Citizens' Health Care Working Group
Public Hearing
Wednesday, August 17, 2005
Boston, MA

Hearing Summary

Attendees

Members

Randy Johnson, Chair
Catherine McLaughlin, Vice Chair
Frank Baumeister
Dotty Bazos
Montye Conlan
Richard Frank
Joseph Hansen
Therese Hughes
Rosario Perez
Aaron Shirley
Deborah Stehr
Christine Wright

Staff

George Grob, Executive Director
Andy Rock
Caroline Taplin
Jessica Federer
Connie Smith
Rachel Tyree

Other Attendees

Jack Molnar, Editing Contractor
Donald Cox, Associate of Michael O'Grady, Representative for the Secretary, Department of Health and Human Services

HEARING SUMMARY

Randy Johnson, Chair, called the meeting to order at 8:40 a.m.; all members listed above were present. Members of the public were also present. Highlights of the presentations and discussions during the day are summarized below. For verbatim record of the speakers' statements, see Transcript.

Mental Health

Speakers:
Elizabeth Childs, M.D., Commissioner, Massachusetts Department of Mental Health
Deborah Nelson, Beacon Health Strategies
Toby Fisher, Executive Director, National Alliance for the Mentally Ill (NAMI) of Massachusetts

Presentations:
See Elizabeth Childs' **Powerpoint slides and CHCWG-provided comments**.
See Deborah Nelson's **Powerpoint slides and CHCWG-provided comments.**
See Toby Fisher's **Powerpoint slides and CHCWG-provided comments.**

For verbatim records of the speakers' statements, see Transcript.

Discussion:

Randy Johnson – To what extent are mental health professionals ready to have their performance measured and transparent?

Nelson – They are not quite ready; however, the science is there regarding what the general measures of quality are in order to measure behavioral interventions. With consumer- and various stakeholder-input, we should arrive at agreed upon measures. The national quality forum is already there. Measures are not now in widespread use. Providers are concerned about being measured and concerned about potential backlash. But I'm supportive of this direction

Montye Conlan – Florida has changed its Medicaid formulary; what is new is a "fail first" approach which is a drastic step from previous drug treatment coverage. Now patients are expected to fail at a cheaper drug first before getting the drug that may be perceived as a preferred drug by the patient.

Fisher – Many states are taking this approach; that needs to be dealt with. Patients and their advocates just have to kick and scream about this change.

Richard Frank – How are you using the tool of the mental health carve out?

Childs – Much of the funding for drugs today is from Medicaid. Many of the drug expenditures are generating Medicaid match. The challenge is to harness nearly a billion of spending to eliminate duplication and maximize services. Use of state maintenance of effort funds is very prescribed. If we're going to move the system forward and increase spending in mental health, we need to do so in a state and federal partnership. The Massachusetts initiative is trying to do this by eliminating redundancy and inefficiency. Seven percent of the 9-18 year old population in Massachusetts has extreme dysfunctional conditions. There is also dysfunction among the very young. The effort is to make the state systems and Medicaid work better together. The major important difference in mental health care, as distinct from physical health care, is that the continuity and transitions of care are critical.

Joe Hansen – Are there any standards when you are dealing with bidders for services of health vendors? If the money is public money, how are standards enforced?

Nelson – If we under-fund the services, we're shooting ourselves in the foot.

Childs – Partnerships are much more effective arrangements in seeking to get good quality of care. I can either try to enforce standards or I can seek to engage the contractors as partners and seek to affirmatively encourage and solicit the best output and quality of care that they are capable of delivering. We have monthly meetings in the Commissioner's office; we bring all the people to the table and we can discuss the alternatives to having to simply pay costs by paying for performance. We can elicit the incredible knowledge and expertise of some providers and then pay for what they deliver.

State, County, and Local Initiatives

Speakers:
Trish Riley, Director, Governor's Office of Health Policy and Finance, Maine
Vondie Woodbury, Director, Muskegon Community Health Project

Presentations:
See Trish Riley's **Powerpoint slides and CHCWG-provided comments**.
Also, see document provided by Trish Riley: *"Preliminary Report; Tough Choices in Health Care;"* May 21, 2005, Biddeford, Orono"
See Vondie Woodbury's **Powerpoint slides and CHCWG-provided comments**.

For verbatim records of the speakers' statements, see Transcript.

Discussion:

Riley – Use of America*Speaks* was useful but challenging. There was still some self-selection (of participants in the meetings) but the meetings were also relatively representative. It's important to make an effort to get a group that doesn't have an ax to grind.

Aaron Shirley – Can you address Federally Qualified Health Centers?

Woodbury – Our FQHCs serve 20,000 individuals. Participants in Access Health can use FQHCs if they wish. And, the FQHC is also available to provide care for those who continue to be uninsured.

Montye Conlan – Do you purchase memberships for people at the swimming pool and are they utilized?

Woodbury – Yes; we have special classes for different populations. Two-thirds of our community is over-weight and typically has joint problems; aqua-therapy has been a major piece of this treatment.

Catherine McLaughlin – What would you like us to learn that should be reflected in our recommendations to Congress and the President?

Woodbury – Include a blend of strong partnerships of communities, states, and National government that fosters creative solutions; encourage Congress to look more closely at these kinds of partnerships.

Riley – I think this is a system issue; people have no idea about what the coverage is that they have. There has to be some sense of what we mean about standards. Shared financing is critical while delivery is local. States really are the laboratories for creative solutions. HIPAA, Patients' Bill of Rights, and other legislation, happened only after states had experimented with solutions to these issues. System reform that is implemented over the long haul is needed, not quick fixes. You cannot look at access alone. What is needed from the federal government is assistance in identifying quality measures, and data requirements, and as well as help in streamlining the system.

Randy Johnson – To what extent has your program experienced adverse selection (e.g., attracting enrollees with high health care needs)?

Woodbury – We got adverse selection among sole-proprietors. Sales/marketing is essential with a new product. Sole-proprietors would sign up only after they needed specific coverage. We had to limit their enrollment period.

Riley – We went with an insurance approach. Insurance providers are very risk averse. We built in a limit on the number of people that we would insure; after the first year, insurance companies were on their own; this introduction seemed to enable the insurers to get involved.

Randy Johnson – We've heard about a fragmented system. What are your thoughts about a single payor system on the one hand, and a uniform set of national rules that health insurance plans would follow, on the other.

Riley – Dirigo, in Maine, builds on employer-provided coverage and also builds on Medicaid. We work with local providers. We also actively pursued making sure that the tobacco court settlement fund has been spent on health care.

Woodbury – We have a collaborative that jointly decides how to address a need; Muskegon county seeks to support these decisions.

<u>End of Life Panel</u>

Speakers:
Ira Byock, M.D., Director of Palliative Medicine, Dartmouth Hitchcock Medical Center

Nicholas Christakis, M.D., Harvard Medical School
Joanne Lynn, M.D., RAND

Presentations:
See Ira Byock's **Powerpoint slides and CHCWG comments**.
See also: "Accounting for the Costs of Caring Through the End of Life" and "Financial Implications of Promoting Excellence in End of Life Care", two monographs from the Robert Wood Johnson Foundation's national program, Promoting Excellence in End-of-Life Care.

Nicholas Christakis, M.D.

For verbatim records of the speakers' statements, see Transcript.

I want to present some research findings pertinent to the deliberations of the Working Group. What is the public sentiment regarding what constitutes a "good death?"

- 93% of Americans believe that being free of pain is important; but only about 1/3 of those who die achieve this objective. This is unfortunate; it is unnecessary for people to die in pain. There have been improvements in this area, however.
- 89% say that not burdening the family when dying is important as part of a good death; this seems a peculiarly American value. Only about 45% of Americans achieve this objective.
- 95% say having a doctor who listens is important but only 30-40% have this.
- 70% of Americans say that being able to be at home when dying is important. But, only 15% of Americans die at home.
- Knowing what to expect is desired by 96% of Americans. Only about 15% have adequate prognostic information.

Most Americans want these and other features that constitute preferences that characterize a "good death." We're not doing very well in achieving these things, however, even though most of these could be achieved without great expenditure.

What are risk factors for dying in pain? The greatest risk factors are: being a woman; being older; being in better physical shape; having a discrepancy in the patient-physician relationship regarding the extent of pain, not having clear communications between patient and physician regarding the extent of pain; and dying from a cause other than cancer.

What are the determinants of the site of death? Patient preferences don't appear to matter but the regional bed supply does: the more beds there are per capita in the area the smaller a person's chance of dying at home (a factor exogenous to the patient). Also, the more spending on hospice, the greater the likelihood of dying at home (some areas, like Indiana, have almost no hospice care whereas others, such as Florida, have a very high percent of people receiving hospice care).

If we provide high quality of care during dying, does it matter? First, what are we measuring? Hospice care reduces pain, increases home death, creates less burden on families, etc; in fact, most of the patient preference parameters are improved, regardless of what is measured, if the individual receives hospice care.

How does care delivered to one spouse affect the health care delivered to the other spouse? Hospice care reduces the chance of a surviving spouse dying – by a measurable 5%.

What is the utility and reliability of prognostication of dying events? In the rush not to abandon the patient medically, we abandoned the patient therapeutically. It is very important that the clinician be able to recognize and know whether a patient is likely to die or not. Learning to recognize dying is essential to delivering appropriate and caring final care.

Americans die needlessly badly. Since we will all experience this eventually, you would think that we would care about this. The vulnerable dying deserve our care.

See Joanne Lynn's **Powerpoint slides and CHCWG comments**.
Also, see Joanne Lynn's and David Adamson's White Paper: *"Living Well at the End of Life"*

For a verbatim record of the speakers' statements, see Transcript.

Discussion:

Randy Johnson – What one question would you recommend that the Working Group ask the American public regarding this subject?

Lynn – "For your family members who are in their 80's, what do you most want for health care and why can't you get it?"

Byock – "What would a healthy last chapter of life look like for you and your family?"

Cristakis – "Please state the key aspects of a "good death" that you believe a health care system can and should deliver."

Byock – We're still not training the new generation of health care providers to address these issues. We're still retrofitting the past graduates of medical training to deal with end of life issues. We still don't know what positive outcomes (i.e.: a "good death") we are seeking. A good death is commonly defined as the opposite of what we most fear rather than the positive things we would seek. The RWJF funding sought to encourage models that would spark Medicare or Congress to sponsor regional demonstrations. We believe we are funding poorer care than we could get. There is resistance from the industry to look at more innovative approaches to palliative care. We're trying to do studies to demonstrate its cost effectiveness. I can't stress enough, that total costs are reduced when palliative care is provided. But there are winners and losers economically, so we need some population-based studies to explore effective and safe forms of care options (and to help identify how to offset the economic imbalances that occur).

Lynn – We have found that it is more effective to ask the doctor "would you be surprised if this patient died in a brief period of time?" (rather than asking whether the patient would die). Then the doctor is more willing to make these speculative judgments, realizing that, on an individual basis, the patient may go on to live for years.

Montye Conlan – There are multiple sclerosis patients that have reached the advanced stage of the disease only to be abandoned by their families. They then have to get care in public nursing homes where they are mostly with very elderly patients. In this environment, they get depressed and have other reactions because they are with people who are suffering from other conditions and whose experiences are unrelated.

Lynn – Having age-related peers seems better; unfortunately a private home environment may cost $150,000/year. What we need is a way to notice and deal with this issue. In Sweden, there are groups of people who are responsible for dealing with this kind of problem. There are individuals working on designing care for special groups. We also need more support for family care givers. We can develop groups of people to address these issues and develop better housing options.

Catherine McLaughlin – Do any of you have data on the age distribution of those in the end of life: if we only talk about the elderly, who are we leaving out? How do we address the care cost tradeoffs?

Byock – Doctors will always provide you with another service. We (doctors) don't communicate to people that by seeking more and more health care, people may be making choices that take away from themselves the opportunities for a fuller and better death. Dying happens to adults, by and large; it is a Medicare topic. About 20% of Americans pass through an ICU immediately before dying.

Christakis – Seventy-five percent of Americans die at ages over 65 years old.

Lynn – Eighty-three percent of the dying are covered by Medicare. The non-Medicare population is known less well since we don't have as good statistics. End of life care is the one area of health care where, as a general matter, less appears to increase the quality.

Richard Frank – You've persuaded me that what is wrong with end of life care is emblematic of everything that can go wrong in the over-all health care system. What are one or two things that are generalizable to the over-all health care system?

Byock – Continuity, care planning, communication; need for a health care "concierge"—it is too difficult to navigate alone.

Lynn – We need to identify the populations and figure out how to serve them. Do data driven reform and we'll get it right; start with assumptions and we'll get it wrong.

Dotty Bazos – Why aren't we using Medicaid creatively to better address end of life care?

Lynn – PACE is a good example for alternative care but it, like all Medicaid, requires a spend down before it is available.

Therese Hughes – Isn't aggressive and effective education with families dealing with end of life experiences essential?

Lynn – Yes; as part of the education, we need to encourage family caregivers to better politically direct their anger and frustration.

Rosie Perez – What about the Hispanic community and other groups?

Byock – Some ethnic and cultural groups have very different attitudes; they may harbor suspicion or have quite different attitudes and expectations regarding care. These gaps in perception need to be carefully addressed.

Christakis – "Taste" and attitudes of different groups have to be addressed

Employer Initiatives: Leapfrog and Bridges to Excellence

Speakers:
Jeffrey R. Hanson, Regional Healthcare Manager, Verizon Communications

Presentations:
See Jeffrey Hanson's **Powerpoint slides and CHCWG comments**.

For a verbatim record of the speaker's statements, see Transcript.

Discussion:

Randy Johnson – Please talk about interoperability and why this matters.

Hanson – The Commission on Interoperability was established in the Medicare Modernization Act. We want our doctors and hospitals to be able to talk to one another, no matter where we happen to get sick; we don't want a perpetuation of segmented proprietary systems. Our medical records should belong to us, not the system. Interoperability will begin to have a positive effect on health care systems.

Aaron Shirley – Regarding quality, what are the variables that are included?

Hanson – Well it's not just doing it quicker and cheaper; it involves seeking improved outcomes, the necessity and utility of the services provided.

Catherine McLaughlin – What is efficiency measuring? You can only compare relative efficiency by holding quality constant. The explanation is a bit confusing. The words may need to be low cost and high cost rather than efficiency.

Hanson – Efficiency includes timeliness, cost and appropriateness of care.

Randy Johnson – Could we ask you to research the definition of "efficiency" used in your slide and get back to us?

Richard Frank – How will you resolve the split between joint ventures and the other models of care? Are you trying to get them to publish the data?

Hanson – Yes.

Catherine McLaughlin – In choosing diabetes, asthma and heart disease, the Bridges to Excellence went after the easy ones, since these are conditions where it's well known what should be done. That's a win-win; there are savings and quality is improved. Are you going to try and push forward into the areas that are much more difficult to change behavior or in chronic care areas that won't be changed much or are you going to stop here?

Hanson – It's going to be a challenge; yes, we picked the areas where progress could be made. Our goal is to continue; but it will be more difficult in other areas.

Randy Johnson – Would you say the same thing about evaluating performance as opposed to pay for performance?

Hanson – Yes. A lot of companies would like to be out of the health benefits business. But we don't have a good market for individuals to go out and purchase health care services. And businesses have a strong interest in assuring care. Looking at increasing cost and quality issues is seen as a good alternative to either not providing health care insurance or to simply continuing to pay ever higher amounts that are of uncertain quality and efficiency.

Catherine McLaughlin – Could there be an alternative market place? Not everyone works for an employer who does screening. A lot of workers are not covered by an employer who is checking the quality. What's the alternative to an employer-based system?

Hanson – CMS may start providing some quality screening. The large employers are going to continue to be concerned. Someone needs to be the repository for quality measures and monitoring. Part of our effort is to raise the quality of care across all providers.

Randy Johnson – Thank you, again Richard (Frank) for hosting this event; we very much appreciate it. The formal hearing is adjourned (at 2:30 p.m.).