pay for high-quality, coordinated care means taking money from somewhere else. To support pediatric medical home probably means taking from adult specialty care, as there is lots of overuse there.
- CMS/Medicare would be the ones who would have to make that happen; they overpay for some specialties, procedures, etc. and underpay for others. What they pay influences what doctors do. But Medicare is not a big player for pediatrics. Medicaid and private payers can influence for kids. National work on medical home focuses on adults; when that takes off, kids will then benefit in slipstream.
- Pediatric care coordination includes things that don't go to the payer, like help with school supports, family supports, optimal achievement, nothing to do with current reimbursement.
    - A paper by Dr. Richard Antonelli that offers a framework for pediatric care coordination will soon be available on the Commonwealth Fund's web site.
- Care coordination for kids with disabilities is an active discussion now with MassHealth, MCO's. If we could add precision to the language about medical home and care coordination they could become shared concepts. Ex. what is incorporated, who executes it, at what level; what is the provider participation, and what payment structures? *See also Medical Home.*
- When we think about DPH funding for support for care coordination, we need to think about the economic impact that a sick child has on a family – this is not measured by Medicaid or DPH. Poor kids get sick. Sick kids get poor. Clinicians need to be able to hire parents as experts who can connect families to what they need.
- Access to care has to be a priority, meaning the ability to get into services quickly, both primary care and specialty care. Ex. kids on MassHealth or CommonHealth who need mental health services don't have access to the same breadth and depth of services if providers don't accept those.

Systems Integration and Communication Between Schools and Health Care Providers

Care coordination needs to happen both at the family level and the system level; i.e.,systems integration should also be a priority. Ex. DPH and the Consortium's work to bring together people across agencies; having one entry point for public services, to make the consumer experience seamless.

Families are looking for coordination and communication between school and medical care.

- Silos, different buckets for paying for things result in problems for families and providers. Ex. a child has autism, how much responsibility is mental health, how much is medical, how much is educational?

- If a child has autism, the family is looked at as a big expense rather than a family that needs support. There's a stigma being one of those families, 'budget busters' for special ed costs.
- Kids disappear from human services at age 3 when they age out of EI and some reappear at 22. In between they are in the education system.
- We need to get DOE here as part of the conversation. IEP meetings can't be only the point of contact.
- It's important to include schools, but we need to remember that the primary role of school is learning. Education can get lost if therapies, care, happen at school. We should support school nurses so they can support CSHCN in school.

8. Underinsurance and Medical Debt
According to the National Survey of CSHCN (from pre health care reform): 32.9% of MA families of CSHCN did not have enough coverage to meet their needs; 15% had financial problems because of child's health. Uninsurance is not the only issue; we need to consider not only the breadth of coverage but the depth of coverage.

RECOMMENDATIONS TO DPH AND THE CONSORTIUM

All of the policy priorities we have discussed are on the national agenda. For the Consortium, a dual strategy:

1) How can we inform health care reform discussion?
2) How can we apply reforms specifically to CSHCN?

We need to create a targeted, winnable campaign, need people willing to give time and money to bring in stakeholders, advocates and dollars.

To do that we have real financial issue: the Consortium has to stay in business.

Sustainability and Possible Roles for the Consortium
Collaboration, communication of diverse stakeholders is one of the things MA is doing right. In our current budget crisis, general economic crisis, there will be tough choices, and the worst thing to do would be to retreat back into our silos and stop talking to one another.

- Try to get DMH, DMR to join DPH in supporting the Consortium.
- The Consortium could be the place that describes the platform precisely, and/or a vehicle for advocacy for going to legislature.
- DPH has 5 year needs assessment due in 2010; there may be role for Consortium in carrying out some of those.
- Medical home is something everybody wants, so membership in the Consortium should cost something. Dues – hospitals, payers, employers.
- The Consortium could play a role in advising EOHHS on kids' needs, clarifying components and outcomes of medical home, care coordination.

Setting and Promoting Policy Priorities

- Health disparities among CSHCN factor into many of the priority issues; when considering all policy priorities, consider whether they are going to make disparities better or worse.

- Most CSHCN have mild to moderate needs; neither their families nor providers necessarily think of them as SHCN. Need to think about all kids to make sure we reach those. Also need to identify wider range of resources available to CSHCN, not just those that are expressly labeled for CSHCN.

- Add precision to language about medical home and care coordination.

- Priorities for DPH: bring in Department of Education (DOE). Kid, family and school are primary drivers of health care system. If medical home on agenda, it could be huge pocket of funding.

- At a national level:
  - Participate with the Patient Centered Primary Care Collaborative (PCPCC).
  - Make sure Medicaid is part of the conversation along with private insurance and Medicare.
  - Advocate for parity of Medicaid with Medicare. Medicaid pays 66% what Medicare pays, kids vs. adults.
  - Work with NCQA and other quality initiatives.

- At the state level:
  - Consider the possibility of going for Medicaid pilots for kids to advocate for Medicaid parity and create an all-payer system for medical home.
  - Consider a role for the Consortium similar to the PCPCC, bringing in the head of Medicaid, all payers, and some employers, to advocate for medical home.

- DMR has great family support program. DPH could grow theirs using DMR as a model.

- Look at the possibility of HCBS waivers, which could support parents as caregivers as they do in some other states. Ex. Washington state. Otherwise one parent quits their job to care for the child, loses income, and the family may go into poverty.

- Advocacy, active stakeholder cultivation, lawmakers not just DPH, those who have funding or can advocate for federal funding being at the table.