STATE OF ILLINOIS

DEPARTMENT OF HEALTH

THE ADEQUATE HEALTH CARE TASK FORCE

TUESDAY

JUNE 27, 2006

160 NORTH LaSALLE STREET

CHICAGO, ILLINOIS

APPEARANCES:

Mr. Wayne Lerner

Ms. Sara Duggan-Goldstein

Ms. Elissa Bassler

Ms. Sylvia Gaydin

Ms. Shell Philburg

Mr. Ralph Schubert

Ms. Stephanie Becker

Mr. Michael Gelder

Dr. Javette Orgain

Mr. David Carvalho

Mr. Dave Koehler

Ms. Ruth Rothstein

Ms. Tracy Printen

Mr. Craig Backs

Ms. Colleen Kannaday

Ms. Jan Daker

Mr. Greg Smith

Dr. Niva Lubin-Johnson

Mr. Jim Duffett

Mr. Jim Boyd

Ms. Diane Rucinski

Ms. Megan Maher

Ms. Beth Najberg

Ms. Megan McDonald

Ms. Carolyn Langware

Ms. Ashanti Rouse

Ms. Sara Golden

Ms. Elissa Butkins

Ms. Lynn Taylor

Ms. Katherine Sreckovich

Ms. Heather Brown-Palsgrove

Mr. Joel Sheffel

Ms. Colleen Daley

Ms. Alicia Huguelet

Ms. Margaret Stapleton

MR. LERNER: Ladies and gentlemen, I'd like to call the meeting to order. My name is Wayne Lerner. I have the honor of chairing the Adequate Health Care Task Force.

I'd like to remind you before we go around the room that if anybody is carrying pagers, Blackberries, defibrillators, anything like that, please turn them off or put them on vibrate so we don't disrupt the proceedings. We have a very full agenda today and we need to stay on time.

Let me quickly go around the room. Sara, do you want to start out?

MS. DUGGAN-GOLDSTEIN: Sure. Sara Duggan-Goldstein, Illinois Public Health Institute.

MS. BASSLER: Elissa Bassler, Illinois Public Health Institute.

MS. GAYDIN: Sylvia Gaydin, intern of the Institute.

MS. PHILBURG: Shell Philburg representing Health Care Family Services.

MR. SCHUBERT: Ralph Schubert, Department of Human Services.

MS. BECKER: Stephanie Becker with Health and Disability Act.

MR. GELDER: Michael Gelder, Illinois Department on Aging.

DR. ORGAIN: Javette Orgain, chair of the State Board of Health.

MR. CARVALHO: Dave Carvalho, Illinois Department of Public Health.

MR. LERNER: Wayne Lerner.

MR. KOEHLER: Dave Koehler with the National Council.

MS. ROTHSTEIN: Ruth Rothstein.

MS. PRINTEN: Tracy Printen.

MR. BACK: Craig Backs, science and medicine.

MS. KANNADAY: Colleen Kannaday, St. Francis Hospital in Blue Island.

MS. DAKER: Jan Daker, representing United Congregation.

MR. SMITH: Greg Smith for Marketing Services in Lincoln, Illinois.

DR. LUBIN-JOHNSON: Niva Lubin-Johnson, Prairie State Medical Society.

MR. DUFFETT: Jim Duffett, Campaign

for Better Health Care.

MR. BOYD: Jim Boyd, UFCW.

MS. RUCINSKI: Diane Rucinski, School of Public Health, University of Illinois.

MR. LERNER: Then we'll go around and ask everybody to speak loud and articularly.

MS. MAHER: Megan Maher.

MS. NAJBERG: Beth Najberg representing the individually insured.

MEGAN McDONALD: Representing the Center for Health Care, Ethics and Advocacy.

MS. LANGWARE: Carolyn Langware, League of Women Voters.

MS. ROUSE: Ashanti Rouse, intern at the Center of Ethics and Advocacy and Health Care.

MS. GOLDEN: Sara Golden, intern for the Center of Ethics and Advocacy and Health Care.

MS. BUTKINS: Elissa Butkins.

LYNN TAYLOR: Lynn Taylor, Mathematical Policy Research.

KATHERINE SRECKOVICH: Katherine Sreckovich, Navigate Consultant.

HEATHER BROWN-PALSGROVE: Heather Brown-Palsgrove, Navigate Consultant.

MR. SHEFFEL: Joel Sheffel with Suburban Access News Association.

MS. DALEY: Colleen Daley, Illinois for Health Care.

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MS. HUGUELET: Alicia Huguelet with Y-me Illinois.

MR. LERNER: Anybody else that has not been introduced?

MS. STAPLETON: Margaret Stapleton from the Shriver Center on Poverty Law.

MR. LERNER: Thank you, Margaret.

Thank you very much for joining us today. I can't ask for approval of the meeting summaries because we don't have a quorum yet. When we have a quorum, we'll come back to it a little later, or do it at another time. So in the meantime, review the minutes. If there's any additions or corrections offline, let Sara know, and we'll try to get to that later.

Also, I just want to mention in terms of how we're going to run today's meeting. In the packet that was sent to you by e-mail, in particular, there's a whole mess of material that

we're going to address at about 2:30 with Niva, which really gets us online for the next set of meetings, which is the meat of the agenda, to talk about the various proposals.

But there's also a letter there that we will address at the end of the meeting, towards the end. And so I'd like to just hold on that so we don't disrupt the plans, if we can do that.

Then, of course, I'll leave time at the end for any personal comments or refections that people want to make, okay?

Margaret just joined us, right, Margaret?

MS. DAVID: Yes. Margaret David. Healthcare Consortium of Illinois.

MR. LERNER: Now we can start, now that Margaret is here.

With that, we're actually ahead of time. And Mike, that means you don't get the extra time.

If you want to tee up the presentation for me?

MR. CARVALHO: Sure. Following the

directions of both the Task Force and the Steering Committee, we have taken what were going to be presentations at this meeting and the next meeting and put them all on this meeting so that you'll have less time devoted to presentations at the subsequent meeting.

So this isn't one of those theme-of-the-day. It's themes of the day. And the first theme relates to special populations and long-term care. And the order is as much dictated by the availability of the speakers and the logical business order, but the common theme is special populations.

And the purpose is probably apparent, which is since the charge under the statute is to develop a plan for access for all residents of Illinois to healthcare, we need to be aware of the circumstances that certain populations may face in accessing healthcare, both because of holes in the insurance network, but also because of holes in the healthcare delivery network.

And so the person who is in a special population may face challenges, even if

they are insured, and even if they are in what otherwise might be reviewed as a resource-rich healthcare community.

So we've asked people who are familiar with those challenges to make presentations this morning.

In addition, one element of the statute asks for you to take a look at issues relating to long-term care. And that could be the subject of a whole task force unto itself with a whole set of hearings, but we're going to focus that down today to long-term care issues as they specifically relate to the charge of the Task Force.

So we are starting off with the Assistant Director from the Illinois Department of Aging, Mike Gelder, who has been involved in issues relating to the elderly, long-term care, healthcare, all different types. But today, he's presenting as Assistant Director of the Department of Aging. Mike.

MR. GELDER: Thank you, David, Wayne, everyone. Good morning.

I have been following this

progress very closely. I think I'm the -- I know I'm the designated Department on Aging Representative to the Task Force, so it's a -- what you're struggling with, as David said, is an issue that's near and dear to my heart and has been for many, many years. And I hope that in these brief few minutes here, 15 to be precise, that we can talk about some of the issues pertaining to the elderly.

Although the topic in the legislation was long-term care in general, I'm speaking about it only in terms of the State's older adult population, primarily 60 and older.

So to give you a sense of how many there are in this state and these are -- so we're not talking about a tiny group of people. We're talking in our -- under the Older Americans' Act, the Federal Act that sort of establishes taking this on aging across the country; establishes area agencies on aging, our purview on those people 60 and older, it was just under 2 million people at the -- in 2000. It's well more than 2 million now.

The 85-plus population was almost

-- probably about 200,000. They're under 200,000 now. And it continues to grow as the next slide will show. This is the -- this is what's coming. These are the males and females in 1990. And these are males in 1990 and 2000. And these are females in 1990 and 2000.

So you can see the gap here represents the growth, generally, of the -- of older adults, both male and female. Of course, much higher proportion of women as you get into later ages because of different mortality rates.

So this is an issue that's important now, and becomes even more important to the State to contend with as the 50, 54, as the end of the baby boom generation ages, as they inexorably will, because we're not dying at the rates we were before.

This looks at life expectancy. As you can see, men at 85 and women at 85. And you see here the life expectancy continues to increase even at a greater rate for men.

So whatever society had been dealing with, going way back into the 1990s, the beginning of the twentieth century, we can see it

remained relatively stable especially for women up until the 60s. And at that point, it began to increase as the rate slowed. But it's still a relatively important trend to contend with, recognizing that all those people in this baby boom generation are going to continue to live.

And we're not dying of many of the things that -- especially heart disease contributes to that. Cerebral vascular disease, stroke, continues relatively to make -- to stabilize and decrease. Clearly the impact of immunizations for influenza and pneumonia has had a dramatic increase as well.

But we will continue to suffer from chronic conditions. And that's the thing that puts the biggest demand on the medical care system at all different levels from primary care, which is the most important entree into the system, even for folks with chronic conditions. Availability and accessibility of physicians. Their training relative to chronic disease and how it affects older adults in particular.

The impact downstream from there. The referral specialist, role of a specialist in a

healthcare system, assuming we have one. And then, what role social support services play. That's the particular concern of the Department on Aging.

But even though we look at the nonmedical side, at the social and support side of the services that people will need, it's clear that they need those services because of chronic conditions.

And so, if we have to have -- we have to. We have to have it now and we don't, but if we're going to have an efficient cost-effective system that takes care of needs of older adults and their younger family members who care for them, that system should certainly be as integrated as possible, and not something that we have now by any means.

Just a few little statistics. In terms of percentages, the average 75-year-old, and we see that there are a lot now and many more to come, suffers from three of those chronic conditions, and they use five prescription drugs on average. That will probably not decrease over time, which can mean 60 different prescriptions a

year on a monthly basis.

These aren't antibiotics that you need to take for ten days, two weeks and be done with it. These are prescriptions to be taken for the rest of your life. And that life continues to expand.

But the most important thing possibly for this group in terms of financing assistance, is the cost of serving someone over age 65 is three to four times higher than the cost overall of serving someone under 65.

In terms of disability, the disability rate of people over 65 is 30.8 percent. Now, that's an important figure in terms of recognizing how much demand and use there will be of the healthcare system and the social supports that need to back that up.

But the rate of increase or decrease of that percentage is really what's going to make a difference in terms of how quickly we bankrupt ourselves as individuals, our families, or our nation, depending on how we go about financing or how we don't go about financing long-term care.

In Illinois, the CBC has a national ranking for each state. I took several figures from Illinois. One of the most important things in any age, of course, is prevention, healthy lifestyle, education, exercise, diet. Illinois does not do a good job. We have not paid a lot of attention in this area, so these numbers, I think, speak for themselves. Our rank is in the second half and at the very low end for many of these indicators.

We're not eating particularly healthfully. Our obesity rate is 46th in the country. We continue to smoke.

Something that we could do and should do a much better job at looking at, the impact immunizations have on life expectancy, is our flu shot rate is very low, and the same thing with the pneumococcal vaccine.

Are we getting preventive care? We have -- mammograms are fair to middling. Colonoscopy, not good. Preventive services to men, we rank 47. Women, we rank 46.

The cholesterol check, we do a little better -- we can do a little better job on

that. But that relates -- these, I think, relatively unflattering statistics for the State, relates to what I said earlier in terms of education of the medical community, and the need for the providers these patients are going to, to pay attention to preventive measures even for someone who is considered an older adult.

There's still a lot that can be done to save money in the medical system. To save years of misery for the patient by attending to these preventive issues.

In Illinois, I think we have -- we sort of talked about long-term care in two stages is that there are two context. Institutional care, and from the best we can get from the Health Care Family Services is 41,000 older adults in institutions as of, I think the last of the year was 2004.

And in-home and community-based care is the other side of that coin where we're now serving -- and I think for the first time possibly -- or I don't know. Statistics are not easily available, so it all depends how you count them.

We served over 50,000 people over the course of the year. Our average caseload is just about the same as that 41,000, but we do so with the community care program budget of about $250 million compared to a multibillion dollar expenditure on behalf of nursing homes for that population.

This is one we put together trying to track the statistics from these private healthcare family services and our services for the elderly. It's careful to scale here. These slopes are not really all that dramatic because of the relatively small intervals, but it does show what, I think, people are looking for. And that we're moving in the right direction.

A general decrease, a downward arrow in the slope of older adults in nursing homes, and a fairly stable upward trend. This was the only year it went down, and that was for a variety of reasons, one of which was the State instituted a mandatory Medicare application requirement.

And that caused a few people not to be interested in service because of their

concern about the sort of hundred percent tax imposed on poor people if they get Medicaid services. And if they have a home, they want to leave it to their children, they don't want to -- they're fearful of enrolling in Medicaid.

But then, its gone up. It went up in '04, gone up in '05, and it went up in '06, so we're now up at about -- on an average caseload over here of over 43,000 a month. So that's the last year for which we had comparable HFS numbers. So that part of the State effort is doing well.

Well, the fastest growing population group, adults over age 85, requires significant support, increasing public expenditures. Continues to provide the vast majority of --

Well, despite the increased number of dollars that we're spending in the public sector, and this is a huge concern within state government, a concern for HFS's budget, a concern for the Department on Aging's budget. Concern for the Department of Human Services, as well, which you'll be hearing about, I presume.

Families continue to provide the

vast majority of care. Eighty percent is the most reliable estimate, so we're only picking up 20 percent of that care, but it's already costing us millions of dollars, as you saw a minute ago.

And then generally, there's a wide dissatisfaction with the availability of home and community-based services. Of those 41,000 people in nursing homes, a big chunk of them don't want to be there, as they indicate to the State every quarter when they do the NBS.

Now, some don't have any practical way of exercising their dissatisfaction, but some could. Many could with the more vigorous program of home and community-based services that would allow clients a real option, and families an option to know they can be safely cared for in their homes, their caregiving network supported so they don't need to rely exclusively on paid homemakers. And we're doing that a little bit. And you can see the numbers are going in the right direction, but there's a big room for improvement in that.

Seniors generally don't want to go to nursing homes. They universally don't want

to go to nursing homes. The one thing people live in fear of in survey after survey, and our own experiences with our own family members, is that they might fall and end up in a nursing home.

Any given day, they wake up, many of them have a conscious -- conscious part of their mind, which is a huge burden to live with, the fact that any little mishap could result in a fall, broken hip, surgery, rehab at a nursing home. And no one knows what happens next. And that's something that we definitely want to try to fix.

The Olmstead decree defines Americans with Disability Act. Requires states that offers services to support those with disabilities, including the frail, elderly, in the most integrating setting possible. Another basis for our program that you'll hear about for a couple of minutes.

And then, the payment rates need to be high enough to attract a quality work force, because it's no good to give people entitlement to services if we can't assure that there's a work force there that are trained, competent,

relatively stable to provide the service.

The elements of our long-term care reform system proposal or plan that we're working on is moving ahead. It's not just a proposal. It's a coordinated information referral and entry resource for all long-term care services available to the community.

We have something now in two areas of the State called Aging and Disability Resource Centers. This a model being pushed vigorously by the federal government. It's an EMS and Administration on Aging.

A comprehensive case coordination to make sure that we cover all the services to serve needs of people. Transportation, pharmacy, the whole panoply of services, compared to what we have been doing, which is just to evaluate them for eligibility for a particular program. So we moved ahead on that.

We need to make sure that there are extensive services to enhance family caregiving. In fact, in this legislative session, the general assembly approved for the first time, a line item called "Alternative Senior Services,"

to make sure that there's more than just homemaker and adult daycare, which are the two basic programs that we've been able to offer for the last 20 years. We'll now be able to offer a variety of services.

And a set of consumer directive service options. The way in which the previous generation may have been satisfied with care is not the way in which the baby boom generation or even current adults want their care.

They don't want a case manager coming in, assessing them, assigning them to an agency. The agency assigning a homemaker, and a week or two weeks later, the door rings. They have no idea who is on the other side of it. It's their homemaker ready to give them a bath or help with toileting. It's a very, very personal thing, and you've never seen this person before. People want to control their own care. And we're integrating that into our program. But these are principles that we hope that the Task Force will incorporate as well.

We want to assist nursing home residents who are there. As I said, there are a

lot in every state, not just Illinois certainly, but there are many people who want to come out.

We have a program that's doing that. It needs to be invigorated, but we have a program called, "Coming Home." We've got about a hundred people who've come out of nursing homes in the last six months. It's nine months now, through that program. And that's just in four parts of the State. So there's a lot that we can do in the other hundreds of communities where that service is not available.

And then we need to encourage our nursing homes to do something more useful, really. And I don't mean that real critically about nursing homes. But this display of the nursing homes of the 70s and 80s doesn't work anymore, by and large, for the elderly.

And so they can convert those resources, their structures. They can adopt progressive practices to be more attractive to people. Single-bed rooms. More control over your schedule. Bathe when you want to, eat when you want to. Many homes are doing that.

And other things they can do is

convert to service -- become adult daycare centers so people can come home at night and use the transportation resources and the expertise of nurses and the highly trained staff at nursing homes to educate the community about tube feeding and things that are being done at home.

We want to encourage comprehensive delivery systems that integrate both acute and chronic care, clinical care and social care, the models of social HMO's, Pace, a program of all-inclusive care for the elderly demonstrate, I think, conclusively, according to the research, that you can do this cost effectively.

But when we're looking only at saving only Medicaid dollars, and the State and the federal government looking only at saving Medicare money, it's very hard to find the value in trying to look at the whole pot of dollars and the whole person and figure out ways of doing that.

But by integrating acute and chronic care and integrating clinical care and support services, that's how you do it. And we can certainly provide more information if anybody

is interested in that.

We need an adequate supply of caregivers, both in institutional, as well as noninstitutional settings.

Lastly, to make this work, there has to be a financing mechanism to cover the cost of long-term care. The state now doesn't have a plan.

I mean, each year there's a budget battle. Every state agency that needs more money has to fight for it tooth and nail from our office of Management and Budget. Their job is to keep the overall expenditure level low enough to support -- to maintain and be consistent with the tax base that the State has since that's apparently not going up anytime soon.

There isn't any clear answers to where we have to -- where the money is going to come from to support the care of the older adult population that is large now, growing larger, living longer, but suffering from chronic disease, both which place a continued demand for clinical services on us, the taxpayers. And hopefully, this will be integrated into the plan you come up

with that you recommend to the State over the next several months.

MR. LERNER: Thank you, Mike. We have time for a question or two.

MR. BACKS: The statistic, 30.8 percent of elderly are disabled. I think we kind of know what the people who are pre-65, where disability statistics might come from, from applications. Where does that statistic -- how is that obtained?

MR. GELDER: That's the number we got from CDC. I could get you their source on that. The Centers for Disease Control.

And the big debate in the field is what that -- what's happening to that rate. You know, is it static, is it growing? Is it declining? What countries that have preceded us? Illinois' population is still relatively younger than the other western European countries, Japan, and the other industrializations in general.

The countries that are older than we are and who aren't having the influx of immigration to keep their population average as young as ours is, they're finding that the

disability rate is declining. Canada has found that.

That's a real godsend to their national health system is that they -- they don't know how they would sustain it if the disability rates had been steady. But they're declining.

MR. LERNER: I'm just got to say -- sorry for interrupting.

The disability rate really revolves around how you define "disability." And we define it in the field very broadly, so someone like me with a hearing impairment or arthritis, if there's a restriction in your activities of daily living, certainly would qualify for that.

But the real key in the elderly as we've looked at it, is the restriction on what's called independent ADLs. Their inability to dress, eat, walk, do checkbook. And those things put all kinds of demands not only on the acute care system, the long-term care system, but the social system.

So when you start to unravel that, that's really what you end up with, a much more complex set of problems.

MR. GELDER: Yeah. I think that number comes from people with two or more deficiencies of activities of daily living. Bathing, dressing, grooming, eating.

MR. BACKS: So it's not equivalent in terms of what one would get for benefits for loss of a limb or --

MR. GELDER: No, it's not consistent at all with the workers' comp. And it's not even consistent with Social Security, although it's more comparable to what they're looking at.

MR. LERNER: But what Mike said, though, can't be lost, which is the rethinking of how you reorganize the delivery system, because the previous focus on institutional care is not only always the most humane and dignified way to do it. It's not the most cost effective and it certainly may not the best for individual. So there are new models that we ought to be thinking about as we start to unravel this.

MR. BACKS: If I can make an outside-the-box comment. That means that there's 70 percent able. And there's a large untapped source of able elderly individuals who could be

enlisted in providing services to their cohorts.

MR. GELDER: Right.

MR. BACKS: They are able to make it to Florida, they're able to make it to the casino. I take care of them, by the way.

MR. GELDER: And not even looking at that -- I mean, one of the concerns especially, we look at employment as well of people over age 55. And there are a lot of professions that are concerned about the percentage of people who are over age 50, over age 55 in those -- social workers, particularly. Nursing. I mean, there's a lot of professionals that are getting older.

MR. BACKS: Physicians.

MR. GELDER: Right. There's a lot of professions that are aging as well.

But now they should be employed, they should be used. They are caregivers. I mean, they're taking care of their parents. You've got a 65-year-old taking care of their 85, 90-year-old parents.

MS. PRINTEN: May I ask one quick question? I know there's an older adult service advisory board that came out with that report and

had recommendations about community-based care. And I'm wondering if it might be helpful for us to have that since they studied it?

MR. GELDER: Yes. I would be happy to make that available. It's on our Website, but we can make nice, pretty colored copies for you as well. I'll bring them in later today if I can.

MR. LERNER: Next on the agenda is Margaret Stapleton, Shriver Center on Poverty Law. Margaret has been a long-standing attendee at these meetings.

For all the speakers, by the way, we've got a schedule out here. If you can allow a little time in your presentation for questions. Thank you. Margaret.

MS. STAPLETON: Margaret Stapleton from the Shriver Center on Poverty Law.

I'm officially speaking to you today. I spoke, kind of wearing my hat as a private person, at the hearings you had in Skokie several months ago.

I'm going to make comments today rather than a presentation. I think the Shriver Center doesn't have any piece of new information

to tell you.

I have been to many of the hearings. I've been to many of the presentations. I wish we did. I don't think we have any great new insights to give you, so my presentation is going to be a number of comments.

The first thing I wanted to tell you is why we're speaking today. Because we hope the Task Force will really keep the needs of low-income people in mind.

We're speaking under the special population umbrella today because there are many ways in which low-income people really are kind of a special population. Mostly, because they don't have the resources to do the things that people similarly situated regarding healthcare could do if they had more money.

We are, as you probably know, kind of long-term supporters of any expansions of healthcare for low-income people and long-term fighters of any attempts to cut that back, through both legislation and through litigation.

We supported creation of this task force. We supported Kid Care. We support

Healthy Illinois. We support Universal Health Care. We support whatever you come up with. We're almost positive we'll do that.

We've also fought a number of federal and state cuts in the federal government programs, both legislatively and through litigation.

Not to utilize statistics, I just want to remind you of how many poor people there are in Illinois, which is a lot. In 2004, which is the most recent statistics that we could find, almost 6 percent of people in Illinois were in what you'd call deep poverty, that's under 50 percent of the federal poverty level.

12.4 percent, under 100 percent. And the shocking figures, almost 29 percent -- almost 30 percent of the people in Illinois fall below 200 percent of the poverty level. That's a lot of low-income people. So we need to keep that in mind, because some of these people are covered by private insurance. Not many. Some -- actually, a substantial number. And some are covered by government programs, but many are not.

And the next slide talks a little

bit about the -- what I'm going to do, I'm going to talk about by group. Who is and who is not covered by government programs.

I have a few suggestions. Well, I only have two. Well, things to include and things to avoid in shaping an adequate healthcare system.

I have a few suggestions on what to include, only two on what to avoid. Then I have a very short footnote on the safety net.

The first point is something that I think you already know. I think this is something that you all know. I think the public, in general, doesn't know this.

The public I think, in general, unless they or a member of their family or somebody they know or somebody in the profession, which they encounter in a professional way; there are a lot of people out, people on the street, people in their community who actually think if you're poor, you get government subsidized healthcare.

People are surprised that people are not eligible for Medicaid because they're

poor. I think I told this story when I spoke in Skokie about, you know, people who are very surprised at the people who care for their elderly relatives. The wonderful home care workers who come in, who are themselves in the early 50s, working hard. They don't have health insurance and not eligible for Medicaid, even though they are pretty poor.

The reason that they're not eligible is because they don't meet any of the special categories that make people eligible for Medicaid.

But just a reminder, Medicaid is available to people who meet certain eligibility categories. Elderly, disabled. Totally, permanently disabled. Very significant standard. And you've heard the complaints from people about their standard at a lot of hearings.

Pregnant women and families with minor children. It's not available for people who don't fit in one of those categories. A person can be very, very sick, but if they don't meet the disabled benefit definition, they're not going to be covered.

And I think when people from the AIDS Foundation speak to you later today, that will be very, very clear about how stringent that standard is. Those are just people who don't have a child in their care.

The other thing I'd like you to remember is that Medicaid can end when a status changes. So when a child turns 19, that child is no longer going to be covered for Medicaid. The parent of that child is no longer going to be covered for Medicaid once the child gets over 19. So we have a lot parents who have been covered by Medicaid, all of a sudden when their youngest child turns 19, the parents are also without insurance.

A disabled person who returns to work may or may not get Medicaid, but I think HDA is going to talk a little bit about a lot of the kind of really expansions of Medicaid to cover people who are coming off disability standards.

So when I talk about Medicaid, I think of Medicaid as an island for low-end income people. A lot of low-income people, 29.1 percent, and only some of those have an island on which to

rest.

Then there's other government subsidized healthcare programs. That kind of disease specific or status specific. Breast and cervical cancer programs, for example, have now been expanded. Sometimes they're very limited.

The drugs, status-specific kind of school health clinic. And again, those are sort of more islands. So there are a lot of islands, but -- and these islands are for some people, some services, some of the time. So we have a lot of islands. We don't have a mainland for low-income people.

What we think will be the components of the adequate healthcare system, we really -- comprehensive, comprehensive, comprehensive. Low income people simply do not have the ability to pay for not-covered medical services. They're not going to get them.

We increasingly think that with low-income people, they get most of medical at home with a primary care provider. We think it needs to be accessible.

People who went to the hearings

downstate prefer the downstate mantra. If you have a toothache, you don't just have a dental problem, you have a transportation problem.

Low income people also need to have some ability to get off-hours care. If you're working a low-paying, pretty demanding job, you're not going to have the flexibility to take the afternoons off. You're working on an assembly line or something, so both time and geography are there.

Then we really think that any plan has to teach patients new behaviors. Low income people by and large -- not by and large. Many low-income people who have not had the benefits of having a medical home and access to medical care on a middle-class basis, have a lot of behaviors that really are their worst enemies.

They don't follow directions. They don't come back. They don't understand. They don't ask questions. They're afraid to ask questions. They think they'll appear dumb if they ask questions. Lots and lots of cultural and psychological things.

Please avoid copayments. They

don't have the money to pay them, which I think is hard for us. We've always got $2 in our pockets. Some of them don't.

SSI benefits for one person is 603 a month. TANF benefits, Temporary Assistance for Needy Families. Mom or dad with two children, 396 per month for a family of three. Out of that, they have to pay for everything and healthcare. And if they get food stamps, they always run out of food stamps around the 20th of the month. So they're paying for housing, clothing, food out of $300 a month.

Please avoid financial incentives to skip healthcare. Skipping is the problem because they don't have the money. They won't do well. So anything like health savings accounts, or as I said, copayments. More people's daily dilemma, choosing which primary to cover. Rent, utilities, food, healthcare. They can't cover them all.

And the last thing that I wanted to say just a footnote on. Safety Nets and Referral Systems did a wonderful presentation about Illinois' truly terrific safety net systems.

I don't want to disparage them at all, but at their best, it's simply not enough.

We've heard about people waiting two years, 18 months for a colonoscopy when they're presenting symptoms. It's not comprehensive enough. It's not available everywhere across the State.

Remember, what's available in Cook County is -- in Cook County, the best of the best. You get to some other counties in the State, there's really not much of a safety net system.

Referral systems. Again, you've heard about the importance of referral systems, getting people covered by benefits for which they're eligible. But even the best referral system often says there's nothing for you. We can't give you. We can't figure out where you should go. Go to the emergency room. That's it. Thanks.

THE COURT: Questions for Margaret? We've got time for a question or two.

MS. DAVID: One of the things that -- as we went around the hearings, we learned that

many of the doctors did not know about the expansion Medicaid rates. And some of the doctors, even though they knew, were not willing to expand their services to new Medicaid people. Has Shriver Center addressed that?

MS. STAPLETON: Well, we have, along with Health and Disability Advocate -- and Stephanie can probably answer this question even better than me.

The Shriver Center and HD brought a lawsuit challenging the problems in the early and periodic screening and diagnostic programs which were caused, in large part, by how low the Medicaid rate was for pediatricians.

We had special legal handle the Federal EPSU Statute and prevailed in that case to get the State to raise the rates for pediatricians and related services for children.

We don't think we have a legal handle for other issues about the Medicaid rates. I mean, that's a very big problem. I think that, you know, the government expansion of Kid Care to cover all kids is sort of a big step in continuing forward on the engine of the higher Medicaid rates

for pediatricians.

I wish Ann Marie Murphy were here to answer the question about the other rates.

MR. LERNER: Well, from a provider point of view -- I mean, at our place, its $.39 on the dollar on costs. Payment and costs. I mean, it's just ridiculous.

And one of the things we'll get to at 2:30 is how we look at the financial incentives and the financial payment issue as we think about expansion of coverage and expansion of beneficiaries.

There may be a whole other subtext of socioeconomic, racial, ethnic, cultural, language issues that underlie that, but we've got to get over the financial hurdle, too.

Not only the financial incentives have to be put in the right place for the population, but the financial incentives have got to be put in the right place for people providing the service. So we've got a long road to go on that one.

MS. STAPLETON: And I think that because the bottom line there is -- maybe we

should have said the age of cost shifting is over. You know, the State can no longer cost shift. Neither the State nor the federal government can cost shift for Medicare and Medicaid after private insurance.

So the game is up, as my father would have said.

MR. LERNER: Last question.

MR. BACKS: Just more of a comment. Just to be careful that solving one problem in terms of reimbursement to pediatricians through litigation, exacerbates a problem in other areas, and affects access in other areas.

So the real problem is the champagne tastes on a beer budget when it comes to healthcare. Everybody desires everything, but nobody wants to pay.

MR. LERNER: Yeah. We're going to take a broad swat at this one. Thanks, Margaret.

MS. STAPLETON: Thank you very much. Thank you, by the way, for all your wonderful work. I'm actually going to leave. I have a day job.

MR. LERNER: I'm not sure we can go on

without you.

11:15. David Munar, did I pronounce it correctly? Associate Director of the AIDS Foundation of Chicago. Thank you very much for joining us today.

MR. MUNAR: Good morning. Thanks for this opportunity to address you. And thank you for your important work.

My name is David Munar. I'm the Associate Director of the HIV AIDS Foundation of Chicago.

I wanted to give you a brief overview of HIV and issues facing Illinois today on National HIV testing day. And I also want to commend you for your work and look forward to your recommendations.

Just starting out, I want to give you a brief overview of where we're at 25 years into the HIV AIDS epidemic. There's been more than half a million Americans who have died due to aids-related causes.

And we actually quietly turned the corner on half a million deaths last year. And in Illinois, there's been nearly 20,000

AIDS-related deaths. About 12,000 in Chicago. Since the mid 90s, with the development of highly active anti-retroviral therapies, that's declined dramatically.

And in Chicago, we're down to several -- sort of a few hundred deaths a year, from a peak of nearly 2000 in the mid 90s. But nationally, there's still about 16 to 17,000 AIDS-related deaths a year. So HIV remains a chronic, incurable condition.

According to the Centers for Disease Control and Prevention, there's over a million Americans living with HIV currently. And that's as of 2003, so it's twice as much higher now.

Our estimates for Illinois is that it's likely 42,000 or more. In Chicago alone, it's probably around 33,000. And the bulk of the epidemic is in Chicago, so Chicago counts for 67 percent of HIV AIDS epidemic in the Illinois. In the metro area, it's about 87 percent of the HIV AIDS epidemic in Illinois.

Actually, it's worth noting that according to the CDC, about a quarter of those 1.1

million individuals living with HIV don't know their HIV status, which is why preventative services are so critical. Why things like National HIV testing day are important. The opportunity to promote testing acceptance.

There's about 40,000 HIV infections that occur each year. This is probably the low end of the spectrum. We're actually going to receive data later this year from the CDC substantiating -- getting a little better picture of this. And an Emory University professor thinks it could be as high as 60,000, so this could be very low.

Based on the 40,000, we believe Illinois' share of this is at least 1600 new HIV infections a year, the bulk of which, as you see, are in Chicago.

So HIV is really a story of disparity, as you will see from the next couple of slides. Actually, Dr. Whitaker, the health department director, unveiled data yesterday that showed that 62 percent of AIDS cases diagnosed in 2005 were among individuals between the ages of 24 and 34, which means those infections occurred

approximately ten years earlier.

And according to the CDC, half of those 40,000 new infections that occur annually are among individuals that are aged 24 or younger. And HIV AIDS is still the leading cause of death for African-American women ages 25 to 34. It's among the leading cause of death for African-American men.

And in a five-city study conducted by the CDC two years ago, they found one in four gay and bisexual men surveyed, was living with HIV. Looking at only African-American men surveyed, it was one in two, 46 percent.

This gives you a -- as you'll see, the trends are pretty constant. When you look at both Chicago, Illinois and the United States, the epidemic among those living with HIV, about half of all cases are among African-Americans. About 15 to 17 percent are among Latinos.

The proportion among Caucasians is steadily decreasing. It still is about a third of those living with HIV. It's still predominantly men, but the proportion is steadily

increasing among females.

And every way you look at the epidemic, it still continues -- the mode of transmission that contributes most to new cases and those living with HIV, is still male sexual contact with other males. As you can see from the previous slide, it was one in four. You can understand how that's true.

So in the United State, it's about 45 percent. In Illinois, it's about half of all cases are among men having sex with men.

Injection drug use continues to be a leading contributor to cases of HIV, although recent data in the last two years has shown continued decline in the number of cases related to injection drug use. And likely the result of efforts across the State to promote sterile injection equipment availability.

There's ample data that I won't go into, which show a strong correlation between poverty, homelessness, or a high risk of homelessness, mental illness, incarceration.

Populations that have a family member or in a community of high rate of

incarceration, as well as individuals that are in and out of prisons and jails.

And AIDS stigma continues to be one of the biggest drivers, as well as other forms of prejudice.

Sexually transmitted infections also contributed to the spread of HIV by increasing the infectiousness of an individual as a sexually transmitted infection, as well as vulnerability of those who have an STD.

For the purposes of this group, I thought this was an important slide to see how people living with HIV in the United States receive their care.

And about half of them receive no care at all for HIV. And the private sources, private programs are the most significant categories of care.

Private insurance is only 15 percent. The Ryan White Care Act, which is kind of the nation's flagship response to HIV AIDS, and it received scarcely any new funding in the last eight years, is about 12 percent of the medical care and medications covering people living with

HIV.

And Congress is right now looking at reauthorization legislation for that program. And we're not anticipating any increase in dollars for the care in the period ahead even though cases continue to climb.

And as you know, these other categories, including private insurance, Medicaid, Medicare, also have barriers, including the cost-sharing issues that Margie described, that make them not comprehensive.

For Illinois, I just want to give you a quick slide about where funding comes from. Most of Illinois' funding for -- federal funding to respond to AIDS is the Ryan White Care Act, and is about 75 million. This slide does not include Medicaid and Medicare federal contributions that are likely double the amount that you see here, and are the largest categories of federal funding.

The other categories here, the 22 is for preventive services. The 9.9 is for housing assistance. Then mental health and substance abuse services is about 3.1 million directly related to HIV AIDS response.

This will give you a narrative about those categories. One portion of the Ryan White Care Act that is really essential to our safety net is a state and federal program called "The AIDS Drug Assistance Program." It's about a $40 million program.

Illinois actually just -- the legislature, the government just raised the appropriations by 2.5 million for that program. About 3500 Illinoisans receive their HIV AIDS medications through this program. It's limited. It's not a comprehensive program. It's only HIV-related medications.

It's payer of last resort. So for many people -- for many people that are long-time users of the AIDS Drug Assistance Program. Others are on the program as they wait for Medicaid eligibility or for other services or when private insurance is no longer available.

Just a couple of recommendations I wanted to echo as you start your deliberations. As Margie said, one of the biggest areas that we see is the way the Medicaid program is structured. Individuals who are living with HIV must become

disabled by HIV before the program will actually pay for the very medication that could prevent disability.

And so, we're very interested in Illinois exploring a waiver to expand Medicaid coverage for individuals, low income individuals living with HIV who are predisabled.

Massachusetts has secured such a waiver, so has the District of Columbia and the State of Maine.

This is not an easy effort to undergo, but we think it's worthwhile. And our back-of-the-envelope estimates are that at least 10,000 HIV positive Illinoisans are uninsured in this state.

I wanted to just echo how important the Cook County Health Care System is to AIDS care. The Core Center bears Ruth Rothstein's name, and it's the largest -- between the Core Center and Provident and the Ambulatory Care Center and Stroger Hospital, it's the largest provider of HIV medical care in the State. It's absolutely subsidizing all our other systems and keeping our AIDS Assistance Program strong.

And we're very concerned about reductions in Medicaid funding to the county. That could put the very essential safety net in Cook County in jeopardy. Effect not only the care for those in Cook County, but really statewide.

Again, just echoing how important the AIDS Drug Assistance Program has been. There's been a long-time commitment in the State to this program and keeping it strong. But we anticipate that with more people progressing in their HIV disease, more people becoming infected, the need will continue to grow.

Care for HIV averages around $12,000 for just the medications. And individuals typically, depending on their different needs, can need anywhere from 18 to $21,000 worth of medications, so it's a very costly condition.

Echoing some of the recommendations that have come from others of the group. We absolutely would like to see an expansion of the health benefit for workers and disabilities. The right to Medicaid Buy-In Program. We think this is a very effective way of reaching more people who are disabled and

interested in coming back to the work force either part-time or full time.

The High Risk Pool Insurance Program. I've seen it in recommendations. It's growing inaccessible and unaffordable for many people. The premiums are too high. The cost sharing is too high. If there were reforms to this program, it could be an effective way of covering people with HIV and other chronic medical conditions.

Small businesses, including my own, it includes -- it covers people living with HIV like me, really face very steep annual premium increases that make care very unaffordable. And any reform that helps small groups could go a long way at expanding coverage in Illinois.

And finally, I just wanted to say how important prevention is. Really, I wanted to ask you not to just focus on healthcare needs, but also take in the lens of prevention. And every case of HIV we can prevent, really would be a savings to our whole system and will help us expand coverage.

And there's a whole range of

approaches, science-based approaches, including comprehensive sex ads. Needle exchange and needle availability. Condom distribution, family planning. Other behavioral intervention targeting high-risk groups. Social marketing program. Programs targeting prisoners and ex-prisoners. The Core Substance Abuse and Housing Programs are essential for prevention.

MR. LERNER: Thank you very much. We have time for a question or two? Covered nice ground. Thank you very much. We really appreciate it.

It's 11:30. Sessy Nyman, vice president of Public Housing Government Relations. Thank you very much for joining us.

MS. NYMAN: Thank you for having me. I'm going low tech. I've got no PowerPoint. I'll make up any time that you are behind today.

I'm Sessy Nyman. I'm with Illinois Action Program. We are a statewide public policy program working with low income families with young children ensuring quality care and affordable care is available to all children.

We work with the Child Care

Assistance program run by the Department of Human Services, serving approximately 187,000 children per month, per year. And at Action for Children, we work directly with families as child resource and referral in Cook County.

We average about $400 million a year in payments directly to low income families using the Child Care Assistance Program. And we also provide assistance, technical assistance and training to approximately 65,000 families and people in the work force.

I want to talk a little bit today more broadly about simply bringing the attention of the child care work force.

Illinois has been blessed in the last couple of years to give a lot of attention -- we've been giving a lot of attention to young children, particularly young children outside of their home who are in need of child care services, or the ones who are able to benefit from high quality access to pre-k.

What we haven't talked a lot about are the people that are caring for those children. And so we want to talk a little bit

about the work force needs today.

There are no federal or state funding that provides health insurance benefits to the child care work force. So we have, again, 187,000 children who are low income, high risk, in the care outside their home, either in a child care home or child care center. And their child provider, their teacher, the person taking care of them, for oftentimes 40 hours a week, oftentimes, about 44 percent of them have no access to health insurance.

For those people who do have access to health insurance, it's oftentimes through their spouse or they also -- about a third of that work force is eligible for family care.

So we've gotten a lot better. Most and more of those families or providers have gotten access to health insurance, but it's still not enough.

And we know that there's direct access to young children when those providers don't have access to preventative healthcare, that they use the emergency room as their primary healthcare home. We know those children are also

at risk.

So as we talk about the well-being of young children and we invest dollars into their education in terms of pre-K and birth of free programs, we definitely want to think about the health of those children as they grow up when we think about the health of the provider.

You have a packet of information in front of you, so I'm going to be really brief. I'll just point out a couple of things within your packet.

Again, approximately 43 percent of home family child care providers do not have access to health insurance. Thirty-three percent of those providers working in a center-based program do not have access to health insurance.

In 1999, Massachusetts did a survey and found approximately 45 percent of the uninsured child care work force used the emergency room at least once in the last 12 months as their primary healthcare home.

So really, some main points we want to talk about -- actually, Illinois Action for Children is a member of the Healthy Illinois

campaign. So really, when we think about child care, we don't really see a successful legislative campaign going to the general assembly saying we think a child care provider should get health insurance over all the other uninsured population.

What we really want to do is bring the child care work force to the table when we think about uninsured, when we think about small businesses, when we think about the nonprofit community who won't benefit from a tax break if that's the recommendation.

Thinking about those providers -- and we can talk about all health human service providers out in communities taking care of the indigent, the elderly, the young.

We really need to think about the work that they do, the services they provide the families and children in the communities in general. And really, how do we come up with a plan that incorporates all of those populations.

And so our job at Actions for Children is to make sure the child care providers are part of that conversation, so we may have a health insurance plan that supports or includes

small businesses.

Oftentimes child providers, both home, as well as center-based providers would be included in that. And we think that that is an important step.

There's been a legislation in the general assembly a couple of years ago that looked at small businesses specifically. And we worked with them to include child care providers as part of that legislation. It didn't go anywhere, but it's important that we continue to have them at the table.

In Congress, for three or four years, there's been legislation introduced that would look at the Rhode Island model that really does something directly for the child care work force in terms of including them for those providers that care for low income children through the child care -- through child care centers, that they would have access to the State child care health insurance program.

So there are models out there that have really taken into consideration those providers that are caring for small children. The

health of that provider directly impacts the health of those young children.

And we know that particularly for those providers that are caring for low-income high-risk children in high-risk communities, that the healthcare needs of those children are substantial. So the most that we can do, the most thoughtful we can be in terms of thinking about the prevention is an important one.

So really, just to bring the child care work force to the forefront of your mind as you move into the final stages of your task force process. And I want to leave you with a couple of final points.

The affordability is clearly a significant issue. And I think Margie talked about the comprehensiveness. We really want to be comprehensive when we think about child care programs for the child care work force in terms of health insurance.

The affordability issue is a big one. California has tried a couple of different models that shows when the cost sharing is too significant, too substantial for the

beneficiaries, that they can't participate.

The average salary for a child care provider is less than $9 an hour. These are families that are often low income themselves. They're oftentimes -- many times they have parents themselves. They oftentimes qualify themselves for the Child Care Assistance Program, which is an income-based subsidy program to help pay for child care. So the affordability issue is a significant one for the child care work force.

It must be -- again, thinking about the larger -- not just about child care, but about the larger small business. So that might be the way to approach it.

When we think about health human service providers, we want to think about the not-for-profit community, those families -- those programs and communities that are serving low-income, high-need populations. That if we do whatever recommendation that you all make, to take that population into consideration.

I know a senator a couple of years ago brought in a group of people to sit together to really think about this. How do we

support the not-for-profit community that oftentimes does not benefit from any kind of tax break or tax incentives that are out there for the corporate community.

The turnover in child care is one of the biggest indicators of not a high-quality program. So we know that children will benefit when their child care provider is there all year. My daughter is just finishing her first year in a child care center. She's two and she's had the same teachers all day -- all year.

The impact that that's had on her is significant. The year before, they had three different teachers in that program. Imagine if your third-grader came home and said, "Guess what. I've got a new teacher today." Well, that's the third one this year.

We don't think that that is acceptable for K through 12 education. We also don't think it's acceptable and brain research tells us it's not good for young children. And yet, if there's one provider that can manage to provide health insurance down the street and my child program doesn't, if we think my kids -- my

kid's teachers aren't going to leave the first chance they get, we're wrong because that's what they're looking at.

And so we need to think about the comprehensive. It's not just program for program, but thinking about how do we really address the work force needs for child care.

Healthy providers make for healthy kids. Also, for the family child care work force where the majority of children are in the State of Illinois, we really want to think about those children and how do we again, incorporate the family child care provider, a self-employed person working out of their home. And how do we address their healthcare needs as well.

So again, I just wanted to bring the issue of the child care work force to you today. You have a package of information. We did a pretty lengthy study a couple of years ago at Action for Children. We looked at other states, looked at the different models that have been tried and true.

Nothing is perfect, but I think

as you collect your information and bring together all the different factors to be included, I appreciate your thinking about the child care work force and the larger not-for-profit human service providers out there and the needs they have, the ongoing need.

There are no funding structures out there. And clearly they don't have a very strong lobby in terms of making sure they're going to be the ones to get child care or get healthcare. But we appreciate your considering us.

So I welcome any questions.

MR. LERNER: Thank you, Miss Nyman. Wonderful presentation. Questions?

MS. DAVID: Do you have any laddering for the staff so they would accelerate their job titles in order to get insurance? Is there a laddering process?

MS. NYMAN: There's no incentive for providers, for a center director to offer health insurance, if that's what your question is. So there's nothing right now that does that.

There have been conversations

about, you know, higher compensation for the work force or for the program if they do offer some type of health insurance benefit, they would be looked upon differently. But right now, that would also only be specific for the people that are cared for through the Child Care Assistance Program.

So we talk about the larger kind of child care work force. I mean, we focus on the low income population that needs child care and the directors that serve those families. But right now, there is nothing in place that could kind of incentivize a program that would offer health insurance.

MR. LERNER: Ruth.

MS. ROTHSTEIN: How many of these healthcare workers are organized into a union?

MS. NYMAN: SCIU last year did finalize a collective bargaining process with the State. They represent the 49,000 family child care providers that are kind of right now registered as family child care providers.

Those include those licensed providers, those licensed by the Department of

Children and Family Services, as well as kind of what we call "Kip and kin," are license exempt. The grandmother, the sister, the neighbor who takes care of three children or less in their home.

MS. ROTHSTEIN: Are their salaries better than those who are not organized?

MS. NYMAN: There was as part of the collective bargaining agreement, a 35 percent overall rate increase at the end of their 39-month agreement with the State.

The largest increase came for those licensed-exempt providers that got a dollar -- right now -- traditionally, the rate for licensed exempt providers in Illinois has been $9.48 a day, per child. Not an hour, a day.

Well, somebody said that's not so bad. I said it's a day. A day per child. So they got a dollar increase. The licensed family child care providers got a slightly smaller, but significant increase. And we were able to reach parity so the center-based providers did get a similar rate increase.

They do have as part of their

39-month agreement, some dollars that will be invested in year two and three into a health insurance fund. That, again, will just cover the family child care work force. And they're not clear yet as to what percentage of the work force would be covered.

I think the State investment at the end of the 39-month agreement is $27 million, so it's unclear how much will 27 million buy for a $49,000 membership.

MS. ROTHSTEIN: Thank you.

MR. LERNER: Great presentation. Thank you very much. Really appreciate it.

The next presenters are Stephanie Altman and Stephanie Becker from the Health and Disability Advocates.

MS. ALTMAN: Actually, I'm going to skip who we are and what we do. All that's in the slides, since you guys are at the end of your morning from hearing from everybody.

And Stephanie is going to present all this wonderful research and data on the stable population. But I think I'm just going to tell you why we do what we do.

I'm going to tell about a typical client. She's also a friend of mine, and a neighbor of mine. And you might say well, this is an atypical client, but she's not. We don't have atypical client.

This is somebody who is disabled and uninsured or was disabled and uninsured in Illinois, and it might surprise you.

Her name is Julie. She was 31 years old. This was 2001. She's a neighbor of mine. Our kids were in kindergarten at the time. She had her second child. She was freelancing as a public relations person, had no health insurance. Her husband had health insurance through his job. He was working for a real estate company.

They live in Wilmette. He was going to grad school at the time. He decided to -- about July of 2001, he decided he was going to finish grad school in August. He quit his job in June. They decided not to Cobra their health insurance because he could buy insurance cheaper for them on the private market.

They waited about 63 days, maybe

68 days, just couple of days past the Health Care Affordability Act Requirement. And guess what happened? September 11th.

He could not find a job to save his life in the financial industry. He just graduated with an MBA from the University of Chicago. There wasn't a job to be had in Chicago, and she got diagnosed with multiple sclerosis. This happened in two weeks.

Their life falls apart. She's completely uninsured. Brad and the kids could easily buy private insurance through a private insurance company. They write to 35 companies. Nobody will cover her. Not a chance she'll be covered.

They tried the ICHIP program. It's too expensive. They have no income right now. He's got no job. He just graduated from grad school. He quit his prior job. And she can't get a job right now because she's right in the second episode, which actually diagnosed her with multiple sclerosis. She had had an earlier one when she was 24. She has no vision for two months. She can't walk. She's got a -- she

cannot go back to anything.

So she goes to pharmaceutical companies. They give her drugs free for the first three or four months. He finally, in December, finds a job with the City of Evanston which he takes at $42,000 a year, way less than he thought he would make.

Barely covers mortgage, because they have an insurance that will not -- preexisting condition on her. He works for a year and a half in order to get her 12 months of certifiable coverage, then she's able to move on.

Think it can't happen to you? It can happen to you. And that is a typical client, in some ways. Even though they are not low income, they were low income at that moment. They have no way of accessing insurance, even as they borrowed, begged, steal. And they had no plan that that would happen to them.

Many people are in that situation. You can say well, they should have Cobra'd and they shouldn't have let it go 63 days. But they didn't know that and they didn't know that perfect storm was going to happen to them at

that second.

We have lots of clients with equally different circumstances and factual situations. And that's why we do what we do. And we'll give you some statistical data on who the population really is.

But the proposals that we put together that we suggested to the Task Force, some of which have been mentioned today, would have helped Julie in several different ways.

One, there would have been potential subsidization of their Cobra insurance had they taken it. ICHIP subsidization. Perhaps she could have gotten a subsidy to get on the high-risk pool for the couple of months when they had no income.

Also the purchasing pool would have been open to her possibly, with a small preexisting exclusion, perhaps not. But it would have been private insurance that she could have accessed for a lower cost and that she actually could have gotten medical underwriting.

So I just wanted to leave you with that. And Stephanie will talk a little bit

about our research. You can read more about Health and Disability Advocates on our slide and on our Web site, obviously.

MS. BECKER: I'll start out with generalizing a bit about subpopulation of uninsured, and the disabled population.

And it really depends -- when you try to look at how many uninsured and disabled people there are Illinois, it depends on the question asked.

And so the CPS survey, one of the surveys we use, has a very narrow question. It says, "Does anybody in this household have a health problem or disability which prevents them from working or which limits the amount of work they can do?"

And if you take that question, in addition to the question of how many people who do not have coverage at this point, that yields 89,000 adults in Illinois who are disabled and uninsured.

If you'll look at the BRFSS survey, which is the CDC survey in Illinois, they ask two questions that are more broad. " Are you

limited in any way to any activities because of physical, mental or emotional problems?" And do you now have -- you can answer yes to either of this.

"Do you now have any health problems that require you to use special equipment, such as cane, wheelchair, a special bed or a special telephone?" That yields over twice as many adults who are uninsured and disabled."

Next I want to talk a little bit about some of the things we mentioned today, but where people with disability do get their health insurance?

This chart shows that disabled adults disproportionally receive insurance through government programs, primarily Medicaid and Medicare. Only 30 percent of disabled adults get their health insurance through private, meaning both group and individual coverage.

This is not surprising since private coverage is structured for healthy, working populations, and rarely provides the adequate coverage for people with disability.

On the contrary, you see that

most nondisabled adults, 77 percent, get their coverage through private insurance.

This slide shows that over one-third of all Medicaid payments in the State are for blind and disabled individuals, even though they only account for only 12 percent of all Medicaid beneficiaries in the State.

This is, in part, because the needs of people with disabilities are often expensive. They rely on Medicaid for both acute and medical care. And a sense of community-based and institutional long-term service support, some of which Mr. Gelder was talking about.

In our analysis, we looked at uninsured people with disabilities across the State along a number of socioeconomic and demographic variables.

This slide shows the percent of disabled adults without health insurance in specific geographic regions in the State. For example, about one in four disabled adults in the collar counties are uninsured compared to almost one in five in Cook County.

Although we were continuing to do

some analysis about this, one explanation could be that the people with disabilities in the collar counties are not quite as poor as the people with disabilities in Cook County; therefore, they aren't eligible for Medicaid.

In this slide we start looking at the uninsured population in Illinois compared to disabled and non-disabled adults along income lines.

As you heard, people without health insurance tend to be lower income than people with the best healthcare coverage; however, that's even more of the case with people with disabilities.

People with disabilities are most likely to be low income or near low income than those without disabilities. The trend switches for those who are above 300 percent of the federal poverty level, where people with disabilities are more likely to have coverage. And this is presumably because the disabled adults need the health insurance more than the nondisabled individual. So if they have the means to purchase it, they often do.

This slide shows that not only are uninsured disabled adults more likely to be low income, they're more likely to be unemployed. And high rates of unemployment among people with disabilities limits their access to employer-sponsored insurance.

At HDA, we work on local, regional and national initiatives to enable people with disabilities to return to work. This slide shows even when disabled individuals are employed, they still are more likely to lack insurance than people without disabilities.

For example, the first bar for those who are employed for wages, 17 percent of disabled individuals still do not have health insurance compared to 13 percent of nondisabled individuals.

The discrepancy is even greater than those who are self-employed. Of those who are self-employed, 26 lack healthcare coverage compared to 50 percent of those who are self-employed and not disabled.

This is not surprising. As we know, it's much more difficult to get insurance if

you're self-employed, particularly if you have a preexisting condition.

This slide looks at the lack of healthcare coverage and educational level completed of disabled and nondisabled adults. There's a lot of information on the slide, but basically, it illustrates that being educated is somewhat of a protective factor against being uninsured, both for disabled and nondisabled individuals.

The lack of health insurance goes down as the level of education completed goes up. It also shows that education is not as much of a protective factor as the more disabled.

The last two bars on the right show of those adults with a college education, disabled adults are almost twice as likely to get insured than nondisabled adults.

And as Stephanie mentioned at the beginning with her story, really being disabled and being uninsured can happen to anyone.

And Stephanie also mentioned how the Consumer Health Care Program, any healthcare proposal that the Task Force considers needs to

prioritize the needs of the disabled. And here are three specific examples which Stephanie already mentioned. So I'll leave you with that.

MR. LERNER: Questions for Stephanie or Stephanie?

I have one. HDA, do you have a position on mandates, on individual mandates for insurance, whether there should be mandates or shouldn't be mandates?

MS. ALTMAN: Well, in the proposal that we proposed to the Task Force which -- I'm sorry. In the proposal that we proposed to the Task Force in cooperation with the Campaign for Better Health Care International Partners, is the position that we take, which is that if necessary, individual mandates is a secondary step that would need to be instituted if offering healthcare coverage for all does not succeed in all accepting or taking healthcare coverage. So we created a secondary step, perhaps a necessary step.

MR. LERNER: Because in your story about the young lady from Wilmette, some type of mandate that would have forced the issue, to at least assist them with the coverage. That then,

if they lost their income, they could have been supplemented later. Would have taken out the whole issue of preexisting conditions and everything else.

MS. ALTMAN: Absolutely. You know, Julie is the first one to tell you she made a dumb mistake. And had she known what she knows now, she wouldn't have done that. But we know a lot of people who do that. Educated people, etcetera. So you're right, the individual mandate, as well as more available options.

What happens is once you hit that crux, sometimes then there's no available option.

MR. LERNER: I understand that. I'm not really trying to pick on her. My point is that if we go from where we are today to the panacea, whatever the panacea is, then I'm not going to worry about that. But more than likely, we're going to have a step-wise process here.

So the question is how do you build these bridges or Band-Aids in there to make sure you've got your outcome in place, but you're still creating the right incentives for those providers and people with the insurance company

and everybody else. I mean, that's all I was suggesting.

MS. ALTMAN: I agree with you.

MS. DAVID: What about the expansion and rollout? What are you doing to get the doctors to accept the Medicaid rate in the southern section and the northern section and the central section of Illinois?

And for those who say they're not going to do it, has there been any discussion with the department to give incentives for them to do it?

MS. ALTMAN: Two things on reimbursement rates.

I mean, one, as Margie as said, we had a legal hook on pediatric rates, and that's why we filed the lawsuit on pediatric rates.

Whether politically, rates for adults will fall, that's more of a political issue. There's no legal hook for adult rates right now in terms of reimbursement hike.

The state has done a few things. One, they raised pediatric rates above cost, which is a huge thing, and hasn't been done before. So

they actually raised it to 89 percent of the Chicago Medicare rate which is above costs for providers. And for downstate providers, that translates to 118 percent of the Medicare rate. So that's one important step, I think, forward.

The second thing the State has done, and I'm not apologizing for the State here, but the second thing they have done in the new Disease Management program and the new Primary Care Case Management Program, for both providers of adults -- for adults and children, they have offered or are offering a per-month, per-member amount to managed care between 3 and $5, depending if it's a child or adult with disability or an older adult.

That amount, even though it doesn't sound like much, in prior years actually has been somewhat an incentive for physicians to manage the care of their patients, because overall for a whole caseload, that's still an increase per month.

Then there's a third thing, which is a bonus system that's been put into place for pediatric providers. Again, to give them a $30,

per-member, per-month -- per-year, per-member amount based on providing all care.

So there are financial incentives built into the system. I agree with all of you. It's just a start. There's still cycle --

MS. DAVID: I was wondering, how are you getting the word out? And how are you creating -- see, again, having this without someone to receive it -- what we're seeing in the 22 hearings that we did is that doctors don't believe it, one.

And secondly, they are not knowledgeable about it.

And then, thirdly, they're not going to do it.

So those are the three types of doctors that we've encountered.

MS. ALTMAN: The reimbursement rates only started January 1, 2006. We've done some media on it. We have done some outreach. So has the State.

They've now hired two big companies to do outreach on both of the issues. One, McKess and one, Automated Help. Part of

their subcontracts includes huge outreach providers and subcontracts to the provider groups, including the Illinois Chapter of American Academy of Pediatrics to get the word out.

Believing it, doctors believing it. I think the State has to build back trust with physicians in terms of really paying in the guarantee 30-day payment cycle for pediatricians. They're not going to believe it until that happens.

And as for other providers, unless that cycle changes, I don't think -- and the penalty actually changes --

MR. LERNER: Let me step back, though. I think this is a great example and I want to pick back up on Craig's point.

We're all aware that the special populations that we have negotiated, or special providers with special groups have negotiated special payment arrangements. We call those, "Pass Groups."

If we're going to go from where we are today with all this patchwork quilt of crazy arrangements that exist -- and we even saw

some of those in the Medicaid programs. And Ann Marie talked about this. To some type of uniform policy. Somebody's ox is going to get gored. There's just no two ways about it.

So again, I suggest from a task force point of view, we need to be real careful about this, because the children's world have been getting -- and they've done a great job of lobbying for special dispensation at the federal and state level. I'm not aware if that exists for people who care for people with disabilities or the elderly or the HIV population or any of the other special populations we're talking about.

So, you know, as we go down this road, let's think about this incrementally as we're going to change it.

The effects on social policy on what we're trying to accomplish has also got to be factored in.

Don't miss a point that they mentioned. Seven out of ten people with disabilities who can and want to work cannot find jobs. Cannot find jobs. And once they find a job, it's likely that they lose some of the State

support benefits that allow them to maintain that job.

So we've got the incentives all in the wrong place here. And these are the kinds of things that I expect we're going to debate and discuss at the July and August meeting. Other questions? Thank you very much.

We are now going to shift gears, as David suggested at the beginning, to special population and prevention presentations. And the first presentation is from Dr. Jarvette Orgain.

DR. ORGAIN: That's correct. Thank you.

Hi, I'm representing the State Board of Health today, but I wear a number of hats.

One additionally is the National Medical Association and the Local Society of Cook County Physicians Association, as well as the Illinois Academy of Family Physicians' which is very concerned about this issue in regards to the Health and Justice Act.

What I wanted to do is just introduce you again -- reintroduce you to the

State Board of Health in regards to our role in this arena.

Annually we're required to give a report through the Director of the Illinois Department of Public Health to the governor in regards to the public health status of the citizens of Illinois, as well as public health policy.

Coincident to the passage of the law that instituted the Health and Justice Act, the State Health Improvement Planning, House Bill 4612 was passed and also became law in August of 2004.

And what we're charged to do in regards to the State health improvement planning process, taking a look at the health needs of Illinois, as well as health improvement planning. Along with the time frame you're working with, it was due to be submitted to the governor in 2006.

We're still working with that time frame, if we can. The first, again. The second would be January 2009, and then every four years thereafter, for a presentation through the Department of Public Health and to the general

assembly, governmental general assembly.

The plan is designed to be produced by a multidisciplinary team of public, private and volunteer stakeholders.

It must include, according to the legislation, priorities and strategies for health status and health system improvement with a focus on prevention, as well as specific goals to reduce racial, ethnic, geographic, age, gender, socio economic health disparities.

If you take a look at the last page of your handout, we began the task force -- the planning team that was created and appointed by the Director of Public Health, Dr. Whitaker, began its process in October 2005. And you can see the flow chart of where we are today.

Where we are today in terms of June 2006 is the draft is being completed. This month we've had all of our meetings. The draft is being completed this month. The last meeting was Friday.

And we are scheduled to hold -- the State Board of Health is scheduled to hold three public hearings. August 4th in Mt. Vernon,

August 8th in Bloomington, August 9th here in Chicago.

The draft plan and throughout the process, the team -- the draft plan addresses six strategic issues. Priority health conditions, which were determined from using National Health Priority. The Illinois Project for -- I-Plan for local health need assessment, and other information to set national standards.

Obesity, physical activity, substance abuse and violence were selected based upon that assessment of the health priority from local health departments, and the I-Plan and national health Objectives, such as Healthy People 2010.

Access to care, health disparities, work force data, information technology, measure, manage, improve the public health system on the strategic issues that the State Health Improvement Plan is looking at.

In regards to long-term outcome, the strategic planning process from the SHIP team included a number of input, initial, intermediate and desired long-term outcomes, those being, as

you can see here, what's in your handout. I won't read them to you.

But particularly, in regards to the healthcare and public health system, a system -- and this is what you're discussing here today. System change, a plan for providing healthcare to all of Illinois citizens.

Then one that is responsive to the culture, linguistics and other population needs. Integrate prevention and care. And utmost, universally available and affordable.

And a health system that is actively engaged in addressing health disparity and the social determinates that affects health outcome.

The additional long-term outcomes include culturally and linguistically competent work force, which you are not necessarily addressing, but what we, as a State Board of Health once you develop your plan, we will be looking at these issues and how they interface.

A well-understood and utilized linked data system. And a system to monitor the State Health Improvement Plan goals and objectives

and implement improvement.

What you're doing here today and what we have to do in terms of the State Health Improvement Planning process is ensure that whatever the health system changes will be, will improve the health response, legitimate expectations of Illinois citizens and the fairness in terms of contribution, meaning federal, state and personal responsibility in regards to healthcare.

I would recommend that as you continue your process, that this is taken from the World Health Organization 2000 annual report that talks about needed health system changes. How we get to universally accessible and affordable healthcare.

And so, I'm not sure where we fit in terms of State Board of Health, whether we're a special population in regards to the presentation, but what we need to do is invite the member of the Adequate Health Care Task Force to our public hearings. Again, on August 4th, 8th and 9th.

And to recap how we see our role in regards to this Task Force and the State Health

Improvement Planning Team, we are not developing a plan. You are. And in regards to the State health improvement planning, we will be assessing the plan that you develop.

And so, in regards to what you do, as we look at and as we hold our public hearings, and as citizens of Illinois, as well as you advise us in terms of the needs assessment and how we improve the health of the citizens of Illinois, then we will take into consideration what you have developed as well.

You have the time schedule for which the plan is going to roll out and so do we. And the information that we provide will be on the Web site for you to look at in regards to the State health planning improvement process.

Our information is designed to be completed by September of 2006. And so the Health Care Justice Act is designed to produce a plan that ensures access. And we at the State Board of Health and at that level, will be evaluating that plan as well. So, any questions?

MR. LERNER: Thank you very much. Questions for Dr. Orgain?

DR. ORGAIN: So from a perspective of inner faith, we hope that -- and we have members of this task force that report to us at the State Board of Health.

Our public hearings will be held. The State Board of Health will meet again in September and December. And we will need the information from you that will allow us to take a look at one of the plans we're looking at.

What we consider to be very important are the costs of the plan. And as you move forward and evaluate the ones that you're considering, those that have failed across the nation have been those that have skyrocketed in terms of costs, attempting to provide healthcare to all the citizens, yet failing in regards to cost.

So we would encourage you to look diligently at that. Thank you.

MR. LERNER: Doctor, there was an article in the Wall Street Journal about a week or two ago about a pilot program at Mt. Sinai in York -- I think it was Sinai in New York, that was looking at really re-focusing chronic conditions

of low income Medicaid beneficiaries away from the acute care to prevention, with incentives built in by the Medicaid payment program. So that the hospital would lose money initially, but gain it later, and they would really focus on prevention. Have you seen that article or --

DR. ORGAIN: The board has not looked at that article per se in looking at -- looking at your work. We have not done that.

MR. LERNER: Okay. This was a great example.

DR. ORGAIN: As a family physician, we certainly are aware of that.

MR. LERNER: It was a great article about a week ago. I just would recommend it because I really think it's another one of the great examples.

We've talked about examples like this throughout our whole deliberations of what we could learn from special pilots in other areas. Goes right in line with what you're talking about. Questions or comments? Thank you very much.

Last on the agenda before lunch is Joe Antolin and Joe Harrington, who are

representing Racial and Ethnic Health Disparities Action Council.

MR. HARRINGTON: Good afternoon and thank you. I'm Joe Harrington, not Joe Antolin. I'll be doing the presentation. I'll be doing the presentation with respect to my role -- two roles.

One, I'm the Chair of the advisory panel of the Illinois Department of Public Health. I'm also the Co-chair of the Racial and Ethnic Health Disparities Action Council.

What I'm going to attempt to do, and I'm going to be try to be brief with respect for the Task Force time, and also allow as much time as possible for questions and interactions.

I'm going to give an overview of the uninsured in Illinois, review problems with racial and ethnic health disparities. Suggest ways to address these disparities through the Health Care Task Force Plan. And there's four key areas that I will get into. And we'll talk about the take-up of programs, low-quality healthcare and limited information.

As you can see by this slide,

there's quite a disparity among uninsured or with uninsured, particularly in the metro Chicago area and the Chicago area specific to minorities.

Actually, 90 percent of the Hispanic population in the State of Illinois lives in Cook County. 56 percent of all minorities live in Cook County, and 49 percent of minorities throughout the State live in the inner city.

While we're looking at the issue of access to healthcare, it's important to remember that if we're talking about healthcare, it's really the social determinates of health that create and breed an environment in which poor healthcare can and does thrive. So while we're talking about access, it is a major factor, but not the only factor in what we're talking about.

What we're going to do is address six plans of the Adequate Health Care Task Force, attempting to bridge them with the REHDAC focus on social determinates, the impact upon health disparities. Again, "REHDAC" stands for Racial, Ethnic, Health Disparities Action Council.

A take-up refers to those that have access or are eligible for a program, but

actually don't sign up for the program.

Some of the explanations we can see here might be transaction costs, misinformation about details in the program. Need for continued recertification. And a lot of times, minorities are not offered employment-based health insurance at the same rate as whites. So we have some specific suggestions.

Current plans could be modified to limit take-up problems for the Adequate Health Care Task Force programs. Some of these might eliminate some stringent access limits currently in place.

Another might be to adopt presumptive response eligibility and provide service until proven ineligible. Eliminate some of the long waiting periods for people getting insurance.

You can use simplified questions, eligibility questions to make sure people become eligible.

And you can have a 12-month or two-year continuous eligibility.

Again, we're looking to get more

people to actually take advantage of those plans that are, in fact, available, because this may go a long way to do that.

Another problem to look at is a problem with quality care. And the limited diversity among the community health work force has negative implications for access, quality and equity.

The Institute of Medicine has found that racial concordance of patients and providers is associated with greater participation in the care process, higher satisfaction and greater adherence to treatment.

There was a study done that actually showed that African-Americans and Hispanics had a greater perceived notion of the fact that they will get poor or lesser care just based upon race alone, which sort of substantiates this.

So some of the recommendations we would make are to establish standards for culture/linguistic competency. To make cultural/linguistic competency part of quality measures. A required training for all healthcare

providers serving minority populations to assure and enforce these standards.

Also to increase incentives -- create incentives for doing the training, because without incentives to do the training, it's highly unlikely that anyone will take advantage of the training.

It's an important thing, we think, but there has to be some built-in incentives to get people to actually take advantage of the training.

Encourage more minority providers to participate in healthcare plans to serve a higher proportion of minorities. A lot of the providers, particularly the minority providers in the minority communities, have somewhat higher costs in terms of actually providing the care.

And that should be looked at in terms of any plan that's developed to compensate them for their higher costs so they can, in fact, actually earn a living by serving the minority community.

And last, create enforcement authority for these standards.

Another recommendation that we'd like to make is around the issue of low quality of care to minorities. And that could -- by increasing reimbursement, subsidy rates to healthcare providers who demonstrate cultural/linguistic competency and managed-care plans and new insurance pools require new plans and/or pools to establish prevention and interventions targeted at minorities.

For example, a plan that has a great deal of African-Americans requires prevention focused on diseases affecting African-Americans. And there's very few that don't, but either provide -- make sure that they require preventive focus on diseases like heart disease. Specifically high blood pressure, diabetes, things like that that adversely affect African-Americans.

The problem of limited data on minority health outcomes. It is difficult to research the problem of health disparities in minority communities because very little data is collected by racial and ethnic categories. Without this data, the health problem in the

communities of color are mass, making it harder to prevent and eliminate health disparities.

A couple of good examples of that. The top three killers in this country for most people are heart disease, cancer and stroke; however, for Asians and Pacific Islanders, the number one cause of death is actually cancer. So there is a dramatic difference when you look at data on the basis of race and ethnicity.

Another telling statistic -- and I heard this probably about five years in my role with the advisory panel on minority health, there was a study that was done looking at different issues involving health, specifically in the City of Chicago.

And when you looked at the Asian Pacific Islander community in the City of Chicago, among that community there was low incidence of suicide; however, if you broke that down based upon ethnic group, the Lao Mung population, who primarily is on the north side of the City of Chicago, had a very high incidence of suicide.

The only ways to tease out a problem like that is not only look at the data on

the basis of race, but look at the data on the basis of ethnicity. So there are ways to do that.

The census allows people to report that; however, there's some inconsistent reporting of race and ethnicity throughout the State.

So our recommendations would be to develop data collection procedures and measure health problems in different minority populations. Change state data collection procedures used in OMB15 at a minimum. And that clearly outlines the current standard on a federal level for collection of data on race and ethnicity.

Require all current and new health insurance, managed-care or publicly funded programs to collect uniform, race and ethnicity in the primary language of patients.

And again, OMB15 is used by the federal government. It's used in terms of the census. It should be adopted by all healthcare providers to ensure consistency, so when we're making comparisons, we're really not comparing apples to oranges.

So our conclusion is to have a

significant opportunity to include small provisions to help decrease and really impact on this issue of health disparity for racial and ethnic minorities.

We respectfully suggest that the Task Force incorporate these and some of the other statistics, I guess that will be made, into their final plan. I'd be more than happy to answer any questions.

MR. LERNER: Questions for Joe?

MS. DAVID: One of the things that -- there's been a lot of federal talk about health providers having to do the citizenship testing of immigrants. And I didn't necessarily see that in the recommendations, but I think that that's one that -- I think that, at least we should probably put.

MR. HARRINGTON: I think that's one that the counsel would support. I see no problem with that.

MR. LERNER: Niva?

DR. LUBIN-JOHNSON: Thank you for the presentation, Joe.

And he's being little a modest.

He also has another title he acquired recently. I believe it's Assistant Commissioner of Health and Retirement?

MR. HARRINGTON: I assumed the position of Assistant Commissioner for the City of Chicago, Department of Public Health, yes. But I'm not here in that role.

DR. LUBIN-JOHNSON: Right. My question is in terms of what the council is looking at, have you all thought about looking or are you looking at the paper performance management that are becoming increasingly prevalent for providers?

I think it's a detriment to those of us who serve, you know, those persons of color because we start out behind -- our patients start out behind the eight-ball already.

So for us to try to get them up to where they should be in terms of paper performance and practice guidelines, is a bit more of a hurdle to do.

MR. HARRINGTON: This is something that the council hasn't looked at specifically, but it's something that I know we would support.

There are -- the technology is available to make the burden of paperwork a lot lower on all providers and could do that also for minority providers as well. So that's something that we would, in fact, support.

What I would make available to people if they are interested is -- actually, our recommendations come out of a report that our council prepared that was released in December of 2004. Copies of that report are available. I don't have the Web site, but what we are trying to do is link our recommendations specifically to the recommendations coming out of our report.

DR. LUBIN-JOHNSON: Are you all going to do another report sometime in the future?

MR. HARRINGTON: It's a possibility. Some of the things that we actually -- the actual strategies that we developed are still being looked at, but until we do a complete and thorough job of what we already said we'd do, it's unlikely we would do another report anytime in the near future.

MR. LERNER: Anymore questions for Joe? Thank you very much.

Before we adjourn for lunch, I need every voting member for one moment.

We now have a quorum. Could I entertain a motion to approve the minutes of April 21st and May 9th?

MR. CARVALHO: So moved.

DR. LUBIN-JOHNSON: Second.

MR. LERNER: Any additions or corrections? All in favor please say aye?

(All say aye)

MR. LERNER: Opposed? Nay. Any abstentions?

The minutes are approved as distributed. It is now 12:25. We actually are ahead of time. I want to thank all the presenters this morning. You did a great job. We really appreciate it. We'll be back in session at 1:00 o'clock.

(Whereupon a recess was had)

MR. LERNER: I'd like to call together the afternoon session. And I'd like to turn it over to Ralph who will introduce the session participants. And he'll be the timekeeper for the next period of time.

MR. SCHUBERT: Well, a couple of introductory things. First of all, I had the opportunity a couple of months ago to talk to you about all the Maternal Child Health Programs within the Department of Human Services, but that didn't tell by half the story of the wide array of things the Department of Human Services does, and the other special-needs populations that it serves. So that's why I put this panel together today to talk a little more about some of our special population and their needs and interests when it comes to health insurance.

The space next to me is for Rob Kilbury, our Director of the Division of Rehabilitation Services. We heard from Rob's office about 20 minutes ago and he's tied up in something. And Rob will be here.

And next to Rob is Connie Sims from our Division of Developmental Disabilities.

Next to Connie is Lillian Pickup from our Division of Alcoholism and Substance Abuse. And next to Lillian is Mike Pelletier from our Division of Mental Health.

And next to Mike is Gerri Clark, who is not from the Department of Human Services, even though we feel like she's family.

Gerri is with the University of Illinois at Chicago, Division of Specialized Care for Children, and as I mentioned a couple of months ago when I presented Every State Maternal and Child Health Program, devotes about a third of its resources to children with special healthcare needs. Illinois is one of three states in the country where that program is not part of the same agency that gets the MCH block grant.

So in order to sort of fully describe, and better that I can do, the needs of children with special care needs, I asked Gerri to come join the panel today.

And so I think I'll turn it over to Connie and I'll go over there and make hand signs at about five minutes.

MR. LERNER: On behalf of the Task

Force, I want to thank all of you for taking the time to be with us here today.

You're actually at a very critical juncture in our deliberations, because you're the last presentations before we really get into delving into the models and the criteria. We really do appreciate your attendance here today.

MS. SIMS: This is Rob Kilbury. We decided I would start first since you weren't here, but maybe you can go next.

MR. LERNER: Let me also remind you that we have a court reporter, so everything that's said is on a transcript. It's the Open Meetings Act, so we'd ask you to speak slowly and articulately so that she can get it all down.

MS. SIMS: All right. So I will get started. My name is Connie Sims and I'm here for Jerry Johnson, who is the Director of the Division of Developmental Disabilities. Can everybody hear me? Is it okay if we just remain seated and talk from here?

I work in the bureau of Medicaid Administration and Program Development in the Division of Developmental Disabilities. I've

worked in the field of Developmental Disabilities for about 26 years, and 23 of those years have been with the State of Illinois.

I have a background -- my first job in state government was with the Bureau of the Budget, which is now called, "the Governor's Office of Management and Budget." And I worked on a long-term care budget for the Department of Public Aid which is now called Health Care and Family Services, so I really feel like I've worked in Medicaid programs for my entire State career.

The main thing that I want to talk about today is -- I want to talk a little bit about how people with developmental disabilities access basic healthcare in Illinois, but I also want to tell you about the home and community-based waiver program that we operate in the Division of Developmental Disabilities.

It is kind of our flagship program, and something we want to make sure everybody has some information about, so I'll come back to that in just a few minutes.

I wanted to give you an overview of the entire DD service system. Currently we

have a budget of about $1.3 billion. Of that $1.3 billion, about 300 million is spent to operate nine, what we call state-operated developmental centers.

And these are located around the State. They are considered long-term care facilities. We get Medicaid matching funds. They are certified as intermediate care facilities for persons with mental retardation by the federal government.

So that is one piece of our DD service system. The developmental centers. And those are typically referred to as institutions. They are large congregate settings. Many of them have large campuses.

You may be familiar with some of the developmental centers, such as Kiley Center in Waukegan. And we operate Howe Developmental Center in Tinley Park and a number of other centers around the State.

The other part of our division is what we refer to loosely as community services. And that makes up the lion's share of the budget, which is about $1 billion. Of the billion

dollars, about 400 million of that is spent for private intermediate care facilities for persons with developmental disabilities, so these are also Medicaid-funded settings. Long-term care settings. And they are considered congregate settings for persons long-term care settings.

So we have about 2700 individuals currently living in our state-operated developmental centers. And then we have another, about 6800, almost 7,000 people living in the private long-term care setting. So we have just under about 10,000 people that are living in what would be considered institutional settings for persons with developmental disabilities.

Then we have -- you know, the other biggest piece of our budget is our home and community-based waiver. And that program is about a $400 million program at this point in time, so that we are spending about the same amount of money on people who live still with their family in a private family home and are getting support services in the community. We're spending about the same amount of money on those individuals as we are the people who reside in the private

intermediate care facilities.

The final piece of our budget is about $200 million, and that's a combination of children services, which are not currently reimbursed by the Medicaid program, and some other grants that we still provide to community agencies to provide a variety of programs. So that's kind of an overview of the entire DD budget and the major pieces that we see.

I wanted to talk about the waiver program. As you probably know, there are seven home and community-based waivers in Illinois, so the DD waiver for adults with developmental disabilities is one of seven waivers that are -- we have authority to operate here in Illinois.

To qualify for the DD waiver, of course, you have to have a developmental disability. You have to be an adult. You have to be eligible for Medicaid benefits, and you have to need the level of care that is provided in an intermediate care facility, so you have to need the kind of care that could result in you being institutionalized. And the waiver services are an alternative to those long-term care facility-based

services.

And we're currently serving over 12,000 adults in our home and community-based program. And it has been growing. It started in 1991, and it continues to grow. It is the growth part of the DD budget right now.

Any new initiatives that we are lucky to be able to sponsor are all things that qualify for federal Medicaid matching funds. Because certainly, the legislature and the governor's office realizes that if we can sponsor programs that can bring 50 percent of the cost back to the State of Illinois, that that's a much better deal for state taxpayers to only have to pay approximately half of the cost of services. And so that's why the focus has been so much on the home and community-based waiver program.

I'd also like to mention that we are currently writing a new waiver. A new home and community-based waiver. And that is for children with developmental disabilities. And it's also going to specifically include children with autism and autism spectrum disorders.

We hope to get the application

together by the fall veto session. And that's a very exciting opportunity to be able to write a new waiver and design services for children. So we are in the process of doing that right now. And we're under quite a bit of -- we've got quite a deadline to meet to be able to get it all in place.

We have an ad hoc committee of people that are advising us on the new children's waiver, so we're getting input from our partners in the State to help design this new package of services.

I also wanted to tell you a little bit today -- we have a new dedicated fund that was started by the legislature a couple of years ago. And it's another really positive thing that is happening in the DD service system.

There's a formula, and a percentage of the growth in federal matching funds that we're able to earn back to the State of Illinois, is being deposited in this dedicated fund which will then be available to help expand and improve community services for individuals with developmental disabilities.

So there's a real incentive for all of our partners to work together to try and increase the federal matching funds coming back to the State so that we can expand and improve the service system.

This past year, the treasurer deposited $2.8 million into the dedicated fund. This coming year, we expect the deposit to be at least 4.5 million, so that we are increasing the federal matching funds and we are being able to deposit money into this new dedicated fund. And this is a very new thing for us and we're very excited about that possibility.

Before I talk about basic healthcare, I wanted to let you know about our statewide advisory council. We have a statewide advisory council that meets quarterly. We meet in Springfield. And the council is made up of one-third consumers, one-third family members and one-third providers. So that we feel like there's a real balance on the advisory council.

And the way the council works is that DHS is now divided into five regions. There are three representatives that are elected from

each of the regions. There's a consumer, a family member and provider elected by each of the regional advisory councils that feed into the statewide council, so that is how the council is organized; however, in the metro area, we actually have four regional advisory councils, so there are a total of eight local advisory councils, for a total of 24 members on the statewide council. So that's how our council is organized. Our next meeting, I believe, is July 13 in Springfield.

The last thing I want to talk about before I delve into healthcare, and then I'd like to take questions from any of you, because I think it's -- you know, probably the best way to spend our time is to tell you about things that you're interested in knowing about the DD service system.

But I wanted to feature a new database that was started about a year and a half ago which is called PUNS. That's the acronym that we use. PUNS. Has anybody in this room heard of PUNS? Jerry has, Michelle has. That's good. I'm glad people in state government, at least.

PUNS stands for the

Prioritization of Unmet Needs for Services. And it is a new database that was started. And we contract with 18 independent service coordination agencies around the State. And their staff are doing interviews with individuals and their families who are seeking services from the State for an individual with a developmental disability.

So right now, we have over 10,000 people enrolled in the PUNS database as people seeking services. And those people are categorized into three different categories. Emergency needs, critical needs, which means within one year. And then planning needs, which is within five years. So that we're gathering information for planning purposes about the people that are seeking services in Illinois.

I don't have much time left on the healthcare front. I wanted to let you know consistently we hear from members of our statewide advisory council that they think the State medicaid plan, which is the primary provider of basic healthcare for individuals we serve, should cover preventive dental services for adults. Annual checkups, and teeth cleaning are services

that are not covered now for adults under the Medicaid plan, state plan.

So that is something that we have heard for the last 20 years, about a need for basic healthcare that I wanted to bring to you today given your role here.

So that's about all the time I have. If you -- just maybe one question if anyone has a question? Yes.

MS. DAVID: At one of our hearings, a dentist that services population, talked about some mortality related to aspirations. Could you speak on that?

MS. SIMS: Aspiration is a problem, a common -- I don't want to say common, but it certainly is an issue for people with Cerebral Palsy. People who have compromised lung capacity and physical ailments.

And, you know, I know that we track mortalities in our DD service system and I know aspiration is high on the list of cause of death, but I do not know anything about the connection between aspiration and dental care.

MS. DAVID: Well, he had a study and

he has been tracking. And you may want to look at that because he's saying that these people have poor access to dental services and as a result, they don't have the proper dentures and care so they can chew their food. And as a result, that's what causes their aspirations.

MS. SIMS: Okay. Well, thank you very much.

REPRESENTATIVE COULSON: I have a quick question on the definition of a DD client. Do you include autism in that or not?

I know you're doing a new waiver on autism, but where do those children fit in in the department?

MS. SIMS: Not everyone with a diagnosis of autism would be considered to have a developmental disability; however, many, many do. And the definition is something that the eligibility for the children waiver is something that we're dealing with right now.

And we've been very fortunate to be able to hire some private consultants. There's going to be an RP issued, and so we'll be contracting that out and relying on some real

experts to help us develop the eligibility criteria for the new children's waiver. And that will address how many children with autism. What other conditions or functional deficits do they have to have in order to qualify for the children's waiver.

REPRESENTATIVE COULSON: The reason I ask the question is -- I know that's all happening, but the concern for this task force is making sure that we don't define a group and then have a whole missing group that doesn't get healthcare for our purposes in the Adequate Health Care.

MR. KILBURY: Maybe we should give everybody healthcare. How about that?

REPRESENTATIVE COULSON: Well, in government, we tend to define and categorize and then all of a sudden, we have this group left out, and I just wanted to make sure.

MS. SIMS: Thank you.

MR. SCHUBERT: Thank you, Connie.

And Rob's got an appointment coming up in a few minutes, so I want to turn the floor over to Rob and shuffle the order here.

MR. KILBURY: I'm Rob Kilbury. I'm with the Deputy Director of the Division of Rehab Services.

I have a few statistics that I brought with me that the Harris poll and census bureau had talked about in terms of people with disabilities in healthcare. But I thought I would talk a little bit about the programs that we have that are healthcare related at the Division of Rehab Services.

I guess our flagship program, of course, is our $400 million home services program, which is also a Medicaid waiver, meaning that everybody that's Medicaid eligible on a day-by-day basis, the State gets 50 percent of money back from the feds and federal financial participation.

About 80 percent of the 30,000 people in our general waiver currently are Medicaid eligible. So if it's a $400 million program, we get in the neighborhood of -- I don't know, 160 or so million back in FFP.

That, of course, speaks loudly to people like Beth Coulson, who is on our Human Services Appropriations Committee.

And what it does is allows people with disabilities to live in the community by living in a nursing home. By definition, these folks are at risk of nursing home stay.

And so the thousand or so dollars that we spend in an average case cost in the home services program, is compared to the 3 or $4,000 that we'd spend on that same individual if they were living in a nursing home. So their quality of life is much enhanced, and it's also a tremendous cost savings to the State.

The general waiver, as I said before, has about 30,000 individuals in it. We also have a AIDS waiver for people who are HIV positive and qualify by their score on the determination and need instrument that makes one eligible either for a nursing home or for home care in the State of Illinois.

And we also have a traumatic brain injury waiver. That's the newest of the three waivers that the division operates.

You know, in terms of healthcare, I remember going to Washington years ago when the federal healthcare debate was hot. And people

were gathering outside the Senate Finance Committee room and urging people like John Groe and people like Dale Bumpers and other people that were less supportive of healthcare than that, that healthcare really had to work for people with disabilities if it was going to work at all.

In other words, the litmus test for healthcare reform in the day should be whether it's going to work for people with disabilities.

You know, even somebody like me that's got a middle-class lifestyle, who has a job that they go to everyday. Who, you know, does okay in terms of many of the socioeconomic demographics and so forth.

The first thing that my wife, my daughter and I think about when we look at employment is, what's the benefits package going to look like.

I've got a condition called syringomyelia, which has had -- has required major surgery twice. And, you know, we're really -- my family is without a good healthcare package. My family is like this far from poverty at any given minute because of the costs associated with that

particular surgery. And there's a lot of people that are in that position that have disabilities.

Harris, the National Organization of Disability, did a survey in 2004 which indicates that people with disabilities are more than twice as likely to report that they did not receive needed healthcare on at least one occasion within the last year than people who do not have disabilities.

The statistics were 18 percent for people with disabilities and 7 percent for people who did not have disabilities.

Similarly, people with disabilities reported significantly greater problems finding a doctor who understands their healthcare needs compared to people who don't have disabilities. The statistics there were 26 percent for people with and 10 percent for people without disabilities.

People with disabilities report being worried about losing their health insurance coverage more than those that don't have disabilities by a statistical percentage of 44 to 31.

And when you look at people by age, in the age range of 25 to 64, basically the employment years for most people, 15.9 percent of those individuals in that age range who didn't have a disability lacked health insurance coverage. 17.2 percent who had a disability that was not characterized as being severe lacked health insurance. And 18.7 percent of those with severe disabilities lacked health insurance.

So obviously, there's a correlation between age and disability. There's a correlation between not having health insurance and having a severe disability.

And I guess the only thing I could say in terms of urging this group of people -- and I've loved working with Jim Duffett over the years and I've loved working with Quentin Young over the years.

The only thing I could urge is that if it's going to work with people in general, it has to work for those with the most significant disability.

So I'm all for a single-payer universal system, what we talked about, affiliated

with the campaign for better healthcare for years and years. I know it's what Quentin has advocated for years and years.

It would be great to see Illinois do something like the State of -- what was it -- Massachusetts just did. And urge all of the employers in the State to cover health insurance for their employees.

MR. SCHUBERT: Questions for Rob?

MR. MURPHY: Rob, Mike Murphy. Was that a personal view or administration view about universal healthcare?

MR. KILBURY: No, I don't purport to speak for anybody but me. Thank you.

MS. DAVID: I wanted to ask, in our hearings, Rob, there was several people who have used your services. You're DORS, right?

MR. KILBURY: Yes.

MS. DAVID: They speak of gaps in services around physical therapy in the home and the long wait times of paying providers. Can you speak to -- if you know about this issue?

MR. KILBURY: Well, our personal -- 90 percent of our program is the personal

assistance part of it. And the RPAs, as we call them, are paid every other week as long as their calendars are submitted on time.

And so we've got -- for the 30,000 customers that we have out there, we have a similar number of PAs, maybe even a few more because some customers have more than one personal assistant. And as long as they get their calendars in on time to our offices, they get paid.

MS. DAVID: This is physical therapy.

MR. KILBURY: Well, that's a very small component of the home services program.

MS. DAVID: But that's the area in which we -- people came out and testified that they are having severe problems.

Like Friday up in McHenry County, crying. I mean, people crying. Daughters having muscular dystrophy and they haven't paid the physical therapist. And this is what keeps them breathing without the ventilator.

And then the physical therapists haven't been paid. Then it was a whole complex group of core agencies involved in the care, and

none of them could talk to each other, you know.

So I was just wondering if -- you may not know about it now, but could you look at those small cases, because that's where our complex crises are.

MR. KILBURY: I'd be happy to look at any case or on a case-by-case basis. The reality is that our program -- Governor Blagojevich has increased this program tremendously over the years.

Our program -- the cost of our program goes up by somewhere in the neighborhood of 10 percent per year, so there aren't a tremendous amount of people out there that are going wanting in terms of home services.

There may be gaps for people with very complex disabilities here and there. And I'm not refuting at all what you've said. No program is perfect. But I certainly am happy to look into anything that anybody has and can bring to us that is a hardship on our customer, because that's the only reason we're there as an agency.

MR. LERNER: Representative Coulson?

REPRESENTATIVE COULSON: Yes. I have

a question that actually came to me yesterday at a meeting last night at 10:00 o'clock. I haven't had a chance to look into it. You may be able to answer it, maybe not.

As you know and I know, there are disabled people under 65 who are eligible for Medicare coverage. And they're able to get the Medicare coverage, which helps, obviously, everybody because they do get health insurance in that way.

The question that I have, apparently, in 22 states they're allowed to get supplemental coverage, but in our states, for some reason, there's no supplemental coverage for those disabled people under 65 who are eligible for Medicare.

That's a gap that I didn't -- I didn't catch in these meetings, and someone told me about it yesterday. Do you know anything about it?

MR. KILBURY: I think that's a Public Aid question. I'm not sure I can respond to that, Representative.

REPRESENTATIVE COULSON: It's not a

Public Aid question, because it's not Medicaid. They're Medicare eligible and they're not able to buy their own supplemental insurance.

MR. MURPHY: Actually, there was a bill that was introduced about three years ago that would have done that, and it didn't go anywhere.

REPRESENTATIVE COULSON: Right. And my question, I guess, is, is that something as an Adequate Health Care Task Force we should be looking at?

So most of your clients -- all of your clients actually are Medicaid eligible?

MR. KILBURY: Not all, but most. I mean, there's a tremendous correlation between poverty and having a disability. And obviously, the thing that drives being eligible for Medicaid, in addition to having a disability, is the poverty end of it.

So, you know, whether we're talking about our home services program and to a lesser degree, even our vocational rehabilitation program.

REPRESENTATIVE COULSON: Yeah, but

we're here talking about the healthcare access of your clients.

MR. KILBURY: And one of the issues related to all that is that people are -- have Medicare or Medicaid, depending on if they are on SSDI or SSI. And they then have to go to work and sometimes they can qualify for an employer's healthcare plan and sometimes they can't. And that's a --

REPRESENTATIVE COULSON: These are for people who are not employed, can't get supplemental.

MR. KILBURY: Yeah. But I think more people -- a lot more people would be employed if there were healthcare for everyone and it wasn't tied to your employment status. And that's certainly what we've been advocating for for years and in any number of context. That's why we were excited about healthcare reform.

MR. LERNER: Conversely, more people will get work who are able to work through the DORS and elsewhere as long as there is employer-sponsored healthcare. The more people to go to work, the more we cover those people as

well, right?

MR. KILBURY: Absolutely.

REPRESENTATIVE COULSON: Illinois is one of -- whatever 22 minus 50 is, one of the few -- there are 22 states that have allowed this kind of coverage to be purchased, and apparently Illinois is not one of them.

Again, I was told this by a constituent who has a son who is 44 who is Medicare eligible. And it's a -- I knew about the bill, but I didn't know if -- because you're probably in the same category, Rob, I thought maybe you would know.

MR. KILBURY: I plead ignorance.

MR. GELDER: Just for clarification, in our program on aging, 53 percent of our clients are Medicaid eligible, so there's a much larger percentage.

REPRESENTATIVE COULSON: Right. But you're over 65.

MR. GELDER: No, no. Just in terms of percentages.

THE COURT: Okay. Thank you, Rob.

Lillian Pickup, Division of

Alcoholism and Substance Abuse.

MS. PICKUP: Hi. I'm representing Theodore Binion Taylor, who is the Director of the Division of Alcoholism and Substance Abuse. I am a registered nurse. Next year will be my 40th year in healthcare, all of which have been spent in addictions and mental health. Ninety percent pure addictions.

I consider that I must be kind of stubborn because I represent one of the most discriminated against illnesses and diseases, which we'll talk about a little bit later.

You have a handout in your packet here. One of the things that the Illinois legislature wrote a number of years ago when they created DASA when it was the department was to improve the quality of life in Illinois by eliminating the human suffering and economic loss, all by misuse and addiction to alcohol and other drugs.

Our budget is approximately $243 million general revenue. Federal block grant funds, close to $70 million. Some special-use-funds which are Illinois general

revenue and Medicaid.

We serve approximately 90,000 individuals a year. We're totally privatized and have been privatized since the 1970s, so my office is highly administrative. We keep begging for money, and so forth. Particularly, we do have federal competitive awards which we're pretty good at getting.

Some of the services that we represent and we purchase from the Wisconsin border down to Anna, Illinois and from the Mississippi to Indiana, case management, community intervention, early intervention, outpatient, intensive outpatient, which I like to call rehab without a bed. Detoxification, residential rehab, residential aftercare in three different levels.

The opioid maintenance, which is an ancillary service. And soon it's going to become medication assisted treatment.

There are more medications coming to the treatment level that are assisting in the services in the provision and the recovery from addictions, and so we are moving to include that in our licensure.

We are the licensing body for all subacute addiction services in the State of Illinois. We're also the DUI payer and a few other things.

We pay for psychiatric evaluations, toxicology. And we also pay for child ancillary services when the parent is in treatment in a limited amount.

About 16.4 percent of Illinois residents, age 16 and above, were found in need of addiction -- some level of addiction treatment in 2003. This was an Illinois-based study paid for by the Center for Substance Abuse Treatment. Almost every county was represented. That translates to 1,580,000 individuals.

This is where I usually say you can pay us now or you can pay us later. We are all paying.

17.3 percent are lacking insurance coverage; however, that number is going up. And the other issue is underinsuranace.

I make treatment referrals over the Internet. I also make treatment referrals through the phone. All different ways. People

are calling.

People who have insurance are borrowing, mortgaging their homes, doing anything they can to manage the copays which are discriminatory against substance abuse.

You pay more in copays. You have limited services on an annual basis. And you have a limit as to what you can receive in that year and lifetime.

The 2003 household survey also had us take a look at those with other disorders. 14.2 percent with a substance abuse disorder have a physical disability. 29.2 percent are also -- have a DSM3 or 4 diagnosis for mental illness. Ten percent -- this is from the 2003 Illinois social indicators study also done by the division and paid for by the feds.

Ten percent of discharges from Illinois general hospitals each year involve diagnoses that are 100 percent attributed to or related to the use of alcohol. Alcohol only. These alcohol-involved hospital discharges have annual costs and charges in excess of $1 billion.

Each year about 40,000 discharges

are drug related with costs and charges of about $300,000. That comes to a total of 1.3 billion. And we're not talking about the other social costs and so forth.

National estimates from a new policy panel that just came out this morning is 20 percent of national acute Medicaid expenditures pay for alcohol or drug-related medical costs. Health care is paying. It's just not paying necessarily for treatment.

The cost of parity have been studied and have been studied over and over and over again. The cost for providing parity to an insurer is .2 percent.

But again, when I said discrimination before, I kind of meant discrimination. Are you aware that the Illinois Insurance Code currently allows an insurance company to disallow payment for treatment of an illness or an injury if you are recorded as intoxicated?

Illinois is the recipient of a $22 million screening, brief intervention and referral to treatment grant commonly called SBIRT.

That grant is up in the Chicago area at Stroger Hospital and a few other hospitals primarily serving public clients.

I don't know that that grant could go into other hospitals because what is occurring and what's commonly called an alcohol exclusion law, there is a federal initiative to remove these state by state. Two states just removed it, Colorado and Connecticut.

But the screening and brief intervention in what would be a wonderful opportunity often doesn't occur because that hospital and that physician may not be reimbursed for anything from a minor to a serious injury.

The next time you see your neighbor painting the side of the house with his friends and if they stop and have a beer, tell them don't get back on the ladder.

The other thing I wanted to make sure people knew is that 70 to 75 percent of all those in need of drug or alcohol treatment are employed. They may or may not be insured, but I can pretty much assure you that they're underinsured. And it's very difficult for them to

get adequate and appropriate treatment and to get it in a timely fashion.

The other thing I want to close with is substance-use disorders. And I heard somebody say this a while back. Didn't understand why insurance wouldn't pay for it and it was discriminated against.

You can diagnose it. It has a diagnosis code. Why don't we recognize it? We recognize heart disease. We recognize diabetes. We recognize other long-term illnesses. But for this particular set of diseases, we discriminate against it, and that shouldn't be going on. And with that, questions?

MR. LERNER: Questions for Lillian?

MS. RUCINSKI: You mentioned before the underinsuranace, the term "under insurance." Can you talk about the number of times that treatment is necessary for a addiction in order for it to be effective?

And I know that there are probably different forms of treatment. But I know, too, that it usually isn't the first time someone goes into treatment that they -- that

they're able to attend to their addiction. And how that fits into what insurance covers for addiction?

MS. PICKUP: Addiction is known as a chronic relapsing disease. My favorite one to liken it to is diabetes. When a kid is diagnosed with diabetes, you have to teach them or they have to learn to live with their condition.

Some people do recover the first time they go through treatment. What causes that to occur, I don't know. But usually there's something adequate and appropriate going on.

Very often it will be a continuum of care. Somebody may go through detox, may go through residential rehab. It has to be of sufficient duration because the person has been physically impacted.

When I was running a detox center in the 70s, I used to say I don't think they wake up for six weeks. And so, you know, you have to take some of these things into account. That it has to be of sufficient duration. And people do come back. And they may receive some of the same treatment again, and it is effective.

But the insurance companies right now, you may have ten days of residential treatment in a year. I'm not sure if that's adequate or appropriate. I'm not going to judge across the board.

I'm saying addiction should be treated as if they were any other disease.

MS. DAVID: Do you have any cost estimates with the emerging amphetamine usage that is more downstate as opposed to the metro area, however, it is encroaching.

And then secondly, are there any cost estimates to this new heroin opiate overdoses?

MS. PICKUP: Methamphetamine -- we have been treating methamphetamine and an increasing number of methamphetamine users over the past five years.

We don't have an overwhelming number of them, okay? But we do have long waiting lists for treatment and we can't always tell who is on the waiting list.

Heroin and fentanyl. Heroin use has been increasing in the State of Illinois for

the last twelve years. It has increased geographically and demographically.

There are 95 deaths in Cook County. We can't get the figures for outside of Cook County. The youngest being 17, the oldest being 65.

This is an epidemic. Heroin use has been an epidemic. Mixing it with another drug, this -- today it's fentanyl. The other issue is that they're also mixing it with cocaine.

We have 600 people on the waiting list for methadone treatment today in Chicago, so those 600 people who are wanting treatment for heroin addiction are vulnerable.

MR. SCHUBERT: Thank you, Lillian.

Mike Pelletier, Division of Mental Health.

MR. PELLETIER: I'd like to read a prepared statement that we had submitted previously to Ralph and the Task Force.

My name is Mike Pelletier. I'm representing Dr. Lorrie Rickman Jones, the director of the Division of Mental Health of the State of Illinois.

We, as the State Mental Health Authority, are pleased to provide this presentation in our opinions regarding specifics to adequate healthcare coverage. This issue is critically important to our consumers, that is persons with mental illness.

The principles which my comments flow are providing real access to and maximizing access to care; and secondly, maximizing availability of appropriate and effective treatment services. Persons struggling with mental illness deserve nothing less.

Four out of the ten leading causes of disability are psychiatric illnesses. Among developed nations, major depression is the leading cause of disability.

Our society and our health insurance structures are only beginning to come to terms with this reality.

I imagine that some of you have had the opportunity to read the surgeon general's 1999 mental health report on -- report on mental illness. I would ask that we have a reference in the materials that we submitted to you, a copy of

the executive summary. And we'd also have references to the Web site where you can get that information.

This report and the data -- this seminal report still stands seven years later as the authoritative review on issues pertinent to mental health and mental illnesses in the United States.

This report and data from other sources, such as the Word Health Organization, describe mental illness in its broadest sense, as the second leading disease contributing to the impact upon disability worldwide.

As we're thinking about the changes to health insurance structures, we need to pay very close attention to the observations of this report. And I'd like to take some time to emphasize some of them here.

One of the most important tasks the Commission has, in my view, is to create real access-effective treatment. That's a very brief statement, but it has two very, very important critical concepts. Real access and effective treatments.

The first issue, real access. The issue here is simple. Real access, when it is there at all now, is quite haphazard.

Insurance companies and third-party payers have been discriminating against persons with mental illness for years. Someone with a serious mental illness who has an arbitrary 8, 10-or 20-session limit for outpatient mental health visits doesn't have real access.

If this same consumer was to enter the hospital, was told that their hospital stay must end, conveniently corresponding to the coverage day limitations of their insurance policy and before their acute symptoms are resolved, that's not real access.

And when the doctor or the social worker who is advocating with the utilization review person is told we're not saying you can't stay in the hospital, we're just saying we won't pay for your care while they're in the hospital. Well, that's just a cruel joke and worst yet, it's a very sad commentary on the lack of value placed upon mental health treatment.

Third-party payers should cover

psychiatric conditions to the same degree that they cover all other serious health conditions. And I certainly hope anything that comes out of this Adequate Health Care Task Force includes a strong recommendation that we end the practice of discriminating against persons with psychiatric illness.

In the states where parity has been implemented, the long-term costs for mental illness has not increased, but rather decreased the expenses to the insurance carriers, especially when preventive and early use of evidence-based treatments are calculated into the regimen.

Finally, of course, we know that our consumers are disproportionally disabled, either temporarily if not permanently, as a result of their mental illness. And that our consumers are more likely than most other persons to have no coverage or health insurance at all.

Second, effective treatments. I want to say a few words about effective treatment. Also and dramatically under-appreciated is that there exists a wide, broad range of well-documented, highly effective treatment

options for mental illness.

The effectiveness of some of these treatment options actually rivals or even surpasses effectiveness rates of treatments for other medical diseases or illnesses.

Clinical depression, for example, has a higher treatment success rate than any other illness. We refer to these highly effective treatment options as evidence-based practices. That's because their effectiveness is documented by multiple, high quality and replicated research studies.

Just to give you a flavor of what I'm talking about, I want to briefly describe one extremely powerful treatment for schizophrenia called, "Family Psycho Education." In Family Psycho Education, the clinician works with the family of the person who is ill.

The family is given information on the illness, on the medication, side effects and expectations. The family is engaged with the primary mental health clinicians and seen as a valuable source of information.

So if Joe, as a schizophrenic,

goes with his wife or dad to the psychiatrist and Joe says "none," when he's asking about hallucinations, his wife or his father can say, you know, Doc, three or four days last week he was talking to people and there wasn't anybody in the room when he was doing this.

The doctor can then prescribe medications based on all the information, and Joe isn't deprived of treatment just because he doesn't have insight into his own condition.

Additionally, the family is given information on adaptations that can be made in the home environment. We currently do this for other illnesses.

With heart surgery, doctors make sure that the patient isn't subjected to secondhand smoke. With diabetes, whoever is doing the cooking or the meal preparation is taught how to prepare meals within ADA guidelines.

As well with schizophrenia in this family psycho-educational model, families are taught, for instance, to minimize situations in which two or more conversations are happening at the same time or at once, in order to accommodate

the ill person's problems with information processing.

The results from family education are absolutely phenomenal. Consistently fewer relapses and consistently lower costs of care mainly due to consistently lower rehospitalization rates.

Over the last 30 years, the value of this treatment has been proven over and over again. And in my section, we have references to research articles that document these findings. This is just another example of a treatment for serious mental illness with an experienced and robust outcome.

So with good news like this, why I am sitting in front of you talking to you today. Because these treatments aren't delivered routinely. It's very hard to change people's behavior. And that statement goes to clinicians in the mental health field as well.

The question as to why a person with mental illness can't walk into the community mental health center or doctor's office and expect he or she will be given the most effective

treatment is a complicated one.

But one of the most important reasons is third-party payers have yet, as a group, begun to change their reimbursement practice to use these extremely effective treatment programs, and to fully reimburse providers for that.

This is one of the most serious healthcare access issues in our country. One of my main goals here today is to convince you to include among your recommendations, one key recommendation for mental healthcare. And that is to cover evidence-based practices.

Public and private insurance companies are literally spending billions of dollars paying for treatments that haven't proved to be effective.

Leaving aside for a moment the obvious injustice to a person with a serious mental illness, let's take a crass and limited financial look at this situation.

It doesn't make financial sense for insurance companies or providers to leave out evidence-based practices, because when people stay

out of the hospital, and they will, and to a greater extent when they receive these effective treatments, the system as a whole saves tons of money.

Real access would need to include acceptance by the insurance provider communities of well-established, extremely effective services that currently most third-party payers don't reimburse. These services, however, often show the greatest benefit to persons recovering from mental illness.

I'll be happy to provide you with any further information or information about these services at a later date.

Services like case management. Certification -- community treatment, supportive employment, are typically not within insurance benefit packages.

The division of mental health wishes to strongly advocate for greatest availability of these effective mental health treatments.

Illinois has done some historic things for healthcare in the last few years. We

were the first to stage -- a large state to step in and guarantee that senior citizens and persons with disabilities wouldn't have to go without their medications just because the federal government had difficulty rolling onto Medicaid Part D.

We have greatly expanded over the years the number of persons who are eligible for public sector insurance. This current effort in which DMH is proud to play a role means that we, as a state, are officially on the role when it comes to doing the right thing for healthcare coverage.

Let's make it even more dramatic and more of a project we can be proud of by expanding the right thing to include real access and real effective treatments for our most vulnerable citizens.

DMH has advocated the use of evidence-based treatments in our state-operated hospitals, as well as we train, support and fund several evidence-based technologies to our community providers.

Adequacy -- or rather

inadequacies of healthcare coverage for mental illness isn't just a matter of the difference between the features of individual medical plans, distinct or differential or high deductibles, or gaps in regard to what services are reimbursable. It is more and mostly about the invisibility of coverage to a very visible, equally viable and historically resilient population of Americans. We live in a shattered world of a very deep crack in the system.

The consumer movement within our sector has had incalculable influence as to how consumers become empowered in directing their care. How treatment providers do consumers. How we are all regularly, consistently and incessantly reminded that persons recover from mental illness. We must do all we can to support these recovery stories.

The Division of Mental Health is developing and strengthening our current systems for facilitating the collaboration with our system partners and our providers towards the development of a recovery-oriented mental health system.

This collaboration can only be

enhanced by increasing adequate healthcare coverage. Increasing healthcare access hopefully will be assisted by the efforts of this task force.

I have provided in this written statement, a research article, reference materials in terms of documenting the quality of the statements that I've talked about.

I've also given an executive summary of the surgeon general's report of 1999 that I referenced.

I've given you five examples, brief examples of definitional characteristics of at least five of the evidence-based programs that we have.

We are in active rolling out of our integrated dual diagnosis treatment plan with our associate Division of Alcoholism and Substance Abuse. We are in active, very aggressive discussions and operationalization in doing some pilot projects in about three or four sites across the State with our division of rehab services, in terms of funding and piloting programs for support of employment programs.

And we are doing in our state-operated facilities a number of programs. Typically the one most commonly referred to is "Medication Algorithm Program" which places strict guidelines in terms of how medications are prescribed, or specific conditions and how those prescription patterns can enhance both the results of -- enhance and track the active results of those medication regimens for our consumers.

I'd be happy to take any comments.

MR. SCHUBERT: I think Sara and I have all that material. We got it a little late, but stuff happens. And we'll get that around to everybody.

MR. CARVALHO: One quick related question.

If an employee wanted to purchase a plan from an insurance company that had parity, are plans available or are they just not even available on the market? So is the choice the insurance company or the employers, is the first question.

The second question is does the

State provide parity under Medicaid? And third, does the State provide parity under state employees' health insurance plans?

MR. PELLETIER: I'm not sure how to answer your first one, whether or not -- obviously, any employer can go to any insurance company and say this is the package of benefits for which I want to purchase. And then based on that package, obviously, it's going to be priced.

I think the larger issue is both the insurance community pretty much and in generalities, as well as the provider community, just doesn't really appreciate or have an understanding of the types of services that we're talking about here that would precipitate a discussion between an employer and an insurance company to say hey, listen, I really want to add on assertive case treatment because it appears that I've got ten employees in my company that have a serious mental illness and have relapsed into hospitalizations, or some types of serious concerns.

And in a current insurance, the way insurance is funded, predominantly through

self-insurance policies, the employer will see that actual cost coming across to them.

So there's just a lack of, I think, real sufficient education and knowledge about what services should be made available to an employer to purchase on behalf of consumers, the employees, or the employees' families that are significant and related to actually effective treatments.

The Medicaid program has basic -- two manners in which Medicaid persons are -- services to Medicaid-eligible persons are reimbursed.

One is through the HFS Medicaid program. And that's typically for medical providers, physicians, dentists, osteopaths and hospital providers. And that's a fairly routine insurance coverage.

That insurance coverage has much more of the quality of parity considerations. There are no arbitrary limits in term of days covered under Public Aid for hospitalization services. There are no arbitrary limits on the predominance of outpatient or in-office visits for

Medicaid.

The second way in which Medicaid-eligible consumers receive services is through the Division of Mental Health, which also has Rule 132 and rule -- under 132 and under Rule 130, that regulates the way in which DMH, Department of Corrections, and DCFS also use these rules to purchase mental health services for their consumers.

Those services are highly regulated, again, under that rule. Those services are now -- in fact, we're in the process of adding some of these evidence-based practices for coverage under these things.

There are specific limits in terms of what we can do. We do have to modify the Medicaid state plan to incorporate these services into our Medicaid state plan to make them available to consumers. But many of these services, assertive case treatment, supportive employment is something we're talking aggressively about bringing into the Medicaid state plan as well.

The state -- insurance for state

insurance is run through a usual type of insurance programming where it's based with one of the insurance carriers. And I do know that psychiatry, as well as alcohol and substance abuse benefits, there is a managed care corporation that manages the benefits in this program.

MR. BACKS: Basically, you're talking about parity. And I guess I would use maybe a slightly different term for it. Mainstreaming in the sense being a clinician, internist who doesn't -- isn't a psychiatrist, but plays one in my office quite a bit, treating chronic depression and anxiety disorders. And actually, those are reimbursed in my practice as medical conditions. I explain these conditions as brain diseases to individuals.

I preface my question with those remarks because I wonder if at the same time we're talking about mainstreaming benefits or parity of benefits, treating mental illness like other medical illnesses with evidence-based treatments and the same type of coverage.

It is also possible there may be time to reexamine the stigma that is created by

the special circumstances that are required for the treatment of patients in a mental health system that requires special consent, special concerns about confidentiality creating this sort of aura that this is somehow something that we need to treat in a special way, when in fact, as we learn more and more from a neuroscience point of view, these are simply brain diseases that are susceptible to the same kind of interventions as heart disease and lung disease and other types of diseases.

My own opinion is that movement in that direction would go a long way to make the people more comfortable with parity of benefits on the benefits side.

MR. PELLETIER: Well, I certainly think, obviously since it's been 35 or 40 years since we implemented both the Mental Health Code, as well as the Confidentiality Act, those codes have consistently been updated, and those things are the things that regulate our industry.

Certainly modifications to those things to make access more transparent would be things that would be appropriate for us to look

at. And we think that that is certainly happening, but, of course, there's also been the reason those legislations were placed into -- into statute is because of the severe abuses that were done in the past.

Certainly it would go a long way to equalizing it to look at ways to equalize that across the board and make it much more transparent within the medical community.

MR.SCHUBERT: Taking a page out of Wayne Lerner's imminent text on meeting facilitation -- we're about ten minutes behind, so I want to pass the baton next to Gerri Clark from the UIC Division of Specialized Care for Children. Then we'll take a break and the panelists will hang around for five minutes --

MS. DAVID: Ralph, this is important now.

MR. SCHUBERT: I'm sure it is.

MS. DAVID: This is about the mental health reorganization. DD told us how much money they had saved through the Medicaid match. We'd like to know how much money you saved and what you're doing with your money.

MR. PELLETIER: One of the things we have done with the Medicaid match is to -- the monies that we get under Medicaid match come back into our systems in our 718 fund. Those -- remember, the Medicaid match is reimbursing the State for which services the State has already purchased.

It's not savings of money. Really just reimbursing the system for 50 percent of what the State has always obligated to folks.

There are -- that money, again, taken in -- together with the monies that are obligated and generated out of the general revenue fund, those monies have been reinvested in the 718 fund. The 718 fund is expected to grow, I think, next year about anywhere from 14 to 25 million.

That would give us the opportunity to, we think -- I think we've got -- I'm not sure if the governor signed that. We did get through the general assembly a modification in the 718 fund language that allows the Division of Mental Health to reinvest a large portion of that money. Like I said, about -- anywhere from 7 to $14 million into doing new pilot projects and new

services back in the community.

But all of those monies that come into the system are predominantly reinvested back into the system. And that's been a major modification over the last two years.

MR. SCHUBERT: Gerri, you're on.

MS. CLARK: I'm representing Dr. Charles Onufer, who is the director for the Division of Specialized Care for Children. He was unable to be here today, so you've got me.

We are the Title 5 program for children with special healthcare needs. Every state has one. As Ralph said, we're one of three states that has this program within a university setting.

We have a combination of federal and state funding. The federal through the Maternal Child Health Block Grant, which Ralph graciously shared with us, or not so graciously.

MR. SCHUBERT: It's a federal law anyhow.

MS. CLARK: It's a law. We serve children up to age 21 who meet our medical eligibility criteria.

We have, because of limited funding, had to basically restrict the categories of health conditions or medical conditions that we serve in order to be able to provide anything to anybody.

But we do help families who have insurance to use their insurance effectively. We help them to advocate when they have problems with their insurance.

We do also require all families who are eligible to apply for Kid Care. And now it will be for all kids.

We won't be able to require the families who are not financially eligible for us to do that, but we will encourage them to because it certainly provides a comprehensive service package for them.

But for the children who would be financially eligible for our assistance, and our assistance would be more in gap filling, we do require them to apply for the public insurance that is available.

So as we look at All Kids being implemented, we will still need to assist the

families who have, perhaps, not fulfilled that one-year uninsured status period for -- depending what the reason was that they lost their insurance. They might be eligible if it's because of a loss of a job on the part of the parent. But I won't go into all those little details. We do try to assist families who are also underinsured.

And if we can go to the next slide, this is a survey that was done by the national or the Federal Maternal and Child Health Bureau. In Illinois, they surveyed about 750 families. And you can see that those families indicated -- families that have children with special healthcare needs, those families indicated that at least 40 to 50 percent of them were not adequately covered by the insurance they had, whether it was public or private insurance.

We serve about 10,000 children at any one time, although we probably touch closer to 20,000 within a year's time.

Families come to us for our care coordination or case management services as much as they do for our financial assistance, and our care coordination staff, our nurses, social

workers, speech pathologists and audiologists who help families navigate the healthcare system.

Help them understand their coverage, and then identify what other services are necessary. And if there are resources within the community, as its children. Also assisting them with their educational services. Helping them advocate through a number of ways.

You can see that we have looked at the payer mix that the families that have been in our program over the last seven years have had. And you can see that the public insurance has gradually increased, and that, of course, was due to Kid Care and our requirement that they apply for and use Kid Care.

Private insurance seems to have decreased somewhat, not extreme, but somewhat. And then the yellow would be where we were the primary payer. And with All Kids, it would seem that we would be able to move that down even a smaller amount. But as I said, there may still be some situations in which the family don't qualify for All Kids.

And the next slide. Actually, it

might be easier if you look at the handout, although that's pretty tiny. I'm sorry. Because I would like you to compare this slide with the next slide in a way.

This slide specifically is an analysis of the top 20 services that DFCC has paid for as a gap filler. You can see ramps and lifts are something that very few other payers will pay for.

Diapers, you can see, were big expenditures in 2002. We had to change our policy and we did also get a contract, so that has moved down as we look at the 2005.

But hearing aids again, are not consistently covered by insurance. And is -- even within Medicaid, it's covered minimally.

If you'll look at line 8 on the 2002 travel for family, that is what we consider an enabling service, and that is to assist families to access the speciality services that are not available in their immediate community.

You can imagine in Southern Illinois we often have families that have to go all the way to St. Louis. And there are costs for

those families. And if they're financially eligible for us, we can assist them with that.

None of this slide or the next slide that you can go to, none of those include -- when it says, "Paid by others," none of those include Medicaid or All Kids. We don't have access to that data, so this is strictly private insurance that would be considered paid by others. And you can see those are pretty much the typical medical services that they tend to cover.

I would say that in conclusion, we have identified gaps, certainly in services, sometimes due to the lack of providers of the specific specialty that would be needed by these children, and sometimes because of the lack of payment that is available to them.

For instance, for children of cleft pallet or other facial anomalies, orthodontics is a critical part of paying for surgery and completing the surgery, resolution from the surgery. And that is often covered inadequately for those children.

We have become involved in the newborn hearing screening program in the State and

we're finding while our goal is to have the babies screened by one month, diagnosed with the hearing loss by three months and have the hearing aids and early intervention services by six months. Because we can not find providers that either have the adequate training and equipment to diagnosis these babies, or because they cannot find reimbursement for the hearing aids, cannot get the hearing aids in time, this affects their special development.

If they can get those services by six months, they're able to be on a par with their peers in speech development. If they do not, it's much slower for them.

And one more thing is since we serve children up to 21 and All Kids goes up to 18, there is certainly that older age group that really don't have good access to either their parents' coverage because they have left high school or because they do not qualify as a person with a disability for Medicaid. They don't have coverage. And you've probably heard that from our groups before. It's very difficult for us.

When it's a person who maybe has

a cardiac condition, who still needs to get the healthcare, and they just don't have coverage for it. And while they like to think that they're pretty much invincible at that age, they really aren't.

MR. LERNER: We have a --

REPRESENTATIVE COULSON: I have a quick question. What happens after 21?

MS. CLARK: We try to have them find some sort of a coverage, but it isn't easy.

REPRESENTATIVE COULSON: So they're eligible for your program, as well as school-based services until they are 21.

MR. LERNER: One more quick question.

MR. MURPHY: Mr. Ralph Schubert, first I want to commend you and the department. These are very direct and unambiguous statements.

I guess, just generally in regard to the same question I asked of Rob Kilbury, are these department opinions or they official sanctioned opinions of the governor or administration or just the agency?

MR. SCHUBERT: I don't think we went all the way to the extent of like vetting them

through the governor's office.

I think what you heard from are people who, in some cases, for many, many years are working very hard on the services for their particular population of interest, and bring the benefit of all of that -- all of that scholarship and all of that experience to the Task Force today.

MR. MURPHY: So they should be considered as agency petitions?

MR. SCHUBERT: I would think so, yeah.

MS. SIMS: I want to point out too, I don't know whether you noticed, when highlighting the need for dental care, preventive dental care for adults, I indicated that that's something that we hear repeatedly at our statewide advisory council. So that's not a position of the administration. That is what our advocates tell us that I wanted to bring to you today.

MR. LERNER: We got it. I know. It's like pulling teeth. I'm sorry. It's mid afternoon.

On that note, I'd like to also

thank Ralph and his colleagues for a really wonderful time. Thank you very much.

We'll take a three-minute break.

(Whereupon a recess was had)

MR. LERNER: Ladies and gentlemen, I'll take a motion approving the model we want to recommend.

What I want to do now is get to the other part of our agenda, which will then be what will take us forward.

Just to remind people of exactly what we're doing, we are going to evaluate, going to talk about the evaluation process that we're going through.

And the time frame, to remind you, is that what's supposed to happen at the July meeting, based upon our conversations today about the evaluation mechanism, the July meeting, six models would be coming back to us well in advance of the meeting so we can do some homework; and we come prepared at the meeting, looking at the six models and how they play out against the evaluation criteria.

Out of the July meeting, we would then recommend one or more -- preferably one, but one or more models to go forward for final discussion at the August meeting.

At the August meeting, we would make our final recommendations. And then August and September would be the final write up. And September is the big party. That's kind of the plan. That's what we talked about in the steering committee. That's what we talked about with the Task Force.

MS. ROTHSTEIN: One question. Did you say we would present only one?

MR. LERNER: I said hopes would be one, but we'd see where we go. That's Wayne. That's not the agency position. That's a Wayne position.

MS. ROTHSTEIN: I'm glad. I was going to ask you that.

MR. LERNER: But I'm still the Chair. That's right. Anyway, so that's where we want to go with this. And I'd like to take it up.

Now, I understand many of us did not get this material until late last night, so

there's some concerns about how far we can go embedding it. So as we start to go through this presentation, I want you to think about something.

I'd really like to keep to the timetable we've got. And if we need more time to vet the evaluation process, we have a couple of alternatives.

One, we can call another face-to-face meeting. Two, we can have a conference call. Three, we can iterate this through e-mail or internet-based mechanism; or four, we can do some combination of the above.

So I want us to have enough time to go through this evaluation process. Navigant and Mathematica will give us the gestalt, the big picture about how they did this, but we've really got to get over this hump, so that they can get to the point of evaluating the models; is that fair?

MS. TAYLOR: It's mostly correct. Actually, in advance of presenting the evaluation criteria, we had a report, a finding from our access study. I think -- and that's what Heather is passing out, and the evaluation criteria part of the presentation which Kathy will present, is

going to follow.

And our sense is we're probably more interested in discussing and debating the evaluation criteria, so I was going to go through the access finding fairly quickly. But please stop me if you have questions. And I'm Lynn Taylor from Mathematica, by the way; is that fine, Wayne?

MR. LERNER: Yes.

MS. TAYLOR: A little part in the front there.

MR. LERNER: Again, I want you folks to be sensitive that we folks have not had a lot of time to sponge this in.

MS. TAYLOR: I'm a very sensitive person. And I want to provide access to the information for you, all right?

MR. LERNER: Go for it.

MS. TAYLOR: So in the interest of getting to the evaluation criteria, which is critically important, I will go fairly quickly. And some of this material you've heard before from the excellent people who have been presenting here. Please stop me if you have questions.

As you know, the Illinois Health Care Justice Act states, "It is a goal to ensure access to quality healthcare at costs that are affordable." This is your task.

It doesn't define what access is in the Act, so I'm providing this definition from the Institute of Medicine, which as you can see, is the timely use of personal health services to achieve the best healthcare outcome.

This implies that -- this includes both the use and the effectiveness of the healthcare services and encompasses physical accessibility of the facility. So this is a working definition.

In terms of reporting back to the Task Force on what access is like in Illinois, we had to look at what data is available to us. And there's a range of data, some of which is better than others.

Over here on your left, self-reported access measures. For example, from the BIRPA data would be the most direct measure of access we can observe in this state; however, that data has limitations that I'll talk about briefly.

So we also looked at other measures. We looked at some utilization and outcome measures which might be indicators of access problems. And we looked at the prevalence of barriers to access. So we'll talk -- so that's sort of the three sections of presentation.

But something to keep in mind as you get down here, this is a less direct measure. We assume that the presence of barrier causes a lack of access. We're not directly measuring it.

The first thing we're to look at is whether or not you have a usual source of care. And there's been a lot of research which says having a usual source of care is even more important in terms of health outcome than having coverage itself, not that coverage isn't important.

We look at this measure using the BIRPA data which is collected within the State. As a caveat, the only thing that's collected for every county in the State is whether or not you have a usual provider.

Usual source of care is typically defined as having the usual place of care, but

that's not collected for every county in the State, so this is a proxy measure. It's a very good proxy measure, but in case anybody is very familiar with these access measures, I wanted to clarify that.

As you can see here, there's a theme from this slide that is repeated throughout our finding. Illinois on average as a state -- it's a large state. And not surprisingly, it is very similar to the US. Around 80 percent of the population, by the time of incorporate standard error, have a usual source of care.

The Healthy People 2010 goal is quite a bit higher. They would like to see, I think it's 96 percent of the population having access to a usual source of care.

Chicago, consistently, is a little worse than the State as a whole. I'm sure that will not surprise you after all the meetings you've had.

MR. LERNER: Can I ask a real quick question.

MS. TAYLOR: Yes.

MR. LERNER: The usual source of care.

Somebody says I usually get my source through the emergency room, is the answer yes?

MS. TAYLOR: The question is, you have a usual place of care. That would be one of the acceptable answers. But sometimes when you're measuring access, you would exclude that answer as being a suitable source of care. But a clinic would count as a suitable source of care.

In that case, as I mentioned before, the only question that is asked at every county in the State was whether or not you have a usual provider in your care. So it was a slightly different question.

MR. LERNER: So someone who is accessing one of the free clinics, for example, would report yes?

MS. TAYLOR: No. Would report no, if it's not the same person they're going to every time.

MR. LERNER: I see, because it's not the same provider.

MS. TAYLOR: Right. The two track fairly closely with the usual source of care -- I'm sorry. Usual place of care, to be more

precise, okay?

Again, here's some themes that I won't repeat incessantly, but is very -- we found a lot as we looked at some of the scales. So that's an example of a direct access major, one of the few really that are available to us.

Moving onto utilization measures, we looked at a number of different data sources that looked at utilization. And the message is mixed. Again, in general, it's the same as the US, not quite up to Healthy People 2010 goals, but Chicago, and sometimes rural areas seem a little worse than the statewide averages.

But here's a few examples of some other things going on. I think this dental statistic is particularly interesting. For whatever reason -- and my investigations have not come up with a good answer. The Healthy People 2010 goal for having an annual visit to the dentist is low, much lower than I expected.

I actually contacted somebody at the ADA to say what do you think of this Healthy People 2010 goal. The way that they came up with it is that it was better than the prevailing rate

at the time they came up with their objectives.

Is everyone here somewhat familiar with Healthy People 2010?

I'm sorry. This is a work group comprised of representatives from all different government agencies and other organizations designed to come up with a set of priorities that will eliminate disparities in care and increase access to care.

And they have oh, seven or ten focus areas. And to support achieving or work in those focus areas, they have just under 500 objectives. And these objectives are things like percent of the population with the usual source of care. And it was this level in 1990. We'd like to see this level -- was this in 2000, we'd like to see this in 2010. And they have different ways of determining what those objectives might be.

It's a common benchmark that a -- for example, you heard today that communities, there's state planning initiatives, and communities have to measure what healthcare access looks like in their community.

Measuring themselves against the

Healthy People of 2010 benchmark is a fairly common benchmark, but it is not the only one. And I'm going to argue in the case of dental, it probably would not be a good one to use. I think it's -- personal opinion, I think it's too low.

A little over 70 percent of state residents did have an annual dental visit, but as you -- you can't see it from this slide, but as you go down the income stream, that statistic becomes much worse. It's highly income related.

Receiving adequate prenatal care, we are above. This is Illinois, and that's the Healthy People 2010 goal. The state is pretty far below that goal, and I think that would be a valid one to shoot for. But, again, at the statewide level, they're not doing too badly on mammograms. Chicago looks worse.

And they have a little ways to go in terms of fully immunizing their two year olds. These are just samples, utilization measures that you can look at that might indicate there are some access problem.

I don't think I mentioned it, but the BIRPA data, which was the source for much of

that information but not all, only surveys adults. It's a little bit harder to come by access measures related to children. This is a little bit of information from a national survey of children health status that we've done. And again, Illinois stacks up well compared to the nation.

We do not have good information at the county level from this national survey. And again, don't be fooled by the preventive dental. There are some large problems as you get into lower incomes, to a much greater extent than you would see in terms of access or having well child visits in the past year.

This is an area where the avoidable hospitalizations are conditions where you're admitted to the hospital that could have been avoided if adequate ambulatory care had been received. And the physicians in the group may want to slightly correct that definition, but that's the basic idea.

This an area where -- again, this is fairly old data. It's 2002. It's the most recent I could find. But this is an area where,

unfortunately, Illinois is a little worse than the US. And you were doing good so far in my presentation.

And as you can see, we don't have Healthy People 2010 goals for all of these areas, but Illinois, in this case, had almost 20 per 100,000 more admissions for this condition than the US as a whole. And it was far, far higher than the best ten -- the states that had the lowest rates where they managed to control it, which is what the red bars are.

I think this is an example of where you should probably look at other benchmarks besides Healthy People 2000, because where you see -- where we do have a measure from those work group objectives, it's often much higher than the top 10 percent of the State, which, again, is the red bars. So you do have to take these with a grain of salt, I think.

MR. ROBBINS: Out of curiosity, if you were to look at hospitalizations per 100,000 for the general population, would Illinois be higher than --

MS. TAYLOR: That is a good question,

and I don't know the concise answer. I know you have a lot beds for 1,000, which usually means a lot of admits --

MR. ROBBINS: My guess would be the answer would be yes, and then I wondered what that tells us about this. Try to isolate this. Whether that's meaningful -- as meaningful.

MS. TAYLOR: Right. In other words, as a percentage of your total admissions, maybe it's in line with some other state.

MR. ROBBINS: That's my hypothesis, but I'm not --

MS. TAYLOR: Right. However, that would not detract from the fact that this may be an opportunity to save -- there may be too little ambulatory care in the system compared to the best ten. And there also might be an opportunity for cost savings.

MR. LERNER: Ken, is that a condition like supply drive and demand, so with enough supply you've established a demand?

MR. ROBBINS: I wouldn't say that publicly, but possibly that would be true.

MR. LERNER: Okay. Well, I didn't

say it publicly either, even though it's on the transcript.

MR. DUFFETT: What's the percentage of those who are insured and those who are uninsured?

MS. TAYLOR: Oh, that is a good question. The State of Connecticut did a study and -- which is a very small state, but I think about half of them were insured. This is not only uninsured people.

One of the things I'll be talking with in my presentation and in the report that's forthcoming, is that there appear to be some -- the access problems exist both in the insured and uninsured population. But there's not great data on that, per the State of Illinois. But I did look at the study through Connecticut.

MR. LERNER: So the takeaway on this one is there's plenty of opportunity from a prevention point of view to bring ourselves in line with other types of benchmarks than simply just tracking previous experience?

MS. TAYLOR: Yes. I would say that there's three takeaways.

I'd say the first takeaway is we may want to look beyond the Healthy People 2010 goals for some of the measures. I mean, we should think critically about them.

Secondly, that there may be instances of inadequate ambulatory care leading to these hospitalizations, which some of them are not avoidable, but in general, they're avoidable.

And lastly, there may be significant cost savings to the system by treating these conditions in the ambulatory settings, okay?

MR. LERNER: Okay.

MR. KOEHLER: Can I ask a question?

MS. TAYLOR: Yes.

MR. KOEHLER: Would this show up, especially with the uninsured numbers that are reflected in that, where somebody would not have the right kind of primary care and would wait until something catastrophic would happen and then would go to the emergency room and end up in the hospital? I mean, does that show up --

MS. TAYLOR: Is that a scenario -- yes, yes.

For example, asthma. We had

pediatric and adult asthma. And I think it was adult asthma that the State really fared pretty poorly on. Yeah, that's the idea.

I think most researchers would not attribute all of these avoidable hospitalizations to inadequate ambulatory care in isolation. There's always other factors going on like, you know, what -- we've talked, I think, a little bit in an earlier presentation about if the population keeps its appointments. Do they do the things that -- there's multiple things going on. Doesn't change the fact that it's still an area for focus.

MR. BACKS: Just to comment on that. These are conditions that's absolutely crystal clear that ongoing, adequate, preventive care has better outcomes, which hospitalization equals bad outcome. The patient got sick. They didn't have to. That's why they're easily picked, whereas there's no question if it's done right, if there's compliance, you get better outcome, lower costs.

MR. LERNER: This is reflective of the article in the Wall Street Journal I was talking about. That's exactly right. Ken?

MR. ROBBINS: I wonder if you might have an opportunity to see if there's another correlation. If you have a state, for example, where it is difficult to enroll physicians in its Medicaid program, would that also be a contributing factor to the kind of outcome you've described?

MS. TAYLOR: Well, I have not seen a study that links difficulty finding physicians to participate in Medicaid with avoidable hospitalizations.

But the larger issue that the difficulty of enrolling physicians leads to inadequate care or problems with access to care, I think nobody would disagree with in the room.

MR. LERNER: Ruth?

MS. ROTHSTEIN: What are the "also" factors in the use of ERs? And there's a whole question of a cultural -- having always gone, yet there could be a clinic ten blocks from there or seven blocks, or one even near their home, near the home of some of the patients.

Fear of going into the clinic, a whole cultural understanding of where you get your

care. It's easier to go to an ER. You're going to be accepted even if you sit there for twelve hours. So I think that's a factor as well.

MS. TAYLOR: It is. I don't have a slide for it, but one of the things we look at in the report is growth in ER visits over time as a -- again, a possible indication. Not the problems with access.

Some of the criteria you mentioned fall into our category of personal theory, which is a perfect segue.

So we touched briefly on utilization and outcome measures that might indicate problems with access. These are some of the barriers to healthcare access that I think you might have spent quite a bit of time talking about in this room.

Probably the most common one being financial barriers to healthcare access, which could result from having a low income. It could be because you're uninsured and you don't have any health covering the payments, or you could be underinsured.

In addition to financial

barriers, there could be structural, which is the point Ken made. Maybe there's too few providers. There could be other ones, which I don't go into, but to keep in mind and maybe have been mentioned in presentations here.

This could also encompass transportation barriers to getting to the clinic. Physical -- that should say "physical." I actually thought I corrected that. Physical barriers if you're disabled.

Enrollment barriers. Maybe you can't navigate the system and get into the coverage for which you're eligible.

And lastly, there are what are called personal barriers. And that's what you were talking about, Ruth. And I'll talk about that in a minute.

If there were one takeaway chart, this would probably be it. This shows -- we have mapped out whether or not -- wait. Let me start again.

Thirteen percent of the nonelderly residents in Illinois have avoided going to the doctor due to costs in the past year.

And that's, again, about average.

You know, it's on par with the United States average; however, the disparities by income and whether or not you have a health plan, those two big reasons for facing a financial barrier care are enormous, as you can see from the slide.

The Healthy People 2010 goal is for, I think it's 7 percent. Yeah. It's for only 7 percent of the population. I'm not sure why it's not zero, but 7 percent avoid going to the doctor due to costs.

So basically, you know, if I call nine a seven, and due to standard error, only these two groups are reaching the Healthy People 2010 goal, those who both have a health plan and have an income over $35,000 a year. I figured out what percent of the population that was for you.

Let's see. Well, no. Maybe I didn't. Must be somewhere else.

But then look at how much this changes. You know, we go from 8 percent avoiding going to the doctor to 38 percent if you don't have a health plan. And actually, these numbers

don't look quite right. I'll have to check these. But these are about -- this is the right area. I'm surprised this one is lower. I need to check that one.

But you can see how much they change as you go down in income.

MR. GELDER: Does Medicaid count as a health plan?

MS. TAYLOR: Yes.

MR. GELDER: So that might be why it's lower.

MS. TAYLOR: But again, this is just adults. You're right. I think 6 percent of adults are on Medicaid. This is from the BIRPAS data. They simply ask do you have a health plan or not.

So what we just saw at every income level, health insurance eases the financial barriers to accessing care, but it does not eliminate that barrier, okay?

Oh, here's what I was looking for. That group that met the Healthy People 2010 target of 7 percent. If I include that 9 percent, still it's 62 percent of the nonelderly

population. So 38 percent of your population aren't meeting that Healthy People 2010 goal. Only 7 percent of the population avoid going to the doctor due to costs.

And I think this is key. You can have health insurance and still face financial barriers to care. I don't want anyone to miss that point.

So who has health insurance? Well, about 60 percent of your population are uninsured. And if you have coverage, you almost -- you are very likely to have private coverage probably from your employer. But a few people have nongroup or individual coverage.

And again, this is the under-65 population, so you don't see very much Medicare in there. And about 8 percent have public coverage.

These are from the CPS. And you have probably heard some testimony in here that exactly how many people are uninsured varies depending on what source you're looking at. So consider these estimates, particularly when you look at the percent of uninsured and the percent in Medicaid. Probably the high end, because

that's where CPS falls on this range of uninsured estimates.

So what do the uninsured people look like? Well, now the children estimate is the most subject to variation because they are most affected by the Medicaid undercount, so this would be the high end of the -- what children represent as a percent of uninsured.

But for working purposes, let's say 21 percent are children. But of the adults, a significant portion are full-time workers. Just over 20 percent are workers in small firms, if I include the part-timers.

A significant number, about 23 percent are part-time workers, which is important if you're thinking about employer-based options for coverage because sometimes part-timers aren't typically eligible for employer-based coverage.

And some are unemployed and some are in the labor force. But they're looking for work. They're not working right now. So this gives you a sense of how they're distributed.

I'm not going to show you a lot of slides about the uninsured. The take-away here

is that it's a diverse group. It encompasses every income level. Encompasses every age, every educational level. All family types. That's the important thing.

If you're uninsured, you are one-quarter as likely to have the usual source of care as somebody who is insured, getting back to that important statistic. In other words, people who are insured are four times as likely to have a usual source of care.

The people who are uninsured are very likely to incur medical debt. To go back to the emergency room, for example, many people are afraid to go to the emergency room because they already owe the emergency room a lot of money and they don't want to increase that debt. It's just an unmanageable level of debt.

Because of the financial barriers that they face, this has been well-documented by The Institute of Medicine. They consume less care. They're at high risk for complications and early death. I think you've all seen these different statistics for uninsured.

MS. ROTHSTEIN: Yeah, but they

wouldn't be true for the County, because they would be afraid to come back. Wouldn't be true of County Hospital emergency room.

MR. CARVALHO: Ruth, I was covering the uninsured week event. And the witness in the audience said she wasn't going to get her care because she had a $600 bill. This was like three years ago. I said, "Where did you get it?" She said Oak Forest.

I explained to her it that it could be wiped out. She just didn't realize it. So there may be people who are afraid, but they don't have reason to be afraid.

MS. TAYLOR: Navigating the health system is very tricky. I'm sure there's very few people out there with perfect information about it. What their financial exposure is to them to visit a healthcare provider.

When we think about the uninsured, it's important to remember that many spells of uninsurance are very short. And when we look at a number like CPS, what they're asking the survey respondent is, were you uninsured all of last year? But researchers conventionally believe

the question they're answering is are you uninsured now. So that's called a point-in-time estimate.

A point-in-time estimate will miss somebody like person B, who was uninsured earlier in the year, but is insured now. Presumably the Task Force cares about both types of people. People who experience any uninsurance in the past year. So that's just something to keep in mind.

One researcher estimated that if you look at the population who had a spell of uninsurance in the previous two years, that would represent one-third of the nonelderly Illinois population.

Diane did some research on this. She looked at people who were newly insured and how long their spell of uninsurance was. And I think 50 percent who were newly uninsured had a spell of less than six months, does that sound right? So, again, something to keep in mind as you think about strategies to ensure access.

The Health Care Justice Act specifically speaks to the problem of

underinsurance. It's difficult to measure the prevalence of underinsuranace, but there's a national study that thinks that about 12 percent of privately insured adults are underinsured.

So if we adapt that statistic to Illinois -- do you have a question?

REPRESENTATIVE COULSON: To me the key question for that previous slide is why were they uninsured for those previous short periods of time? Did anybody ask those questions?

MS. TAYLOR: Well, there's a national survey that can get at that, and we could -- but I cannot see anything specific to Illinois unless that survey --

MS. RUCINSKI: We asked about that. And it's primarily loss of employment.

REPRESENTATIVE COULSON: And they pick it up when they get reemployed?

MS. RUCINSKI: Sometimes there's a waiting period.

REPRESENTATIVE COULSON: For us as a task force, we really need to answer that question because if we're trying to look at access, we kind of need to have that information.

MS. TAYLOR: Well, that's my understanding as well. It's primarily related to employment.

MR. DUFFETT: I believe a 2004 study, I'm not sure if it's on our individual Web site, that Families USA did, they not only looked at people who were uninsured, but I believe there were reasons on why that increased on that third happening.

Some, as you said Diane, too, people were in between jobs. Also many employment areas you have to be there for three months before you can get onto health insurance. But that could be on the overall Web site that we all have access to.

MR. LERNER: I'm smiling because if Quentin were here, he would say the answer to your question would only be relevant if we're going to be dependent upon employer-sponsored health plans.

REPRESENTATIVE COULSON: No, it's not, because depending on how we're doing it. If we're going Quentin's way, you're right. But if we're going any other way --

MR. LERNER: I understand.

REPRESENTATIVE COULSON: We need to have some idea of why they're uninsured.

MR. LERNER: When Quentin gets back, you just tell him that I said that. That's all.

All I'm saying is there's lots of different ways to the end point.

MS. TAYLOR: And if you see the wedges of pie that was the full-time uninsured workers, especially if they're in the larger firm, a lot of those people are in the circumstance that Diane mentioned where they're in the waiting period for their coverage.

MS. RUCINSKI: Or they're not eligible -- or they're ineligible for coverage. There are, in the report that I did in 2001 -- and I think the Task Force has that.

We also looked at whether or not people working in a similar position had access to coverage, and also for other positions. And it is, in fact, true that even people working for large employers, sometimes are not offered health insurance.

MS. TAYLOR: That's rare for full-time. I think it's very common for

part-time.

MS. RUCINSKI: It's not unheard of. So yes, you're right.

MS. TAYLOR: For over 25 full-time becomes not too common.

MS. RUCINSKI: But it is possible.

MR. LERNER: Keep going.

MS. TAYLOR: So anyway, this would be -- this is about half of the uninsured population, so it's a big number.

All right. Employer coverage. When you have employer coverage, you do have pretty good financial access to healthcare with a caveat. But this insurance with employer coverage is how much the premiums are going up.

This is the employees' contribution to the premium for Illinois private-sector employees. And this is the average weekly wage, which includes people both insured and uninsured. But you can see, you know, since 1999 it's gone up by almost a hundred percent, and this is the big concern.

MR. SMITH: This is the percent of increase, not the percent of the premium they're

paying?

MS. TAYLOR: Right. This is the rate of increase. This is the cumulative increase in what the employee has to pay. The graph for the employer would look almost the same because the share that -- of the premium paid by the employee stayed roughly the same.

MR. SMITH: What's the source of this data?

MS. TAYLOR: The Medical Expenditure Panel of survey insurance components, which surveys private-sector employers.

MR. KOEHLER: Does that also include self-insured?

MS. TAYLOR: Including self-insured.

MR. BACKS: In this data, what has happened to the amount the employer identifies as the employer contribution during that period of time, has it gone up also?

MR. LERNER: She said tracking is about the same.

MS. TAYLOR: Yeah. The total premium line and the employer share line and the employee share line all look about the same because the

share, the split -- the single -- the employees' contribution to single coverage has been about 17 to 18 percent of the total premium all these years.

MR. BACKS: So the percentage really hasn't changed?

MS. TAYLOR: Right.

MR. BACKS: In reality, though, it's all coming out of employees' compensation anyway.

MS. TAYLOR: Economists would say so.

MR. BACKS: Well, this is all economics, so why are we even talking about this as being an employees' contribution versus employers contribution, when its all the cost of employing an employee. That's it. I mean to --

MS. TAYLOR: The weekly wage -- I would have to inflate -- if I included the employers contribution, if I viewed it as wages, I would have had to include it in the weekly wage line.

MR. BACKS: Not in terms of taxation, that's the difference. But in terms of total costs of employing someone, that is in the -- if you're making a decision to add somebody to the

payroll and you're a smart businessman or woman, you're supposed to figure the cost of benefits for that person as well. And it doesn't really make any sense for us to sit here talking about it as if they're coming out of different universes. They're all coming out of that cost of employment.

MR. LERNER: Well, not quite, because the employer gets a deduction, and there's some other issues.

But you're generally -- if you would do a compensation analysis that went total cash versus total comp, or total comp includes the value of the benefits that you're talking about, then you're absolutely correct.

MR. BACKS: That's my point.

MR. LERNER: Because then we're looking at how do you use disposable income and how do you make those decisions.

What the employer gets from the commerce point of view is a deduction and all kinds of tax treatment, which we can get into that as well.

MR. BACKS: But the reason part of this is important is during that Cobra period, if

they lose employment, the employee sees the entire cost of their insurance for themselves and their employer, which is why they're given the impression Cobra payments are inflated when they lose. It's all been money coming out of your compensation all along.

MR. LERNER: That's why Lynn is correct by saying it's -- the percentage of premium contributions is tracking similarly because it's the premium itself that's tracking at a certain rate. That's just how you split it. Niva?

DR. LUBIN-JOHNSON: It's 3:15 and we're halfway through this presentation. I'm just wondering if we've got enough time to hear the rest of it knowing we've got some other things to talk about?

And with all due respect, Lynn, I know you guys came in late in the game, but most of this we've heard before several times.

MS. TAYLOR: I know you have. Well, maybe -- I would not disagree that talking about the evaluation criteria is the more important job. Should we just move over?

MR. CARVALHO: Well, let me remind everybody what I think Lynn said at the beginning was there's a major lengthy report on this subject. It was the first significant deliverable under the contract. This is their delivery of that deliverable.

Her presentation today was a summary of that report. That report will be sent to you soon, but this was just to give you a framework in which then to read a long, lengthy document. So shortening this presentation just gives you more homework at the back end which you can do on your own time.

MS. DAVID: The only thing I want to say, Wayne, is this piece on provider supply, I think that you really have to speak on that because that was a significant issue when we had the hearings.

MR. LERNER: Well, what's your pleasure? Do you want to cram through these slides real fast -- no, you don't want to take any -- it's up to you. What do you want to do? I've not seen this before.

MS. DAKER: I have to leave in 30

minutes.

MR. LERNER: Let's do this. Let's hold this portion. Let's talk about the evaluation criteria. And to the extent that this study played into the evaluation criteria, you can kind of lay that out for us.

MS. TAYLOR: Sure. I think that's a good plan.

MR. LERNER: Okay. This means more homework for all of us. I think you're right. I think if we had gone through this, we'd have spent two hours on this, because this is really meaty good stuff. Then I would have ordered breakfast.

MS. SRECKOVICH: First of all, there was some questions that were raised at the last meeting, and we provided responses to those. And again, I'm not going to go through those, unless you'd like me to.

If you have specific questions, we can certainly address those. Or if you have other specific questions that I can answer via e-mail, just feel free.

MR. LERNER: I thought your responses to the questions were quite good. Thank you very

much.

MS. SREVKOVICH: You're welcome. We also sent out to you a revised interest matrix, and this basically reflects each of the proposals -- each of the proposer's proposals with regards to how they respond to the specific interests that were raised by this group.

And I want to add that we will continue to -- for anybody here who wants to continue to comment, provide additional information about your proposals, we'll certainly continue to take those into account.

My assumption is that now that everybody has seen the evaluation criteria, there might be some additional comments you'd like to make.

I think the one -- if you are a proposer who submitted information to us in a proposal, and if you have submitted additional information that is not reflected in the matrix, it's because we really could not determine from your response that that particular feature was included in the proposal. So that suggests that we need some additional, more specific information

from you other than to say yes, the proposal addressed that interest.

Okay. Getting on to the evaluation criteria then, I think this will be a very, very important part of our evaluation in the next several weeks.

What we attempted to do, first of all, was to take into account all of the interests that were expressed by this group. And I attempted to categorize those into some major categories of criterias.

So for example, the number-one criteria, obviously, very easy access. We've got financing, benefits, implementation, quality, prevention, cost efficiency.

The availability of financing for resources and planning. Consumer and stakeholder participation. Consumer autonomy, provider autonomy and provider payments.

And then what we attempted to do was take all of the interests and group those into these major categories. And where there are obviously a lot of interests expressed, then that particular criteria may have received an

additional weight.

We also created a weighting for criterias based on what other states and other programs have done in evaluating their programs.

I'll say that this weighting process that we established is really very subjective. And we are looking for input from you. I don't know that had all of us gotten together to do this again, whether we'd come up with the same weighting criteria. I think we're in the ballpark in terms of the relative importance of certain features.

We know, for example, that if there's not a good implementation plan, that states have not been able to implement their programs. If there's not clear financing and support for that financing defined in the proposals, that we certainly have seen states not being able to implement those.

So this whole process was based on your own interests expressed here, as well as what has worked, what has been successful in other states. And as well as the results of different studies with regard to access to services in

Illinois.

MR. LERNER: So if I go to attachment B, which is a summary of all that, the weighting is what you said came out of -- I'm repeating it back to make sure I got it.

The weighting came out of the interest that we expressed through our exercise, plus your experience from the other states, is what I heard you say?

MS. SRECKOVICH: Yes, that's correct.

MR. LERNER: And where did the points come from?

MS. SRECKOVICH: The points are -- let me add one thing to the process that we used to establish the weight.

If you have expressed a specific interest that you don't see represented in the chart, it's because we, again, made some assumptions about what criteria that particular interest rests in.

So, for example, if somebody talked about prevention, it's very easy to figure out what criteria should go in. Some were less obvious.

At the very end of the process, we ended up with six -- six interests that we believe are not represented in here, so we're thinking that at the very end of our evaluation, we'll have a separate category that will say other considerations, and we'll address those as well because they have been addressed in the interest matrix, so it's not as though they've disappeared.

In terms of assigning the points, again, this is a very subjective --

MR. DUFFETT: I was going to say, what percentage up here -- or did you analyze this on the legislation in terms of what the legislation calls for.

I mean, I sensed, just looking at it quickly last night, that there's a lot of overlap in terms of the interests that went there, but I didn't know if you also then did a filter process to see that the things that the legislation calls for, are they also in here as criteria?

MS. SRECKOVICH: Yes. That was our first check process, to make sure everything that was in the legislation is reflected in here.

I think in some areas you might say -- for example, long-term care. There's quite a bit written in the legislation about long-term care. We felt that that was adequately represented in the criteria that says "Benefits, " but that's something we might want to think about.

If that's particularly important to this group and there needs to be a separate criteria for inclusion of long-term care services, then we can certainly -- we can do that.

MS. PRINTEN: May I ask a question? I'm a little confused, because when we went through the process of expressing our interests -- I thought we were going to narrow it down. My understanding is whatever came after the interests -- I can't remember what they're called. I believe the negotiation options.

I mean, that's what I would think these criteria would be drawn from, are the options, not the interests. My understanding was the interest was just sort of a brainstorming. I mean --

MR. KOEHLER: I think the interests is right. Options are how you get there,

interests are what you want.

MS. PRINTEN: But it was presented to us in a way that these are not necessarily --

MR. KOEHLER: Presented in a way that there shouldn't be evaluation by the group in vetting, you know, expressing our interests.

MR. LERNER: What David said, the step we didn't take, because we didn't have the time to do it. So if we would have had another time period, another meeting, we would have put all 87 or 98 interests up. We would have all been given ten votes or some number of votes.

We would have voted them. Those would then have come out to be a weighting, so what we're going to have to do is work backwards to see if we can get at some of that same weighting, which is what they're helping us through. That's the step I think we're missing.

MR. KOEHLER: Yeah. But I think one of the points your make though, if you start with the matrix of what the legislation calls for and take and put with it what we have said as interests and used those two things, it should get us pretty close even though we didn't go through

that process ourselves.

I'm guessing that this probably, even though it's interest-based, it also is a bit option-based as well. Because our options related to our interests. We said this is what we want, this is how we get there. So those two things really have to, in a sense, kind of dovetail.

MR. BACKS: We have something in front of us, so are we ready to react to it, regardless of how we got there?

MR. LERNER: Not quite. I still haven't heard the answer to the points, so if there's some qualifying questions, we have to get them. Ken?

MR. ROBBINS: If I'm asking this at the wrong point, I'd certainly be happy to wake up.

I'm still not sure I have a clear sense of what -- how the weightings were arrived at.

If, for example, you had a very important matter when we did our interests conversation. And everybody saw that the first person said that's important. I think that's

important, too, but I'm not going to repeat it, so I'm going to say something else. We went around the room several times to elicit that.

Somebody looking at that list would say well, that important thing was mentioned once. It must not be that important.

MS. SRECKOVICH: I can answer that. For example, this is -- and this is, again, based on our experience in looking what other states have done in terms of evaluating their options.

This goes back -- this whole process of evaluating options, we looked back for 20 years because these kind of commissions have been around for 20 years evaluating this.

For example -- a good example is financing. You know, not -- hardly anybody mentioned financing, except I think there was one that said no smoking mirrors, inequitably financed, those kind of things.

We know that that is just a very, very important criteria that other states have had to address in their programs. We know that's been the make-it-or-break-it kind of criteria for some other programs, so we've weighted that heavy.

One that we may not have weighted quite as heavily, but because there was so much interest expressed in it and we talked about it again today, was the area of prevention. That would generally be included under benefits and some of the other states' criteria.

Is there a complete benefits package? Is there a benefits package that includes preventive service, so we gave that some additional weight.

MR. ROBBINS: So these are merely -- these are your subjective calculations of what you think our interests are?

MS. SRECKOVICH: Yes. It's a combination of our subjective assessment of where you think -- where we believed your interests were expressed, as well as the criteria that have been used in other programs to evaluate --

MR. ROBBINS: That seems to me to be a pretty thin reed upon which to carry the weight of what we actually think these weight things ought to be.

Whenever the right time is to come to the question of whether I agree or

disagree with any particular weight, I can't wait to get there, but at least to set the stage, I find this to be a pretty flimsy kind of reed to bear all of that weight.

MR. KOEHLER: Let me -- I think that actually, as this is unfolding, it's kind of how I envisioned it, at least. That we would, as a group, discuss what our interests are, then go into not only talking about what we want, but how we thought we might get there.

But the fact that our consultants, Katherine, and the others were able to listen to that conversation and to hear how we discussed those things, even though only one thing went on the wall or whatever.

I think, you know, by other discussions and by how we've discussed this issue in the past, kind of what we feel about it. It's not as if they took a written report and said okay, here it is, and we're going to attach this to it.

So I think that's been kind of a give and take. You know, still we may have some overview points on it. And if that's what you're

talking about, I think that's perfectly valid.

But I don't think that this has gone awry at this point because, you know, the reason we hired these folks in the first place is because they have some expertise and they've been around the block on this thing.

And we bring our individual perspectives into it as well. So it becomes kind of a marriage, at this point, of the best of what we all have to bring to the table.

MS. SRECKOVICH: Yeah. We didn't propose these are the suggestions that everybody would vote on it and say yes, that's fine, go ahead.

What we wanted to do was present this with some tentative weighting and have you all engage in the discussions about whether those weights are appropriate or how they need to be changed or if we need to include it in some criteria.

We had actually also came up with a template where we said we were not going to assign weights. We're going to just try to do this in a very subjective process. Then as a

group we said no, that's not going to work very well because we have to put some form and substance to the evaluation.

So we're definitely looking for you all to make recommendations on how these weights should be changed.

MR. LERNER: Jan, did you have a question?

MS. DAKER: I did, but it has to do with the weight of something and we evidently didn't get there yet.

MR. LERNER: Can you explain also the points, so we can make heat of the whole thing, then step back and see where we want to go?

MS. SRECKOVICH: Yes. This does come from the review of the options that have been presented to us.

In some cases it was very easy to determine whether or not an option met a specific interest or criteria. Yes, no. And so in those cases, we said okay, we're going to assign a point of one to go. Either the proposal has that feature or it doesn't have that feature.

In some cases, though, it was

obvious, again, looking at all the options that some proposals kind of addressed something and other proposals addressed it completely.

So in that case, we gave a range of points saying, for example, if the proposal is very complete in how it's addressing a specific feature, that would be three points.

If it addresses, for example, administrative costs, but not as completely as another proposal, then we were going to give that two points. If it just moderately mentions it, we're going to give it one. If it doesn't mention it at all, we'll give it zero.

So we tried to create a more differentiation for specific areas where we've seen some of the proposals addressing that specific criteria.

MR. LERNER: Was that also pretty subjective?

MS. SRECKOVICH: Yes.

MR. LERNER: So it's a subjective evaluation of the proposals that were going forward?

MS. SRECKOVICH: Yes. Again, you

know, we want input on that as well to determine if there are better ways or if you have other suggestions on how we should use that point scheme or some other point scheme.

MR. LERNER: Niva?

DR. LUBIN-JOHNSON: Didn't I read somewhere that part of the criteria was going to also use what you said, the plans from other states, how these plans compare to plans from other states?

I thought it would be in their documents, our legislation, something, somewhere. But that was going to be part of it. Dave is nodding his head --

MR. KOEHLER: That was my understanding.

DR. LUBIN-JOHNSON: So at least part of that, I understood to be the case.

MS. SRECKOVICH: And you're right. That's why we had this column, "Other considerations" as well.

This is where we're going to address some of the really much more subjective kinds of features or proposals that can't be

appropriately weighted, perhaps. But we can identify tradeoffs.

For example, you know, if something has a zero in one and six in another, we can highlight for you in a subjective analysis that this resembles the Deargos plan, and here's specific features of that plan. That even though these features at present makes it more successful than another approach.

So that's our ability -- that's where we have some ability to provide the more qualitative information.

MR. LERNER: Here's the problem. In a half hour, another day or whatever it is, we're not going to be able to rule on these evaluation processes, plus half the Task Force is not here right at the moment, so we need some time to sponge this in.

We have a couple of different ways. And remember, our starting point was we'd like to be done by September 26th or whatever that date is.

The question is, how would you like to get to a point of being more comfortable

with the weighting and the point system, which have to be in place before they can go do the evaluation of the six models? I mean, you can't put the other cart before that horse.

And so what we have to do is help them get to this point so the evaluation process is clean. That's really as I see it, the next step.

MR. BACKS: I would like to comment specifically on some of the proposal, so that you can then go back and if the group agrees that some of these comments or critiques, if you will, are legitimate, that when we come back together again, we actually have revisions that come closer to where we think we ought to be.

It's hard to talk about without getting specific, so if I might. Criteria one, it says "Access." But everything from there on refers to coverage.

And we have spent -- in all of our deliberations and group presentations, there's been a repeated theme that coverage does not guarantee access if providers are not enrolled or participating because of inadequate, low or slow

or both, payment, which struck me as a rather ironic contrast to putting provider payment at number 12 with a weighting of 2.5.

I don't know how it is in other states, but if provider payment is not going to be a significant issue, I'm going to have a real problem defending this to the provider community. I suspect other representatives of other provider communities will have the same problem.

A possible solution is if you really mean access, that provider compensation and incentives to participate, if that's included in access and weighted along with that, combine 1 and 12 and give it a 20, but include provider payment in that access issue, then I think you'll be getting someplace.

But I'm going to -- I saw red when I saw provider payment as being relatively insignificant. You'll have coverage but no access. And if this is the Adequate Health Care Coverage Act, we'd be okay. But since it's the Access Act, then it's not.

MR. LERNER: Right. And that goes to Margaret's point.

MS. DAVID: This is helpful to me. And thank you, Craig. Because when Ken said it was flimsy, I had a difficult time with that word "flimsy," you know, because I just needed to see examples of how we could help you to do it.

And so, Craig, this is -- if you could continue, if you have anymore, this is helpful to me because it gives me a way of helping them to give us the evaluation criteria we need to go forward.

MR. LERNER: We're getting to the point we wanted to get to, and the question is how do we get there?

Let me ask a procedural question. I don't mean to be so crazy about the dates, but I'd like to stay crazy about the dates for a moment.

Would it make sense to take a subgroup of the Task Force who would work offline with you to massage through some of these evaluative points, come up with some clarification, then get it out to everybody well in advance of the July meeting, the results of the subcommittee, who would work with the consultants?

Then that summary would come out, right?

So that the July meeting -- we still have to come in with some evaluation, so we'd have to try to use Internet-based -- we'd have to use Internet-based communication. Can't do it, because of the Open Meetings Act?

We have to find some way. Let me just finish. Find some way to take the subgroup's work with the consultants, get it out to the Task Force, get the Task Force to respond to it. That will allow you still to have time to evaluate six models, so we still get it in in enough time to review it before the next meeting. That's what I was trying to get at. I'm asking a procedural question.

MR. BACKS: My position is this meeting was scheduled to go from 10:30 to 4:30. Everybody on the Task Force knew about the meeting scheduled well in advance. And I have allowed, and I think most of us have probably allowed enough time to attend going up to about 4:30.

And we have 50 more minutes in which the people who are here can react to this, give that kind of input, rather than doing it

online or selecting from this group or selecting it from people who are unable to attend today. That's my position.

MR. LERNER: Jan?

MS. DAKER: Five more minutes that I'm going to be here. I just wanted to mention that I saw red when I saw prevention and wellness weighted 5 points. That's not what we were after. That's the most economical thing to go after is prevention and wellness. It just seems very strange.

MR. LERNER: I'm happy to take the time until 4:30. I mean, makes no difference.

MR. BACKS: You warned us.

MR. LERNER: Because I want to make sure I'm accommodating people. Niva?

DR. LUBIN-JOHNSON: When Jan leaves, we will lose a quorum, okay? So when she leaves, we won't be able to take a vote as to whether we approve this or not, so we will probably end up doing some part of what Wayne has suggested anyway.

And let me say this. To avoid -- if the option is a subcommittee, to avoid

violating the Open Meetings Act, I believe we can have a subcommittee which is no more than six persons.

MR. CARVALHO: Actually, if you create a subcommittee, then the Open Meetings Act applies to the subcommittee. So if you have a subcommittee of six, then four of them -- I mean, no two -- more of those two can get together.

DR. LUBIN-JOHNSON: So then once it's called a committee, they meet, then that's it.

MR. CARVALHO: There's a couple of questions to what you said. One is do you want the -- well, first off, the process of having a weighting system and a point system.

And then do you want the process, what each weight is to be something that is based on a motion made and seconded and roll call taken, or do you want to go around and give feedback, listen to each other's feedback and ask the consultants to react to that, incorporate it in another draft, which then gets to the -- if that's the case, which then gets to the next question, which is if you then want to react to that as a group before the consultants apply this to their

analysis, which is due to you in about three weeks, then you need a meeting.

MS. ROTHSTEIN: It's not going to work.

MR. LERNER: Ken?

MR. ROBBINS: I think I would be more comfortable in appointing some subgroup that could go over this at some level of detail, if for no other reason than I only got this yesterday.

DR. LUBIN-JOHNSON: We all did.

MR. ROBBINS: Haven't had very much time to carefully think my way through it. I suspect that if others who aren't here had this in advance, and thought it was important, maybe they might have made adjustments to their schedule to be here.

So I think it an important enough issue that if you want to put enough time and energy into this to make this a useful --

MR. LERNER: Right.

MR. ROBBINS: I agree it would make sense to have a framework like this, but I think it ought to be a famework that is approved by the entire committee.

MS. ROTHSTEIN: I think if we stay here 50 more minutes, and I'm willing to do it, I'm not sure we'd complete the job.

MR. LERNER: Here's the other thing. We said earlier on the steering committee if we had to call a special meeting that's not scheduled in order to get our business done to complete the time line, we would. We would do that. So fair warning. Sometime between July and August we may have to do that.

MR. KOEHLER: Let me suggest that we schedule a meeting, and actually just have it as a committee as a whole. Maybe even try to get it where we can have people phone in to listen to it. I think this is very important stuff. I agree.

I wish we had started our day with this, but we had a backlog and we had to do that. But this is the real meat. This is the nuts and bolts of what we're doing.

I'm looking at my calendar. The 11th is the next Tuesday between here and our meeting in July. Again, if we can schedule a special meeting and have people where they could phone in if they can't be here.

MR. LERNER: 11th of what?

MR. KOEHLER: Of July. Because I think we need the interaction, because we can all think about this individually, but I need to play off of what you all are thinking, what you're saying.

MR. LERNER: So that between now and the 11th of July, a subcommittee would be called together, they would work with the consultants --

DR. LUBIN-JOHNSON: No, no.

MR. LERNER: Not even do a subcommittee? Oh, that's an interesting idea.

MR. CARVALHO: One procedural suggestion. If you're comfortable with your steering committee process, if you call it as a meeting of the steering committee, the only quorum necessary is the steering committee.

All of you can come. All of you can talk with your steering committee representatives. Any of you can leave at any time. Your quorum only disappears if three of your steering committee members go away. If you call it as a meeting of the whole group, you need to have 15 people to have a quorum.

REPRESENTATIVE COULSON: Could I just ask? This and the rest of what we're going to be doing is the meat of what we're trying to do here. I know a lot -- I've missed some of the other things. We've gathered information.

But I'm just concerned that we're so stuck on having this by September 26th when I don't even know --

Let me ask you as a consultant, if you have this done sometime around July 15th and our meeting is July 24th, are you going to be able to get the evaluations back to us in time?

MS. SRECKOVICH: Well, we had anticipated having a preliminary evaluation that was not, you know, a bells and whistles. Just some very basic review.

We've done some of the review of the proposals already in the interest matrix. And so there's that.

Mathematics and our actuarial consultant is already starting to develop the cost of the models. So we recognize we're really going to be hustling to get it done. Our biggest concern, obviously, is you --

REPRESENTATIVE COULSON: So we'd have less than a week to look at it.

MR. LERNER: Well, I expect if we had a week, I'd be thrilled to have the week, at this stage of the game.

MR. CARVALHO: The plan has been to get the first cut a week before the meeting?

Now your point, Representative Coulson is, if they get the weight the week before they're supposed to get you the first cut, can they do the job?

REPRESENTATIVE COULSON: And then the final issue is then we're making decisions on a partial evaluation, is that what --

MS. SRECKOVICH: No. We would continue to work on the materials and continue to circulate.

REPRESENTATIVE COULSON: So by August, we'll have a full evaluation, but it won't have been -- you see, I guess what I was thinking, the July meeting was a meeting where we'd have everything we can discuss.

MR. LERNER: The real key meeting is August when the work that we would do between July

and August would have come to fruition and we'd either agree on one model or not one model or some hybrid model.

MR. BACKS: We've spent now about 45 minutes discussing the model. I would personally feel comfortable delegating that after the steering committee having heard that, with the opportunity to attend the steering committee and comment. And having the steering committee actually make the decision what to go ahead with after reviewing what the consultant comes back with --

DR. LUBIN-JOHNSON: My only concern with that is that, you know, as of today, one member of the steering committee is facing some serious family challenges. And so, if we're going to do that, then we've got to make sure they're going to be available to do that, or we have to have some provision that allows someone to be in that person's place.

MR. LERNER: Let's do this. I hear you. Let's look at July 11th. We'll send out an alert to people, tell them we're going to look at scheduling something on July 11th. Either be the

full task force or the steering committee. The steering committee is meeting after this anyway, so we're going to finish it out.

My suggestion is as follows: Let me see if I can make this quick. I think we take as much time as we have got until 4:30, going through this. To the extent you want to stick around and talk about it, I want to stick around and talk about it, give the consultant as much information.

MS. SRECKOVICH: Is there any way to do it on the 8th instead of the 11th, because then we have the weekend? I mean, every day is really critical.

MR. LERNER: The 8th is a Saturday --

MS. SRECKOVICH: Friday. Either Friday or Thursday, because we really need as much time as we can get.

MR. LERNER: First of all, do we need an all-day meeting or do we need a half-day meeting?

DR. LUBIN-JOHNSON: I was thinking 10:30 to 1:00, 10:30 to 2:00.

MS. SRECKOVICH: I'd like to leave

the meeting with the criteria, because I think if there's any --

MR. LERNER: Leave which meeting?

MS. SRECKOVICH: I think if we leave that meeting with you telling us do our best to interpret what you said -- I think you all need to make the decisions about tradeoffs and how you want to assign those points.

MR. LERNER: You mean July 6th -- 8th, I think.

DR. LUBIN-JOHNSON: The 7th is a Friday.

MS. SRECKOVICH: Either the 6th or 7th.

MR. KOEHLER: Is there anybody who can't come on the 7th? Anybody that can't come on the 6th?

MR. LERNER: Can we do this by conference call or whatever --

MR. KOEHLER: Can we do both in this room?

MR. CARVALHO: We can do a conference call in here. I'm speaking off the top of my head now. I think there's a new state law that

requires that if you have a meeting that includes attendance by phone, that half of the members have to be present. So if it's a steering committee meeting, at least as long as the steering committee members are here.

MR. LERNER: What's your pleasure? I've got to change my schedule no matter which day you pick, so makes no difference to me. The 7th, a Friday.

DR. LUBIN-JOHNSON: 10:30 to 1:00. Two and a half hours enough time? 10:30 to 1:00, then the steering committee needs an hour afterwards. Then 1:00 to 2:00.

REPRESENTATIVE COULSON: Make sure you have a quorum because I know I can't be here the 7th.

MR. LERNER: Unless it's just the steering committee.

DR. LUBIN-JOHNSON: So are we going to send it out as a Task Force meeting, then change it?

MR. CARVALHO: My suggestion is to send it out as a steering committee meeting, so that your quorum issues are taken care of, but

invite all Task Force members to be here.

MR. LERNER: Yeah. I know. And Joe has got to be there. Diane?

MR. RUCINSKI: I know you based the current weighting or the suggested preliminary weighting on other states' experiences, and you made the point that if you didn't have a good implementation plan, then it didn't make a difference.

And would you write up a brief paragraph or something that talks about the states that you looked at or how these weights in the subjective process? Because I know you probably -- there was a process you went through, so we have a frame of reference how you came up with that and what states have been effected in your opinion.

DR. LUBIN-JOHNSON: I just have a question about how this came about. And was this total the consultants? Was just you all at Navigant or was there any participation review or comments from IDPH staff?

MR. CARVALHO: You know, it's funny, about ten minutes ago I was going to make that

comment.

All the material that's distributed to you always comes to us for review. This particular one, I got ten minutes before our conference call, or at least I looked at it ten minutes before our conference call.

I looked at the gestalt of it and said this is brilliant. Good work. But I don't particularly care how any of the plans were rated, so maybe I didn't look at the weights carefully.

So we made no changes to this. Theirs is one percent pure --

DR. LUBIN-JOHNSON: This is a conference call you had with the consultants?

MR. CARVALHO: Yes, we do that before every one of your meetings.

MR. LERNER: I'm going to suggest that for the sake of discussion, we got the word out, Sara. We schedule the steering committee meeting with attendance requested of the Task Force members. I need to start at 11:00 o'clock that day rather than 10:30.

And as far as I'm concerned, we'll go to 11:00 to 2:00 or 2:30 or 3:00 o'clock.

It's your pleasure, but we've got to be done, all right?

MR. KOEHLER: The train comes in at 10:00.

MR. LERNER: So you can start the meeting for me. So 11:00 to 2:30 or 11:00 to 3:00. We'll figure out what we're going to do about lunch, whether we eat before you show up. But if we do eat, we'll be eating and working at the same time. There'll be no break.

The idea is we'll take as much time today as we have left for people who want to stay and we'll finish it on the 7th. Is that the deal? Everybody okay with that?

Okay. Back to the agenda.

MS. PRINTEN: I guess this ties in with what Dr. Backs said. Talk about creating incentives --

DR. LUBIN-JOHNSON: What number is that?

MS. PRINTEN: Number five. It struck me when he talked about creating incentives for providers to adopt practices, when you put provider payment as the last, you know, criteria

with the least weight, you're talking about a punitive source of incentives.

And it seems to me that a better way to do it would be to involve -- to increase consumer autonomy up on the criteria list as well, because I think physicians will -- and other providers will probably respond better to their patients being involved in their healthcare, and that sort of relationship than they will to pay for performance things that are slammed down on them from top down. Does that make sense?

MR. LERNER: What are you suggesting? I lost you.

MS. PRINTEN: To include -- I'm not sure what I'm thinking.

To think about consumer autonomy and provider autonomy and whether or not they belong. They seem to me to have a lot to do with quality and implementation of -- I mean --

MR. BACKS: Yeah. In terms of the nuts and bolts of how to do that, I think what Tracy is saying, and the way I would say it is that we are, as providers, as physician/providers, we're rather suspicious of anything that sounds like imposed

paper performance program or penalties for failure to adhere to guidelines, those kind of things.

We'd like to see a consumer-driven quality program where patients are empowered with information and know what to ask for and collaborate with their physicians.

So in essence it would be moving -- I don't know so much as moving things up in the ranking, but maybe it is taking some of the points assigned in weighting to the top numbers and moving the weighting down a little bit.

So instead of a 2 1/2 or consumer autonomy, move it to a five and take 2 1/2 from something else like financing or one of the other areas.

MS. ROTHSTEIN: I think that under financing, number 2, and number 7, number 6, are really a combination of financing. Cost efficiency. The availability of resources, so that somehow you need to be able to couple those and come up with a number that is appropriate for all three of these things.

MR. LERNER: This could be interesting. We start to do -- either be lumpers

or splitters. If we lump up enough things, it's the Others Considerations column that gets longer and longer every time we do it, which is fine.

MS. ROTHSTEIN: But it makes some sense.

MR. LERNER: Can I ask a question? The model for this in your mind, I kind of think about things that enable something to be successful. There are obstacles, things to be successful. And you kind of think of this like an algebra equation. This has to be in place before this, before this, to the extent you can create a linear relationship recognizing that nothing in life is linear.

Have you kind of worked through a model in your head of how does accessing, financing and quality, which ones need to be before the other, that then become an inherent weight? Is there a model for this?

MS. SRECKOVICH: Actually, the first draft that we did of this had them in order. As you said, what you have to have in place first. And it ended at implementation and ongoing administration, I think we had as a separate

criteria.

Then we decided we'd better flop them around, put the most important things you wanted in terms of weighting. But, yeah, I think there's some clear steps.

It starts with -- does start with a benefit design. You know, work on the way down, ongoing operations of the model.

MR. LERNER: Would you want people to take this home and send you information or send you critique between now and July 7th or whatever it is?

MS. SRECKOVICH: Sure. What we could do is take that information, compile it, get it back to everybody before that day. You know, rather than -- I think if we make all the changes everybody wants, I think we'll end up with something close to 500 percent.

But I think we can certainly take comments, summarize those. Maybe even provide some suggestion based on that without redoing the scoring so you have an opportunity to do that.

MR. LERNER: Is that reasonable, Ken?

MR. ROBBINS: Yes.

MR. LERNER: I'm being sensitive to the fact we all basically got this last night and we need some time to think about it, think about how we group it, what weighting to give to it.

MS. SRECKOVICH: If somebody else sends us something -- everybody thinks the same way, we won't have to have a meeting. I guess we'll have to have a meeting, but it will certainly make it a lot easier in terms of the time.

MR. LERNER: So then could I ask this? I'd like you to send this out again as an e-mail with a notice that's called to meeting on July 7th. And we'll work this through, Sara, at the steering committee meeting. And to the extent that you have a model that overlays this that talks about that relationship, that you think may be helpful to us.

If it doesn't confuse us more than we're already confused, then don't bother. But if you think it would be helpful. I mean, thinking about causality and attribution is always helpful to me as I think about policy design.

This may not be able to do that,

but at least give us some thought about that would be helpful. That would then get you into discussions like Craig raised, which is provider participation and access and what's the relationship between the two, or provider participation and financing and what's the relationship between the two. That's what I was trying to get at.

MS. SRECKOVICH: I'll actually send it out in a format that you all can edit so we can take your scores or whatever.

MR. CARVALHO: Encourage everybody to do two things. First, read through the back up to the table because, you know, for example while on first blush, the financing cost efficiency is very similar. If you read through, financing is -- how does this program get paid for. Cost efficiency is what is the incentive on the provider community and consumers to make sure that they're making good, rational choices.

The other thing, the obvious mathematical point that it still has to add up to a hundred. So you probably need like the congressional balanced budget idea; you really

can't propose that another number go up if you can't propose another number goes down, otherwise every number gets doubled.

MR. LERNER: If you try to vote more than once, your vote's out. This is Chicago.

I've got to tell you something. I think that the first pass read on this is a very good piece of work. This is very complex stuff.

MR. BACKS: I think the process is a good process. I think it's just hearing the input and the weighting of the things is the things you need to fine tune.

MR. LERNER: So here's the deal. We're going to call a meeting for July 7th. The steering committee will talk about the mechanics of that after this meeting.

We'll get this back out in the format that people can respond. We'll ask people to respond between now and July 7th. July 7th, the meeting will take place. Out of July 7th, will hopefully come the evaluation methodology.

Then we're still going to try to hold to our schedule with enough time to review the responses before the meeting. Everybody okay

with that? Good.

It 4:00 o'clock. I'm right on schedule. IDPH update?

MR. CARVALHO: Actually, this is just a space filler to allow for the rest of the schedule to go over. Since it didn't go over, I don't really have any updates.

I was thinking of maybe updating you on SHIP, but actually that was part of Dr. Orgain's presentation, so you've already been updated on that.

MR. LERNER: Okay. I will do other business. I've got two pieces of other business. Does anybody have any other business they want to raise? Hearing none, we did receive -- I have something on -- we really haven't seen before. On the market for individuals in Illinois.

Beth has been at several of our meetings for individuals and asked if she could share this, and I neglected to do that, but this is information about what an individual faces in securing information in Illinois. Some of the data on percentage of people who are in Illinois, who participate as individuals in the healthcare

market, insurance market.

You've heard presentations over the year on states that have particular methods of underwriting, rate regulation, pre-existing conditions, etcetera. And what Beth is presenting here is what is the state of affairs in Illinois.

MS. NAJBERG: I think that covers a lot of it. And where this fits together is how do you -- the individuals who pay high premiums. I've been trying to figure out how they get the information about the breakdown of the individuals.

Looking at the table in the center, 623,000 people. What's the age range, what's the average premium, and I haven't been able to get that. So if anyone here can access that information, I think that would be helpful.

I think the real impact of this is when we're talking about the 1.790 million uninsured. If we can move -- we're talking about getting those uninsured into an insured group and some of the barriers for the individual market.

And up on the top are some of the restrictions that medical underwriting is allowed

without restrictions. So someone who applies for an individual policy, if an underwriter is a 20-year-old -- and I've talked to them on the phone -- who doesn't have experience and woke up on the wrong side of the bed, you could be rated up 20 to 75 percent. And there are no rate caps.

So with the present system, if we're going to get uninsured to buy policies, we haven't made much progress to get those into the policy.

And the bottom is a sample of the rate spread for an insurance -- an individual policy that I looked at. How it jumps up to -- if you're over 50 years old, you jump up way over three times the base premium that is in there. That dotted line going as across is three times the base premium.

Most people immediately get rated up the 20 to 75 percent, so that 314 is going to go -- at 75 percent going to go way, way off the chart.

So these are things to take into consideration when we look at some of the pricing. Any questions?

MR. LERNER: Thank you, Beth. We appreciate that. We appreciate your diligence.

All right. Other issues real quickly. We all received a copy of a letter that's dated June 7th. Many of us did not get this until recently, from Senator Halvorson and Representative Flowers.

I would like to mention, for the record, that each member of the Task Force received this letter. That the Task Force continues to engage -- has and continues to engage in open, candid, and objective analysis of models before us.

That part of the Task Force is to debate and argue, then decide. And that's exactly what we did. That we subsequently concluded that we would review five models and allow the consulting firm to come back and work with us on a sixth hybrid model. And that is still the process in place.

And we do accept the letter. We enter it into the record. And I don't choose or think that we should respond any further than that, except to receive it and recognize that this

is part of the process. Any comments? Niva?

DR. LUBIN-JOHNSON: I'd just like to know when it was received because it was dated June 7th and we got it yesterday.

MR. CARVALHO: It was received by me last Thursday. Joe Roberts forwarded it to me. I forwarded it to Dr. Lerner, and asked whether he thought we should distribute it to the Task Force as a whole. He decided that we should. And it got in the same e-mail transmission Elissa tried to send out to you all on Friday, and I guess you got it yesterday.

As far as I know, interestingly, the governor's office never received it directly, but Joe got ahold of it and sent to me or sent it to Elissa on Thursday and she got it to me and I then got it to Wayne, and he got it to you.

MR. LERNER: I received a copy from Senator Watson as well, in a letter dated June 20th, so it hit about the same time I got the e-mail. So clearly, we all got it at the end of this process, okay? Other comments about that?

I have one personal comment to make, and I do want this entered into the record.

As many of you know, if you've been reading the papers, my picture was on the front page of the business section not too long ago, which isn't bad for a poor kid from the west side of Chicago, but not the way I wanted it to play.

I did resign from the Rehab Institute of Chicago. I did it because I'm the person responsible for when staff members do bad things. And I have a staff member who did bad things. And I have to take responsibility for that.

I had a great nine-year run at the Institute and I love that place. I'm going to be there through the end of summer. But as I told David Carvalho and Dr. Whitaker, I choose not to give up my role here, nor do I choose to give up the chairmanship. So we're going to finish the job we started.

If you have any questions about any of this offline, I'll be glad to answer it. But in the end, you've got to do the right things for the right reasons. Do you have any questions?

MR. ROBBINS: I might question your sanity, but I applaud it.

MR. LERNER: That was Ken Robbins asking about my sanity. Are there any other items before the Board?

MR. BACKS: Just to draw attention to materials sent out to the e-mail. The AMA acted as the annual meeting calling for an individual mandate for individuals who have incomes greater than 500 percent of FPL as a starting point.

And once the mechanisms are in place for tax incentives and penalties for procuring or not procuring individual insurance, they're favorable to individual mandates, as well as the end of a long-term process of moving toward this mandate. And I think it dovetails pretty nicely with what's happening in Massachusetts. And what's timely for our discussions here.

Obviously, that is a national organization policy. It is not directly applicable in every way to every state. And ISMS has yet to act specifically on our policy for Illinois. It would obviously have some implications on the insurance market and some of the issues brought to us in the analysis in the individual market.

But I wanted to call it to the attention, that that is our profession's policy based on the AMA.

MR. LERNER: Thank you. Any other items?

MR. SHEFFEL: Dr. Lerner, if I could make a comment? Joe Sheffel, S-h-e-f-f-e-l.

If you have advocates who are willing to spend a day here at the meeting, then there should be some process in place for us to make comments, perhaps at the end or something. So that perhaps if we have information you are not aware of and would help the Task Force in doing your job.

MR. LERNER: Thank you. Why don't we talk about that at the steering committee meeting. Thank you. Other items? Motion to adjourn.

DR. LUBIN-JOHNSON: So moved.

MR. LERNER: You're out of here. Happy 4th of July.

(END OF PROCEEDINGS)

STATE OF ILLINOIS)
) SS:
COUNTY OF COOK)

I, ANNETTE WASHINGTON, Certified Shorthand Reporter of the State of Illinois and County of Cook, do hereby certify that I reported in shorthand the proceedings had in the above-entitled cause, and that the foregoing is a true and correct transcript of said proceedings.

In witness whereof, I have hereunto set my hand and affixed my seal at Chicago, Illinois, this 24th day of July 2006.

Annette Washington, CSR
084-001004
Notary public.