FOIA Number: 2018-0758-F

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Series/Staff Member: Todd Summers

Subseries:

OA/ID Number: 21089

FolderID:

Folder Title:
Issues - HIV Surveillance-Washington State [1]

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STATE OF WASHINGTON
WASHINGTON STATE BOARD OF HEALTH
1102 SE Quince Street • PO Box 47990
Olympia, Washington 98504-7990
September 1, 1998

Todd Summers, Deputy Director
Office of National AIDS policy
736 Jackson Place
Washington D.C., 20503

Dear Todd:

Thank you for your excellent perspective and background information on the HIV Surveillance matter. The upcoming meetings in Washington are October 14 and November 12-----anticipating some decision in December. Tentatively, your briefing would be on the October 14 Agenda in the A.M. for an hour. Michael Zimmerman is standing by for your call to arrange details of travel and any special needs, e.g., audiovisuals, you need.

Background material about the Board is coming to you in the mail. Should you have written materials for the advance Board Reading Packets, 20 copies, 3-hole punched, would be needed here no later than October 2. Please let me know if you have questions about that.

Looking ahead, imagine you would travel with us on October 13, and fly home again following the meeting either Oct 15 or 16? But that detail level can be worked out after your confirmation to us when you return from vacation. We are all looking forward to talking with you, as your points will be critical to the decisionmaking. Thank you again, Todd.

Sincerely.

Sylvia I. Beck
Executive Director

Enc.

WASHINGTON STATE BOARD OF HEALTH

The Washington State Board of Health was established in the State Constitutio in 1889 to protect and promote the health of Washingtonians. Its ten members ar appointed by the Governor to represent the health needs and concerns of all th people. The mission of the Board is to develop policies to promote, protect maintain, and improve the health of all Washingtonians. To fulfill this mission the Board solicits information through public forums, assesses the reports on th people's health status, establishes health-related goals and priorities in th *State Public Health Report,* and adopts administrative rules to implement statute and Board policies. The Board recommends steps to assure optimum use of publi financial and human resources to prepare Washington to meet the challenges of th twenty-first century.

Warren Featherstone Reid, J.D. (Chair) Consultant, Seattle	Representing Consumers
The Honorable Neva J. Corkrum (Vice Chair) Commissioner, District 1 Franklin County	Representing Elected County Officials
Sheri S. Barnard Consultant, Spokane	Representing Consumers
Charles R. Chu, D.P.M. Podiatrist Factoria, Puyallup, Enumclaw, Kent	Representing Health and Sanitation
Ed Gray, M.D. Northeast Tri-County Health Officer Colville	Representing Health and Sanitation
Thomas H. Locke, M.D., M.P.H. Health Officer Clallam and Jefferson County Health Departments	Representing Local Health Officers
Bruce Miyahara, M.H.A. Secretary, Department of Health	Representing Department of Health
Carl S. Osaki, R.S., M.S.P.H. Chief of Environmental Health Seattle-King County Department of Public Health	Representing Health and Sanitation
The Honorable Margaret Pageler, J.D. Seattle City Councilmember	Representing Elected City Officials
Florence Reeves, R.N., B.S.N. Consultant, Tacoma	Representing Health and Sanitation

Sylvia I. Beck, Executive Director

WASHINGTON STATE
PRIORITY HEALTH GOALS
1999-2001*

- REDUCE PREVENTABLE INFANT MORBIDITY AND INFANT MORTALITY.
- REDUCE THE INCIDENCE AND PREVENTABLE CONSEQUENCES OF INFECTIOUS DISEASES.
- CONTROL OR REDUCE EXPOSURE TO HAZARDS IN THE ENVIRONMENT IN WHICH WE LIVE, WORK, AND PLAY.
- REDUCE TOBACCO USE AND EXPOSURE TO SECONDHAND SMOKE.
- REDUCE MISUSE OF ALCOHOL AND OTHER DRUGS.
- REDUCE THE INCIDENCE AND IMPACT OF VIOLENCE AND PREVENTABLE INJURIES.
- ASSURE ACCESS TO POPULATION-BASED AND PERSONAL PHYSICAL AND MENTAL HEALTH SERVICES, INCLUDING HEALTH EDUCATION, PREVENTIVE SERVICES, AND ILLNESS CARE.
- REDUCE THE INCIDENCE AND PREVENTABLE CONSEQUENCES OF CHRONIC DISEASE.

*not in ranked order

PACIFIC MAGAZINE

PACIFIC PICKS

NORTHWEST LIVING
Sloped site on Hood Canal

ON FITNESS
Shaping up on the road

NOW AND THEN
Delivery wagons

people of influence

PAUL REDMOND. The leader of Spokane's impressive economic development efforts, he's a dedicated civic activist and visionary. In his day job, he runs Washington Water Power, Eastern Washington's largest utility and one of the state's biggest public companies.

WARREN FEATHERSTONE REID. The key behind-the-scenes figure in state health law for 40 years. He was an aide to Sen. Warren Magnuson and adviser to Gov. Booth Gardner. He helped expand federal financing of medical research and write such legislation as the federal Nurse Training Act and the state Basic Health Plan. He's the namesake of the state's Warren Featherstone Reid Award for excellence in health care.

LOUIS RICHMOND. There are those who do and there are those who promote: Richmond's a promoter extraordinaire. He "created" Northwest celebrity chefs like Kathy Casey and Monique Barbeau, and landed "news" coverage estimated to be worth $1 million for a dinner train. If you think you're hungry, he probably planted the idea.

TERRY ROGERS. His name's not well known, but as chief operating officer of King County Medical Blue Shield, the state's largest health insurer, he has a big say in deciding which medical procedures are covered, how much consumers will pay and which doctors will get the work.

KATHLEEN ROSS. The founder and tireless president of Heritage College in Toppenish and Omak, she's brought higher education to thousands of disadvantaged multicultural students who wouldn't otherwise have the opportunity. She recently won the state Medal of Merit Award for exceptional public service.

JUDY RUNSTAD. She can raise big money faster than you can say "power breakfast." Her job, land-use attorney, barely hints at her influence: She's part of the inner circle of top politicians in both parties — a trusted bridge between business and government.

GEORGE RUSSELL. He's better known elsewhere than in the Northwest, but he's one of the world's most influential money traders. His Tacoma-based Frank Russell Company recommends investments to the managers of huge pension funds. The amount at stake, based on his advice, is said to be $500 billion. That's *billion*. Dollars.

FAYE SARKOWSKY. She's a barrier breaker, a business role model who offers women guidance as they bump against the glass ceiling. She helped get the Seattle Art Museum built and influences art and commerce as a member of several boards of directors, including Children's Hospital, the Fifth Avenue Theater Foundation and Commerce Bank.

PAUL SCHELL. When the UW thought it wanted an interim president to take over for William Gerberding, the outgoing dean of architecture was one of those mentioned. Developer, innkeeper, educator, philanthropist and president of the Port of Seattle board, he's at the center of the state's money and power network.

HOWARD SCHULTZ. Until he took over, Starbucks was really just a pretty good cup of coffee. He's made it a near-religion, jangling the nerves of a double-tall nation and creating a new vocabulary in the process.

PATRICK SCOTT. Not a household name, but as the head of the last locally owned broadcast operation of any size in Seattle, he has a lot to say about what we watch on the tube and hear on the radio. Among Fisher Broadcasting's holdings are KOMO-TV and KOMO-AM, hot-talk KVI-AM, KPLZ-FM, KATU-TV in Portland, and a dozen small radio stations in Eastern Washington and Montana.

BELDING SCRIBNER. Few others have saved so many lives. Working at the UW Medical Center, he pioneered kidney transplants and kidney dialysis as a continuing treatment: there are now some 750,000 people worldwide on dialysis.

MARTIN SELIG. He's always been the developer people love to hate, but nobody's had more influence on the Seattle skyline. He built the 76-story Columbia Seafirst Center, the black "Darth Vader Building" at Fourth and Battery and other office towers, as well as many mid-rise buildings in Lower Queen Anne and the Denny Regrade.

FRANK SHRONTZ. What impact does Boeing have on the state? Right: any it wants. As CEO of the largest and most important business in the region, Shrontz can make or break the economy, from how many people are working to who pays what taxes. And his company's planes have shrunk the world.

RICK SIMONSON. Few cities anywhere are as book-crazy as Seattle. A big reason for that is Elliott Bay Book Company's manager, who founded and developed the popular and much-copied author-reading series. The success of Elliott Bay and the U. Bookstore paved the way for literary efforts like the Seattle Arts & Lectures Series, founded and directed by Sherry Prowda.

STUART SLOAN. He's at the head of the table or somewhere nearby when decisions get made at

* Our Board Chair — FYI only

Excerpts Background for Todd

AIDSNET COUNCIL POLICY PAPERS ON: 1) NAMED REPORTING OF HIV INFECTION AND 2) PROVIDER ASSISTED PARTNER NOTIFICATION FOLLOWING HIV DIAGNOSIS

M. Ward Hinds, M.D., M.P.H., Snohomish Health District (SHD) Health Officer, said it was a pleasure to speak before the Board, which he had once chaired. His presentation was based on position papers in the Board Reading Packets recently developed and approved by the AIDSNET Council and Washington State Association of Local Public Health Officials (WSALPHO). The AIDSNET Council is composed of directors and coordinators of 6 regional AIDS Service Networks created in the 1988 Omnibus AIDS legislation.

It has been 17 years since the AIDS epidemic was 1st recognized in the U.S. Many changes have occurred both in ability to recognize the epidemic's course and public health's ability to prevent and treat the disease. During the last several months, the Council has re-evaluated its position on several prevention and control measures based on current research.

The Reading Packet contains 2 position papers for consideration. Both relate to existing Board regulations. The 1st is to require name HIV reporting by providers and laboratories while maintaining current laws and regulations which require access to anonymous testing in the public sector. WSALPHO supports this position. In 1984, the Board approved name repor-ting of AIDS cases. There is an average 10-year lag between the time when an in-dividual becomes infected with HIV and when AIDS develops. The lag period has always been problematic in terms of trying to track the disease's course. In re-cent years, treatments for HIV infection have become available which are effec-tive. These prevent a large proportion of people infected with HIV from progres-sing to AIDS and may also reverse effects of HIV infection on people with AIDS. This has made it more difficult to use AIDS reporting as an accurate indicator of the epidemic's trend and is likely to worsen. Without HIV reporting, Dr. Hinds said public health will have poor knowledge both about HIV prevalence and population groups being most affected and about associated behavioral risks.

Dr. Hinds stated the majority of states include HIV as a reportable condition, as has been recommended by the federal Centers for Disease Control and Prevention (CDC). Besides the need to track the epidemic more closely, it is also essential to be able to identify people with HIV infection early so they can be linked with effective treatment as soon as possible. This is particularly important for population subgroups including young children and women in childbearing years. We now have the ability to prevent in most cases transmission of HIV from pregnant women to their offspring by instituting treatment during pregnancy. It is important for public health authorities to know when pregnant women are infected so they can work with providers to ensure treatment.

The AIDSNET Council also recommends public health work with HIV-infected persons to sensitively and appropriately identify sexual and needle-sharing partners and provide HIV counseling, testing, and referral to care services. Barriers to provider reporting of HIV-infection persons and their partners in regulations, policies, or procedures should be eliminated. Currently, there are barriers to partner notification being undertaken by professionally training public health staff. Private providers cannot give names of infected persons or their partners to public health authorities unless the infected individuals refuse to notify partners themselves, or indicate they are unable to do so. By removing these barriers, public health would assume major responsibility for partner notification.

The goal is to maximize knowledge about people who are HIV-infected as early as possible to make sure they are aware of effective treatments for themselves and prevent further infection from occurring. Recent research suggests people in relatively early stages of HIV infection are potentially the most infectious, as they have the highest viral loads. Behavioral changes can interrupt the transmission cycle.

Dr. Hinds is aware these positions are controversial and must be carefully

considered by the Board. It has been suggested that instead of name reporting, unique identifiers might be used to accomplish some of the same objectives. The AIDSNET Council is unconvinced that unique identifier would accomplish the objectives fully or as efficiently as name reporting. Texas and Maryland have had mixed results with unique identifiers and considerable difficulties in getting their systems to work. Name reporting is important if public health authorities are to make individuals aware of treatment options and contact partners.

Ms. Reeves asked whether name reporting would be in conflict with federal law, which requires those who voluntarily submit to testing in correctional settings not have their HIV status revealed. Dr. Hinds said he suspects such a conflict does not exist. Partner notification as conducted by public health officials never reveals the source of potential exposure. He reiterated that the Council also recommends anonymous test sites still be maintained by local health jurisdictions. These serve an important purpose in making contact and providing education to people at risk of infection. 98-99% of people who seek anonymous testing are not infected. Once infected persons enter care, anonymity would no longer apply.

Dr. Locke praised Dr. Hinds' presentation. From local health officers' perspectives, these are critically important strategies for the next stage of controlling HIV infection. Strategies of name reporting and provider-assisted partner notification are linked. He underscored the importance of early treatment as a way of preventing disease spread. Worldwide, 9 out of 10 infected people do not know it and would not find out unless they were told they were exposed and were appropriately tested. Local health officials are sensitive to confidentiality issues. Systems have been set up to protect privacy rights. The goals of optimal health care and prevention of new cases are mutual. AIDSNETS' position is supported by the Washington State Medical Association, CDC, and other national groups.

Responding to Mr. Reid, Mr. Miyahara said DOH has started the rulemaking process. Mr. Reid said the Board is just in the information-gathering stage. Replying to Mr. Osaki, Mr. Reid said the Legislature has power to take action on the issue if they choose but the Board must approach the issue as a public health matter. Responding to Ms. Beck, Mr. Miyahara said Board discussions about a potential rule would likely take place next Spring, though there is no emergency and no need to rush. The issue is a question of balancing the potential of better prevention and care against legitimate concern for confidentiality and other issues. Ms. Reeves suggested better education of communities regarding how care would improve might help the argument for name reporting and partner notification. Dr. Hinds appreciated Dr. Locke's comments related to confidentiality. There is distrust regarding the government's ability to maintain confidentiality, even though the state has an excellent record. Mr. Reid thanked Dr. Hinds for providing valuable information.

FOLLOW-UP ON LETTER OF INQUIRY FROM JOHN NORDQUIST, CHAIR, SNOHOMISH HEALTH DISTRICT BOARD OF HEALTH, WAC 246-217, TESTING AND LICENSING FOOD SERVICE WORKERS

Mr. Reid directed the Board's attention to letters in the Reading Packets from SHD related to food safety and foodhandler permits. Bill White, DOH Office of Community and Environmental Health Programs Director, cited additional materials on the issue in the Packet from the November meeting, which indicate the main concern is with lack of consistency in training and examination of food workers. The Food Safety and Enhancement Advisory Committee (FSEAC), a joint workgroup of DOH and WSDA, put together a number of different strategies and recommendations for dealing with this issue several years ago. Ms. Beck indicated there is reference to the FSEAC report in a past Board Annual Report which condenses it well. Mr. White said most of his presentation today would deal with revisiting those recommendations. Food workers do not receive uniform information at the time they are instructed and examined for their permits. In 1996, Environmental Health Directors (EHD), in collaboration with DOH, developed some food program standards and also addressed the issue of training, recommending interactive training as part of every local food program. Neither RCW nor WAC contains specific guidance on training, only on conducting examinations (RCW 69.06 and WAC 246-217). As a result, about 1/2 of foodhandlers go through some sort of classroom instruction prior to

elderly. There are many individuals with traumatic brain injury in both nursing and boarding homes, and about 1/3 of adult family home residents are developmentally disabled. Mr. Hyre requested Board support for legislation that would promote fuller disclosure from both providers and prospective residents coming into facilities, so that everyone would be clearer about what was being offered and what was really needed. He said such a bill had passed through both houses of the Legislature in 1997, but DSHS advised the Governor to veto it. Ms. Beck thanked Mr. Hyre for providing input for the *WSPHR*. Mr. Hyre appreciated the opportunity to talk with Board and hopes to do so again.

OPEN PERIOD TO TAKE PUBLIC TESTIMONY ON ANY HEALTH ISSUES

Mr. Reid invited the public to testify on health issues of their own choosing. Gérard Sheehan, Legislative Director, American Civil Liberties Union of Washington (ACLU), said his organization strongly opposes HIV name reporting for the same reasons Washington choose not to require such reporting previously. There is still discrimination and social opprobrium attached to HIV/AIDS. Mr. Sheehan shared an ACLU report which discusses the interplay between name reporting and civil liberties. There have been studies of states where name reporting has been instituted, and HIV testing rates have declined. This is why name reporting may not be advantageous from a public health perspective.

Mr. Sheehan noted case law is tending toward individuals with HIV not being protected under Americans With Disabilities Act. People with HIV are not strongly protected under disability law, and the trend is going in the opposite direction.

He noted the euphoria about the efficacy of drug treatment for HIV is wearing off. In addition, it remains that society has not chosen to fund such treatment for all those infected at a cost of $10,000-$15,000 per year for drugs which may or may not turn out to be very useful. It is too early to use the pharmacological argument to support name reporting. A confidential system of HIV testing was not adopted in the past because of dearth of pharmacological treatment. Such treatment should not now be a rationale to begin name reporting.

Mr. Sheehan suggested that Dr. Hinds' comments regarding states requiring name reporting were misleading. 27 states have adopted name reporting, but these represent only 24% of AIDS cases. Many of these states have social policies very different than Washington. California, New York, Illinois, and New York do not have name reporting. He indicated the Governor's Advisory Council on HIV/AIDS (GACHA) is deeply divided on the issue and will not recommend name reporting to the Governor.

Mr. Sheehan distributed materials about name reporting to the Board. He noted the Northwest AIDS Foundation opposes name reporting. He suggested CDC, which was the driving force behind the proposal, may now be rethinking the question. Responding to Ms. Reeves, Mr. Sheehan noted that those opposing name reporting understand that it does not create treatment, and the links between the 2 are tenuous. Studies from other states seem to indicate that name reporting deters some people from getting tested, hence defeating the purpose of the reporting system. Once one has the disease, the name is reported as treatment is received. He wonders why someone would choose to go to a test site which did name reporting if there was an option for anonymous testing. Mr. Sheehan agreed that the state does a good job of protecting confidentiality, though there are exceptions. Responding to Dr. Locke, Mr. Sheehan said ACLU favors use of unique identifiers and has some concerns about the proposed system for partner notification. Unique identifiers do not get in the way of appropriate partner notification, which should be discussed in post-test counseling.

Replying to Ms. Reeves, Mr. Sheehan said Texas and Maryland are using unique identifiers. Both have had some difficulties in making the system work. Public health officials in Maryland believe these difficulties can be surmounted and are retaining the unique identifier system. The main problem with such a system appears to be in training.

Kelly Scott, GACHA Member, has been a member of the GACHA taskforce studying these issues for the past 6 months. A taskforce report will be given to GACHA in January. He stated he was not speaking on behalf of GACHA or the taskforce today but rather reporting on their activities. Mr. Scott said the taskforce intends to take no position in its report but will provide the best thinking for name reporting and use of unique identifiers. Dr. Bob Wood, Seattle-King County Department of Public Health, and Mr. Scott are drafting the respective report sections.

Mr. Scott is a member of the statewide prevention-planning group, which prioritizes interventions for preventing AIDS spread and how funds can best be used. He reported that: AIDS Action, a Washington, D.C. lobbying arm of 2,000 community-based organizations involved in prevention and care, opposes name reporting; Connecticut has decided not to go forward with name reporting; Hawaii has sent a delegation to CDC requesting they not take a position favoring name reporting; National Association of People with AIDS, ACLU, Positive Voice Committee of the Seattle-King County Title 1 Planning Council, People with AIDS of Oregon all oppose name reporting.

Mr. Scott suggested that while public health has a good record in keeping names confidential, the real issue is misuse of data by government, which is a well-grounded fear. He cited several cases of personal disease information being misused as part of official government policy, with negative consequences for those infected. He noted that during the 1997 Session, AIDSNET Council and DOH favored legislation that would have mandated turning of HIV information to law enforcement given any well-founded suspicion that a person was behaving in a risky fashion. The bill was vetoed by the Governor. Having worked around these issues since 1991, Mr. Scott noted there have been proposals in every legislative session which make no public health sense but which are difficult to stop. Increased lifespan for someone with HIV requires greater protection for individuals so they can live productive lives without being stigmatized.

Mr. Scott indicated that a CDC-sponsored study found 20% of those responding said they might not have been tested if they thought their names would be reported. He indicated the public does not distinguish between anonymous testing and having their names reported when they seek care. In fact, most individuals at the 6 public hearings held around the state thought this unfair. If people are driven away from testing as a result of name reporting, partner notification at the time of greatest risk of infection will suffer. Furthermore, there is no new money for care, either at state or federal levels. Name reporting will not increase dollars available for treatment. Rather it will lower the percentage of those diagnosed able to access care. Research provided by the Names Reporting Taskforce found that just as many partners are identified when people are tested anonymously as when there name reporting. Infected individuals still have to give the names of contacts. Given that there are no new funds, Mr. Scott questioned public health's desire to reach out and provide greatly expanded partner notification services. Funds could only come from gutting other community-based prevention programs and other interventions. Such a decision would not be made by the Board but by the planning groups involved in AIDS prevention and would be separate from a decision about name reporting.

Mr. Scott suggested the Board might want a 1/2 hour information session prior to rulemaking which might include Mr. Sheehan, rural representatives, and people of color who could respond to questions. There is largely a consensus that better case reporting is needed but might not result from a name reporting system.

Karen McDonell, Citizen, Gig Harbor, acknowledged the Board's interest in reducing exposure to substances that undermine health. She has been working with a number of community groups to draft a legislative 'right-to-know' bill on pesticide use in occupied buildings. Under the bill, occupants would be provided notice when pesticides were to be used indoors.

Ms. McDonell said pesticides are capable of causing injury, particularly to vulnerable populations including pregnant women, infants, and young children. They

technologists. So I can give you an update as this process develops.

It was very good, because it did create a different environment to talk about the issues. There are some areas where there are agreements, and some areas that are just gray, and the hearing format that we're used to seeing doesn't necessarily allow the ability to talk about the issue, so I think this is just another approach that can augment the Sunrise process. Overall, I think it was successful. We all learned a lot, and I think the associations learned quite a bit, too, about a way to augment that process.

MR. REID: Any questions of Bruce on this item?

Is this something where perhaps the Board should join you on that letter to the legislature, or let well enough alone?

MR. MIYAHARA: Well, let me go back and see. I'm sure there wouldn't be any problem with it. You did ask me to go through that process, so it could be a joint letter. I'll have staff try to get the latest draft of the letter to the Board and we can figure out timing-wise how to do this. We do want to get it there quickly, because they're starting to put the bills together now.

MR. REID: No later than January.

MR. MIYAHARA: I think the cut-off's in a week or two on some things. I'll go back and check.

MR. REID: Any questions?

MR. MIYAHARA: We can bring it up with Patty, too, when she comes at 1:00 o'clock.

MR. REID: Okay.

MR. MIYAHARA: Legislative staff.

MR. REID: Good.

Okay, moving back, we welcome a former member of the Board, and Chair, Ward Hinds, on Item Number 7.

DR. HINDS: Mr. Chairman and members of the Board, thank you very much for inviting me here today. It is good to be back here today. Before I--

MR. REID: And for the record.

DR. HINDS: Yes, my name is Ward Hinds. I'm the Health Officer for Snohomish Health District in Everett, Washington. I also am a mail carrier today, and I have some small packages for Neva Corkrum and Margaret Pageler that come from Rick Mockler who's been working with them on something that's going to happen in January--saving postage.

MS. CORKRUM: Thank you very much.

DR. HINDS: Sylvia, it's good to see you again today, too. It's very much a pleasure to be back here.

The topic on which I wish to speak today has to do with position papers that have recently been developed and approved by the AIDSNET Council--and I'll say some more about that group in a minute--and also the Washington State Association of Local Public Health Officials at their most recent meeting on December the 4th.

The AIDSNET Council, as many of you are aware, is made up of the directors of the six regional AIDS Service Networks and the coordinators of those same networks. These are networks that were created in the 1988 Omnibus AIDS legislation passed by the Washington State Legislature.

Amazingly, it's been almost 17 years now since the AIDS epidemic was first recognized in this country in 1981, and it has been almost 10 years since the landmark 1988 Omnibus AIDS legislation was passed in this state. During that lengthy time period, obviously there have been changes that have occurred in many areas of this epidemic, both in our ability to recognize the course which the epidemic is taking, our ability to effectively do prevention, our ability to treat people who are infected with HIV infection.

We, on the AIDSNET Council, over the last several months, started looking at some of the changes that have taken place, and reevaluated our own position relative to some of the prevention and control measures that we believe needed a second look, given some of the changes that have occurred. There's been a large amount of research that has had some important conclusions in the last several years, and taking that into account, we are bringing to you today two position papers that we would like for you to consider. Both of these position papers relate to specific State Board of Health regulations that now exist.

Let me just read the first of the positions, and I believe you all have these in your packet. The first has to do with HIV infection as a reportable condition. The position of the AIDSNET Council, which has also become the position of the Washington State Association of Local Public Health Officials, is that there should be changes in regulations during 1998 that will require named HIV reporting by providers and laboratories in Washington State, while maintaining current laws and regulations which require access to anonymous testing in the public sector.

Let me give a little bit of information behind this position. In 1984, the State Board of Health approved named reporting of AIDS cases. I know that this Board is aware that there is approximately a 10-year lag period on average between the time when an individual becomes infected with HIV, and when they develop the condition known as AIDS, which is reportable in this state. HIV infection is not reportable in this state until such time as it becomes symptomatic, or AIDS develops.

That lag period has always been problematic in terms of trying to track the course of the epidemic here, because you're always really looking back at what happened 10 years ago, in terms of HIV infection. However, in the last several years, treatments have become available that have not only allowed us to much more effectively treat some of the opportunistic infections which occur as a result of HIV infection, but have also allowed us to treat much more effectively HIV infection itself.

I know that you have all seen much of the information that has come forward, particularly with regard to the protease inhibitors, but also with regard to some of the other new drugs in the reverse transcriptase inhibitor category that are also becoming available, and together in combination, the new drug treatments have been shown to be highly effective in preventing a large proportion of people with HIV infection from progressing to AIDS. They're also very effective in treating people with AIDS, and largely reversing many of the effects of HIV infection in many people.

This progress, which is very, very welcome, has then made it even more difficult for us to use AIDS reporting as an accurate indicator of the trend of the HIV epidemic in Washington State. Because there will be an even further delay before cases become reportable, it will be more than 10 years, on average, between the development of HIV infection and the development of a reportable condition as a result of that HIV infection, so we will have very poor knowledge of current trends in the epidemic in terms of not only the prevalence of HIV infection in our population, but also the population groups where that infection is most rapidly penetrating, and the behavioral risk which may be most strongly associated with current infection with HIV infection.

This is one of the reasons that we believe it is important to implement in Washington State HIV infection as a reportable condition. I might mention also that a majority of the states in the United States do now have HIV infection as a reportable condition. In addition, this has been recommended by the Centers for Disease Control as a change that should take place in all states in the United States.

Besides the need to be able to track the epidemic more closely, there's also a need to be able to identify people with HIV infection as early as possible in their infection so that they can be linked with the effective treatment now available, as soon as possible. This is importantly, obviously, for all people that are--that have HIV infection. It's particularly important for certain subgroups, such as young children and such as women who are in the

childbearing years.

Some of the other research that has become available in the last several years indicates that we have the ability now to prevent the great majority of transmission of HIV infection from infected pregnant women to their offspring. By instituting treatment during pregnancy, almost all the time that transmission can be prevented, so it is very important that women who are in the childbearing years know their HIV infection status and that this also be known to public health authorities so that they can try to work with providers to ensure that these women are identified early in pregnancy as women who need to be treated to prevent transmission to their offspring.

Some of the other research that has become available in the last several years relates to partner notification, and let me just read the second position statement that the AIDSNET Council is recommending for your consideration. That statement is that public health will work with HIV-infected persons to sensitively and appropriately identify sexual and needle-sharing partners and provider HIV counseling and testing and referral to care services. Barriers to provider reporting of HIV-infected persons and of partners of HIV-infected persons, in regulations, policies, or procedures, should be revised or eliminated.

Again, this specifically relates to some regulations that were passed actually when I was on the State Board of Health several years ago, having to do with partner notification. At the time that those regulations were initially passed, the knowledge that we had about the epidemic, the availability of treatment, and some of the social considerations surrounding the epidemic were quite different.

Things have changed considerably, and for some of the reasons that I gave to you today, we believe that it is time to take a careful look at those regulations and to make some modifications in them such that the barriers that now exist relative to partner notification occurring by professionally trained public health staff are removed. The current regulations when an HIV-infected person is identified by a private provider do not allow either that infected person's name or the names of the partners, be they needle-sharing or sexual partners, to be referred to public health authorities unless that infected person either refuses to notify those partners themselves, or indicates that they are unable to notify those partners themselves.

We would like to see that barrier removed so that not only is the HIV-infected person reported by name to the local public health authorities, but also if there are potential sexual or needle-sharing partners known, that those would also be referred, but then that public health would also assume the major responsibility for doing the identification of partners and for doing the notification of those partners.

Obviously, the goal here, again, is to maximize our knowledge about people that are HIV-infected again, so that we can know about that as early as possible in the course of the

infection, and that we can not only make sure that these people are aware of the treatments that are available, both for themselves--and in the case of childbearing women, to prevent infection of their infants--but also so that they can be aware of any behavioral changes that they need to adopt in order to minimize the chance of transmission to other persons.

Some of the other research that has come forward in the last several years is that it is now recognized that people that are in relatively early stages of HIV infection are often potentially the most infectious. They have the highest viral loads and therefore are capable of transmitting to others, whether through sexual intercourse or through needle-sharing, than are people later on in the course of infection. So again, it is very important to identify HIV-infected persons as early as possible, to get education to them to try to create behavioral changes that can interrupt the transmission cycle.

I know that there are certainly areas of controversy in these recommendations that the Board will obviously have to consider. Particularly, there's an area of controversy around the need for named reporting of HIV infection. People have suggested that instead of named reporting, we could look at using some sort of unique identifier reporting system that might accomplish many of the same objectives that we're trying to accomplish with named reporting.

Let me say at this time that we remain unconvinced that unique identifier reporting would, in fact, accomplish the objectives fully, or that they would accomplish them as efficiently as would named reporting. There are a couple of states in the United States that are trying to do unique identifier reporting, Texas and Maryland, and they've had mixed results with this, and considerable difficulties in trying to get this system to work for them. While I think that public health would certainly be interested in looking at recommendations in this area and in trying to evaluate whether it might be an alternative, again at this time we don't see it as really the best alternative.

One of the other reasons, which I've already indicated to you, is that we think it's important for public health to actually have the names of HIV-infected persons so that we can contact them with regard to ensuring their access to effective treatment, and also so that we can work with them in terms of identification of sexual and needle-sharing partners, and obviously we would not be able to do that with a unique identifier reporting system.

I think that is probably the primary area where there is concern, although there is some concern in a few other minor areas relative to the position statements that I bring to you today, but I think I'll stop at this point and see what kinds of questions you might have, and will try to discuss those with you.

Thank you.

Yes, Florence. How are you?

MS. REEVES: I'm confused about the federal law regarding any notification of people who had voluntary testing. We have recently had some departmental guidelines around, for example, in the occupational area, if someone is exposed otherwise, not being able to reveal the person's HIV status, if the person was voluntarily tested versus mandated through court or any other way. Are there any conflicts that you are aware of with giving names or notification of a person who were covered under those previous federal laws that protected them if they were voluntarily tested if their status was discovered as a result of voluntary testing?

DR. HINDS: Conflict with federal laws. Well, that's a good question. I am not aware that there would be. Again, in the majority of the states in the United States, there is HIV reporting, and most of that is named reporting. But that knowledge--I suspect that such a conflict does not exist.

MS. REEVES: I mean as it relates to partner notification, because we can't, for example, in prisons, notify an employee who may have had a bioexposure from an HIV inmate, if that inmate's HIV was discovered in voluntary testing.

DR. HINDS: Okay. Well, let me go back and talk about partner notification. Partner notification as conducted by public health officials never reveals the source of the potential exposure. I'm sorry, I should have made that clear. That has always been true for sexually-transmitted disease partner notification. We do not tell the person who has been potentially exposed the source of that potential exposure by name. Now sometimes it is obvious to them, because there may only be one person in their life that could have potentially been the source, and we might have to deal with that, but we do not divulge that information to them in the course of partner notification.

MS. REEVES: Okay.

DR. HINDS: It seems like there was--Oh, I did want to make the point, in case I didn't make it clearly enough, that along with our recommendation for HIV infection as a reportable condition, we are also recommending that anonymous testing sites still be maintained in local public health departments. We are concerned about eliminating anonymous testing sites as an option at this time. We believe that they do serve an important purpose in terms of making contact with people that may be at risk of infection and providing education to them, and we're concerned that elimination of those anonymous testing sites might prevent many people from seeking testing.

Let me also say that in Washington State, about 98 to 99 percent of people who seek testing at anonymous testing sites are not infected. So the great, great majority of these people are not going to be infected. There would only be a very, very small percentage that would be found to be infected.

MR. REID: But those sites are a good safety valve.

DR. HINDS: They are, we believe, for people who wish to find out their status, but are concerned about going to a place with the knowledge that if infected, they would be reported. The reality, we believe, is that if we identify people that are HIV-infected at an anonymous site, that we will counsel them and work with them to try to get them into care, and of course, at the point they enter care, then their anonymity would no longer apply. But that is our current thinking on that issue.

Are there other questions?

MR. REID: No other questions of Ward?

Tom.

DR. LOCKE: Well, you know, just some comments perhaps, and very much to echo Ward's excellent presentation. From the standpoint of local health officers, these are critically important strategies in what is essentially the next stage of trying to control the HIV epidemic, and I would emphasize for the Board that they're very much linked strategies. Named reporting and provider-assisted partner notification go hand in hand. One really won't work without the other.

And I underscore what Ward said about what we're learning about the HIV epidemic, and that is that the majority of cases seem to be transmitted in the very early stages of infection. There's really two intensely infectious periods of HIV disease: when you first get it, and then at the very late stages when your immune system has essentially collapsed. We have a lot of experience with that late stage AIDS management, but we're only now learning to deal with the very early infection, and with all other STDs, the only way we really find new cases is through partner notification.

It's still a fact in this country that most people who are HIV-infected don't know that they are HIV-infected, and worldwide that statistic is nine out of ten people who are HIV-infected don't know it. The only way they will know it is if someone tells them they were exposed and they get appropriately tested.

So I would just add the final point that from a local health standpoint, we're very sensitive to the issues of confidentiality and protection of confidentiality, and we feel we have an excellent track record in this state in maintaining confidentiality, and so I appreciate the concerns of those who feel that privacy rights may be affected by named reporting, but I assure them that we have set up systems and we're always trying to improve them to maintain that confidentiality, and work with people who are HIV-infected to achieve our mutual goals of optimal health care and prevention of new cases.

So I really appreciate Ward's presentation, the leadership that the AIDSNET has shown on these issues, and that of other groups. We have a letter included from WSMA, which has taken a very strong position on this, the CDC and other national groups likewise, so I think this is really an idea whose time has come, and I look forward to the Board's opportunity in the near future to deal with these regulatory changes.

MR. REID: In that regard, I would want to stress we are not in an action mode at this time.

The department doesn't have a position, do they, Bruce?

MR. MIYAHARA: We've started the rule process.

MR. REID: Right, and--but we are in an information-gathering, and we certainly appreciate what you've given us, Ward.

Just a minute, Carl.

There was a question from a member of the audience as to whether we would taking, quote, public testimony. We're not in an action mode, so we aren't taking public testimony, but I would advise the ACLU or anyone else that has a counter . . .

(End of side 1 of tape 2)

MR. REID: . . . make time available for a panel that might do that, but again, we're just in an early alert, early warning system.

Carl.

MR. OSAKI: You may have answered my question in a way, because I really wanted to know what the actual role of the Board was going to be on this particular matter. The reason I ask that question was because in a recent legislative health conference I heard a statement from a state legislator taking a position on this particular matter, and almost hinting that this was going to be a legislative issue, as opposed to a public health issue, which, if in fact, put into a different venue, might be a different way of looking at this issue. So I just wanted to make sure that I was clear as to what this Board was going to do in terms of this particular matter, and I think it's been answered for right now.

MR. REID: Well, saying that something is a reportable event is a power of the Board, but if the legislature wants to do something crazy, that's their power, and so they could take the power away from us. They could launch into this field any way they wanted to, and predicting what the legislature might do in the future is an extremely risky business.

MS. BECK: Along with that, I was wondering, Bruce, would you be comfortable at this time in maybe taking an estimate of some sort of a time frame of when the Board might possibly see something coming along, or from the department, or--

MR. MIYAHARA: Well, I think we're shooting for discussions about spring. That's one of the other comments I wanted to bring up. It's not as though this is an emergency and we need to rush. There are serious concerns in a variety of arenas about named reporting. As a matter of fact, I think the public health system has been as sensitive as they can be to this issue in that it hasn't been done earlier. It was originally on the table back when we were talking about AIDS reporting.

However, the balance has been the issue over time, and I think what is happening is now the balance of better care and better prevention is now on the table if this information is available, so there's some risk, you know, and concern--legitimate concern about confidentiality and other issues. But I think, because of technology, we have reached a point where, from a public health standpoint, not advocating this is a detriment to better prevention strategies and better care for individuals. So it's been a balancing act over the past 10 years, and I think what you're seeing now is best public health judgment that this is now time to talk about this issue. There is a balance there; no doubt about it. We will hear balance as we go through this discussion.

But I think what I want to make the Board aware of is it wasn't--we're not rushing into it, but we also have not dealt with it earlier. The time has come where, because of technology, we can improve the situation of care for individuals and the population.

MR. REID: Any other questions?

MS. BECK: I think Florence has a question.

MR. REID: Florence?

MS. REEVES: I think that you've done a terrific job in presenting this, and I think for some of the communities that have great fear about this, some simple explanations of the impact of better care might make them feel this is more valuable. Sometimes when we say things are better or important for that community, for those communities, better or important for whom becomes the question.

In this case, better care is for them, but if we don't define, for example, preventing drug resistive, appropriate triple level treatment, not getting--getting stuff out of your lymph system, reducing viral loads and how that really makes you healthier for them, they don't know what that better care means, and I think that there are people who can simplistically put out why it is we want it earlier, and what the impact of that is on their bodies and on their lives, and then it becomes a difference in how I choose to balance, and I think

particularly for them, it would be important so that they do realize, in fact, this is to their advantage, and this isn't better for the laboratory, better for the doctor, better for everybody other than me.

I would say your presentation is excellent, but in getting it out to the community, I would suggest that the better care be translated a little more at the patient level.

DR. HINDS: Good advice. Thank you. I appreciate that advice.

I also appreciate Tom's emphasis on the confidentiality issue. That is, of course, one of those that will be very important as we discuss this as well. There certainly is a certain level of distrust relative to government's ability to maintain confidentiality of files, of records with names on them, and I think it's going to be a very heavy responsibility on public health to ensure that confidentiality is maintained very strongly. I will say that we have had named reporting of AIDS cases since 1984 in this state, and I believe we have a very excellent record in terms of confidentiality with that information, but nevertheless, we also have a very large responsibility, and we recognize that.

Thank you. Thank you very much for your time.

MR. REID: Thank you, Ward.

DR. HINDS: It's good to see you again.

MR. REID: We thank you and your chairman of your board for the next item that we're going to be discussing.

DR. HINDS: I'll just hang around.

MR. REID: Well, you don't have to hang around. You can trust us.

DR. HINDS: Always.

MR. REID: And this is a followup on a letter of inquiry from John Nordquist, Chair of the Snohomish Health District Board of Health, and we have David Peterson and our old friend Bill White.

Bill, are you going to take the lead, or are you the followup?

MR. WHITE: Oh, I don't know. I'm just tickled to be here talking about something other than my usual topic that I'm--I'll take a quick lead and give you--just to describe the packet that we provided for you, and a couple of points in there, and then maybe David and I can respond to any questions you may have.

MR. SHEEHAN: Good afternoon, Mister Chairman, ladies and gentlemen of the Board.

Mister Chairman, you should have let me speak this morning, because I went back to my office and generated some paper for you, otherwise.

[Laughter]

MR. REID: Killed another tree.

MR. SHEEHAN: Exactly so!

But seriously, I do appreciate the opportunity to speak to you on this very important issue, and that is the question of name reporting, and various discussions of the State moving to such a rule that are underway presently.

The American Civil Liberties Union strongly opposes the idea of government creating lists of persons infected with the HIV virus, for all of the reasons why the State of Washington chose not to do so long ago. And this is the questions of discrimination and social opprobrium that were attached to the issue of HIV/AIDS which still exists.

We have a produced a report that I will share with each of you, that discusses the interplay between the issue of name reporting, and civil liberties. And the report discusses the studies which have looked in other states where name reporting has been substituted for by a unique identifier system, but even more appropriately--for our discussion here--those states which were studied which have name reporting and the issues where HIV testing rates have gone down in the face--apparently--of name reporting being the system in a particular state.

That's the public health reason why we strongly urge that there not be name reporting in our state. The public--the civil liberties answer also is again that the opprobrium of this disease is still present with us. The discrimination surrounding this disease is still with us. Particularly in our populations of non-white citizens. And in fact, the case law is going in a bad direction with respect to the attempt to make HIV disease be protected under the Americans With Disabilities Act. In the report you will see our discussion of how the assertion that we are protected in our society, persons with HIV are protected under the disability law, is in fact, not strongly the case. And in fact, as I said, the case law is going in the opposite direction, unfortunately.

This morning you heard some assertion that one of the rationales why name reporting should be begun, is that there is--we are at a new threshold of drug treatment of HIV disease. That is true and not true, in my view. First off, it is not true in that the reports that I am reading are now saying, unfortunately--and unfortunately they are saying--that the

euphoria about the efficacy of drug treatment that had been before us earlier this year and in the previous year, may not be so much the case--again, unfortunately. And also, the fact, remains the case, that we--our society--which does not provide those services anyway, by and large.

By that I mean, how many among us can, in fact, afford a 10,000 or 12,000, or 15,000 dollar whatever it is now, cost per year, for HIV treatment drugs, that may or may not be terribly useful. I certainly know that if I were HIV positive, I would not be able to afford such a course of treatment. So it may be the case that science and pharmacology is turning the corner--I sure hope so--that is a chimera in terms of any kind of answer why name reporting is something to be moved to.

We did not adopt a confidential system of HIV testing in the past because there was a dearth of treatment, pharmacologically. And so to say today that there may be a--may be hope--pharmacologically about this disease, is not an answer or a rationale that makes any sense to begin name reporting. The reason we did not adopt name reporting a number of years of ago was because, as I said, of the discrimination and social opprobrium that attaches, unfortunately, to this matter, and still does.

It was asserted this morning that a majority of the states do name reporting. And that is true. That is also misleading. The majority of states is 27. A bare majority, but far more important, is that those 27 states represent only 24% of reported AIDS cases. And I might say, that the majority of those states that do name report, are basically places that I would not wish the State of Washington to emulate in terms of their social policy. In the packet I will leave with you, I will leave you the list of states that do not have a name reporting rule, and they are the states that I think that we in the State of Washington should continue to ally ourselves with, with respect to doing things other than name reporting.

They are the states of California, of New York, of Illinois, of Michigan. And the places that do name reporting which encompass only 24% of AIDS cases, as I say, are the Alabamas, the Mississippis, the Louisianas, the Texases. Those are not where I think the social policy of Washington should look for emulation in this very divisive issue.

I attended the last GACHA meeting--the Governor's Advisory Council on HIV/AIDS, and it was clear to me as an observer, that GACHA is deeply divided on this question. You have the public health professionals strongly pushing for it, and you have the HIV/AIDS service providers and persons with HIV disease, strongly opposing it. It is my personal belief that GACHA will not recommend to the Governor that name reporting be the changed rule for the State of Washington.

Basically, I will leave you, as I said, the report. Plus a range of other material that I hope you look at. Editorials opposing name reporting that range from the *Seattle Gay News* to the *New York Times*. Articles that have been in the Washington press about the issue,

which makes it abundantly clear that it will be an incredibly divisive issue, should bodies such as the Health Department, or the Board of Health, or GACHA, or others move our state to the area of names reporting. And I sure hope they do not.

It may be something that does erupt in the legislature. I've been the lobbyist for the ACLU for 15 years and I've seen a lot that happens in the legislature, and I'm quite cognizant of the changed political rules, if you will, in the legislature and it may very well be, as Mr. Reid earlier mentioned this morning, that they do some wild and crazy stuff down there. I would fully expect that the forces of darkness, as I call them, will try to run with something on this issue, and they will be opposed by us very strongly. By the Northwest AIDS Foundation, which opposes name reporting. And anyone else who really wishes to do the best by public health and civil liberties, as opposed to some narrower view, some statistical view of the need for data.

Finally, I guess I would wonder whether in fact at the highest levels of government, the CDC, whether they may not in fact, be rethinking the question. Certainly the push for name reporting over the past year has emanated from the Centers for Disease Control, but in my discussions recently with my organization's national and congressional lobbyists, there is the emergence, perhaps, in the administration of concern about the somewhat low-level but perhaps emerging firestorm on this question that may be erupting politically, such that the administration may be not terribly interested in seeing this thing go forth from the CDC levels.

I have yet to see that documented, and I certainly hope that is the case, but that's the latest glimmer from within the beltway that I am understanding.

Thank you very much.

MR. REID: As you know, the democratic system is a little bit risky.

MR. SHEEHAN: But it's the best we have.

MR. REID: Yeah, yeah. And who was it that said something about liberty is--the price of it, is eternal vigilance.

MR. SHEEHAN: That's correct.

Thank you very much, and I'll leave--

MR. REID: Any questions for Jerry?

MS. REEVES: I've got two. I'm concerned about maybe what the covering opinion is, since name reporting is done at disease level. I don't quite understand the difference in

the value in the population. Is for a fact, that most people get to the AIDS disease level they're less concerned about it? I mean if at this point we have HIV, I mean, AIDS as a disease, is reported, and it seems to be working well, and people in Washington are accepting it, and confidentiality issues seem to be pretty subliminal, we have very little in the media or whatever, about breaches, I don't understand the difference in that, and reporting it at the onset of identification.

MR. SHEEHAN: Sure. And let me address that.

I won't address it as well as I could if I still had the packets with me, because I don't have a copy of our report. But our report does ask that--at the back of our report you'll see the logical questions to ask of which this is one, are asked, and answered. The answer, as I'm recalling it, is that first off, name reporting does not create treatment. And so to believe, necessarily, that because name reporting might come into existence, that will necessarily hook one into treatment, is misplaced.

And in fact, as I say, the studies from other states do seem to indicate that moving to a system of name reporting deters people from going in for testing. And so that, at least, is a very important decision--er--distinction. If name reporting does deter people from going in for testing, then you're defeating the whole purpose of wanting to get more people tested, or more people hooked into the health care delivery system, if they can afford it, even.

So if name reporting is creating a deferent to getting tested, that's a prime reason not to do name reporting, and as I say, a distinction between HIV versus the disease, which is, yes, a reportable fact. When you have the disease, you are--and your name is being reported because of that--by definition you are hooked into treatment, hopefully. Or at least certainly counseling, things of that sort.

MS. REEVES: My second question dovetails on that one. Given is Washington, is it a protection or it seems to me would be, if we continue anonymous testing for those people who plan not to come, because they don't want their names known, that part being highly marketed, would it not answer the situation you just named, and that is, people have no reason then, to be deterred from being tested, because they have the choice. They can be openly tested and their name reported, or they could be anonymously tested anyway.

MR. SHEEHAN: Sure. I guess in the face of that, I would stumble for--I would search for--why one would be wanting to do name reporting. Or one why one would chose one over the other--I mean, I would have to see a study that examines that kind of a scenario, but I would be searching for a reason why would someone would go to a testing place, knowing that it is a name reporting place, versus deciding to go to an anonymous testing locale.

If I am understanding your question, you're saying, if we have both. Name reporting

under some testing locale, and anonymous testing under another available testing locale, I would be searching for the reason why very many persons wishing to be tested would go to the one where they knew the government would be taking a list of their names.

MS. REEVES: I guess because I've been a service provider and I've watched the patients. And some could give--could care less--who knows. And a huge number could care less. I've seen a small majority who really cares who knows, then those who don't.

MR. SHEEHAN: Okay.

Sure.

I would like also to speak to one of the points that raised from a Board member this morning, if I'm recollecting correctly, and I think it was basically that we same to be doing a good job in terms of keeping confidentiality of names under the whole--whatever the current range of testing schemes available in Washington presently.

It's my understanding that the breaches of confidentiality have stemmed from a private physician context of HIV testing. I'll accept that for what it is worth. I will also tell you that a month ago I received a telephone call from a person who was outraged that their name was divulged to a third party who had no reason to have it, by a public health person in a western Washington public health district, and as I say, that is simply human nature. It can happen. And the discussion I had with this person seemed very credible to me, and I certainly could discuss with them contacting with you, if any of you have the desire to explore that particular alleged scenario.

DR. LOCKE: I would--to the extent that occurred--it is a criminal offense, and should be prosecuted.

I had a question in terms of the--we heard the AIDSNET policy presentation this morning. Does the ACLU have a position at that point on the other recommendation they made in terms of provider--

MR. SHEEHAN: Ah-ah--absolutely. Absolutely. And in fact the report is basically a discussion of name reporting versus unique identifier and looking at the studies that have studied unique identifier systems in other states.

DR. LOCKE: But specifically on the issue of partner notification. Once HIV diagnosed, whether through anonymous or some kind of named reporting, does the ACLU have concerns on how partners are notified.

MR. SHEEHAN: We do have concerns, under some systems of partner notification. And we do not view unique identifier system as being something that gets in the way of

appropriate partner notification. Post-test counseling is the appropriate place where discussions of partner notification do arise, and should arise. We believe that persons should be given as much useful and credible information about the desirability of partner notification and having partners be notified to come in for testing, etcetera, etcetera. So we have no position in opposition to partner notification, done under reasonable procedures. And that, as I say, is discussed in the report also.

MS. REEVES: I didn't hear, and don't know, what the down-sides that were considered of unique identifier program were, but I'd like to ask you if you have recommendations to us or someone else, about how to overcome the downsides that's been observed in other states for unique identifier programs.

MR. SHEEHAN: Visa Solomon, Maryland. Two states--Texas and Maryland--it was mentioned this morning, are the states that are doing unique identifier. It was said that there are difficulties viewed in those systems. I think that was not a correct representation of the case. In the latest issue of *AIDS Policy and Law*, from October 31, there is a discussion by the health officials of Maryland and of Texas, with respect to what difficulties are they encountering with unique identifier systems.

Maryland says, sure we're having some difficulties. We're getting around the difficulties, and we intend to stick with unique identifier. In Texas they are saying we are having some difficulties getting all the digits on the right place that someone is supposed to do, and as I read this report, it is basically saying human beings are failing to do their job to make unique identifier coded systems work. It's not saying that there is a logical flaw in unique identifier systems. And in fact, the comparative data between Maryland and Texas with respect to how many of the digits are getting filled out or not, was quite dramatic. Texas was doing a lousy job doing X, and Maryland was doing a fairly much more decent job, doing the same X, though there was some need for improvement.

And so that tells me that there's a problem of the different places doing the same task, more or less diligently, more or less, oh, I don't know what the word would be.

MS. REEVES: It was a training problem--

MR. SHEEHAN: Exactly. Exactly so.

This report does not say that there is again, a problem in the system, not being able to work. People need to make it work.

MR. REID: Thank you, Jerry.

MR. SHEEHAN: Thank you very much.

MR. REID: Kelly Scott?

MR. SCOTT: Hello. I was champing at the bit on the very same issue back there.

MR. REID: GACHA?

MR. SCOTT: Oh yeah. I'm a member of the Governor's Advisory Counsel on HIV AIDS. I'm a member of the task force studying this question. And that task force has been meeting for about the last six months. The time table is that it offer a, oh, fairly polished, pretty draft, but fairly polished report to the full council in mid-January. The plans of the task force at this point--let me be clear, I'm not speaking on behalf of GACHA today. I'm not speaking on behalf of the task force today. I will report to you the timeline that it's going through.

The task force intends to take no position in its paper, in its full report to GACHA. Instead, covering the best thinking in favor of names reporting--that will be written in draft, by the AIDS Control Officer of Seattle-King County, Bob Wood, along with several other members of the task force. It will also present the best thinking and most persuasive arguments for encrypted identifiers. That's actually being written in draft by me, and Northwest AIDS Foundation, in conjunction with others. So it's our intention to offer the Governor the best advice behind all the issues, so that he can choose, if necessary, by virtue of whatever the legislature may do.

And in fact, we continue to--or intend to continue--to polish the document to provide it as a source document for you in your spring decisions.

I'm also a member of the state-wide Prevention-Planning Group, which looks at issues and actually decides how to prioritize interventions for how to prevent the spread of AIDS. What do we spend our money on to best prevent its spread. And I wanted to respond to some of your questions, and also detail some things that again, were not mentioned this morning.

AIDS Action, which is a lobbying arm of 2,000 community based organizations in AIDS prevention and care in Washington, D.C., has taken a position against names reporting. The State of Connecticut has recently decided not to go forward with names reporting. The State of Hawaii has sent a delegation to the CDC requesting that they not take a position for names reporting. The National Association of People With AIDS has taken a position against names reporting. The ACLU. The Positive Voice Committee of the Seattle-King County Title One Planning Council. The People With AIDS of Oregon. In other words, there is a great body of opinion that says yes, we do need to track the disease at the case level, but no, this is not the way to go.

And in the six months of study the GACHA task force has done, several issues have

come forward, that again, were not mentioned today. And I'll try and weave in some answers to your questions also.

And I'll mention three arguments. One, it's been noted that public health has a very good record as far as confidentiality of HIV information, and this is true. In fact, if I were to be worried about my information, I'd be far more worried about the private systems. But the issue of misuse of data by government, is one that is very much on the minds of people with HIV. And it is not an irrational fear, it's a very well-grounded fear.

In one state, it is law, that if a child attends a public school and he or she has HIV, they must notify that school principal. And yet we know that policy makes no rational public health sense. In one state they attempted to match the list of people with HIV with the list of health care licenses, and yet we know there is no scientific basis in most instances, for inferring a significant risk by a person with HIV as a health care provider. In other words, somewhat as you pointed out Feather, boy you really can't tell what they're liable to do with some information down there, and this is still an extremely charged issue.

So it's not a lack of faith in public health. And in fact, it's not a suspicion--in most cases--of just what they're going to do. It's more that we think the legislature does indeed represent the public, in many ways, and the public is not at peace with this issue. So the issue of misuse of data. How will this be used? Will it be used against adoptions? Will it be used against marriages? Will it be used against health care professionals?

Indeed, in the last session of the legislature, the AIDSNET Council and the Department of Health in conjunction, favored a piece of legislation vetoed by the Governor, that would have mandated turning over HIV information in their hands, given any well-founded suspicion that person was behaving in a risky fashion. Now that's shorthand for what the law involved. But that was promulgated by public health and law enforcement. That was vetoed by the Governor last session.

I've been working on these issues since 1991, and in every single session of the legislature, again with reference to the dark forces, there has been some law which may make no public health sense, may make no scientific sense, but it is extremely popular and very difficult to stop. The Brugalis Scare of 1991. Wherein it was thought--*it was thought*--that a dentist had transmitted to a patient. And again there were laws that said no HIV infected dentist can practice. The concept of universal precautions is not well understood by the public, to say the least.

You asked, what is the difference between names reporting of AIDS cases and names reporting of HIV. If there's no difficulty, or there's not all this hullabaloo with AIDS, why would there be with HIV. I was diagnosed with AIDS, two and a half years ago. At that time my life expectancy--I should be dead in June of this next year. A person with HIV, given new technology, can however, live 10 to 15 years, during which time they will be

working, they will be getting married, and so forth.

So the concern is for their great deal of their productive lifetime, their name will be on a list, a very stigmatized list, and who knows what could happen that list under public policy.

You also asked anonymous testing--would this not solve the problem. Would then not this still continue to bring people forward? In a CDC sponsored survey, 20% of those responding said they would have significant problems and may not have tested, if they thought their name would be reported. And I must tell you, in the six public hearings that the Names Reporting Task Force held around the state, the public doesn't really distinguish between anonymous testing, and having their name reported, only when the seek care. And in fact, those who really understood that concept said, you mean, I can go forward and get anonymous testing, but if I'm positive, and when I go to a doctor, bango, then I'm reported. They thought that was a little bit of a non-starter, and not really fair.

There has also been stated to be a great link between partner notification and name reporting. Now partner notification is an extremely effective means by which to target prevention. You already know these folks have some degree of risk, you very much want to tell them they have some degree of risk. Usually partner notification does not happen in the time period during which they are most infectious. It simply does not happen anywhere around the primary infection of the source case. Therefore, you are unable to reach that time period that you referred to when you would most like to reach.

You would, however, if you had names reporting instead of anonymous testing. You don't want to catch people when they seek care in order to get into that time period for partner notification. You want to do it at the level of testing. And yet, if you do that, we already know many, many, many folks will not want to be tested, and that blows the whole ball game.

Further, and it's a reality that we face on the Statewide Prevention Council, and GACHA realizes, there is no new money. There won't be any more new money for care, very likely not, there is no anticipated money at the federal level, not much. There is certainly not any anticipated money for the APDP Program at the state level.

At the same state-wide conference that you note you heard legislators talking, Senator Deccio pointed out, that this is not a state problem, he's kicking it back to the feds. No more money for these AIDS drugs. Right now, there's enough money nationally, to handle 25% of the people with HIV. So to use as an argument, Oh, Gee, if we have your name we can get to you and make sure you're hooked up to care, when we already know that we can only do that for 25% of you, ooh, that's not going to produce good results when you reach out and tell them that it's an illusionary argument.

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Further, research that the Names Reporting Task Force has come on, versus partner notification is, that you get just as many names from people testing anonymously, just as many names of their contacts, as you do if you get the name of the people you're testing, or who is seeking care. In other words, it's still voluntary. That person still has to tell the name of his contact. And given that there's no more new money, any additional loops, any additional desire by public health to reach out and contact people, will take money. Where do you get it? You could get it from gutting all of the community-based prevention programs. You could get it from stopping all the other interventions, which we know work. And putting it into partner notification, and indeed, you may want to.

But that decision is not by the State Board of Health. That decision is by the state-wide Prevention Planning Group, the Community Planning Groups, all the apparatus of AIDS prevention. It is a largely separate decision from names reporting.

So what I would like to offer you, and oh by Golly, you gave me time, so I'll produce a favor for you too, and I'll just leave it behind. It's a letter from AIDS Action Council to the Centers for Disease Control, encapsulating some of these arguments, but I would ask that possibly you may want a half-hour informational session prior to your actual rule-making, where perhaps Jerry, I, maybe a rural person, maybe some people of color, could respond to your questions, or present other arguments.

There is largely--again I state--a consensus that we need better case reporting, but very much a difference of opinion regarding either going with encrypted identifiers, or names. I've been in contact with folks around the country. The article that Jerry referenced in *AIDS Policy and the Law*, I think I was quoted in. It's either November or October. But one of the leading advocates of Eis, AIDS case reporting is the gold standard. We've done it for years, we have high reporting, it's good. No one's put any money into encrypted identifiers. They haven't had to, yet. So to compare the reporting rates is somewhat--

[Tape off]

[End tape 7, side 1]

[Tape 7, side 2]

[Tape on]

MR. SCOTT: --So again, I'll give you note suggesting, by golly, we'd like a half an hour too. And it might be worth your time.

MR. REID: We have one other person. Karen McDonell.

MS. MCDONELL: I've gotta dance with these guys for a minute.

Name: Ed GRAY

FOR ACTION
Agenda Planning

Priority Goal #2: Reduce the Incidence and Preventable Consequences of Infectious Disease

Members have expressed interest in receiving additional information in preparation for future decisionmaking regarding HIV surveillance in Washington State. In the space provided below, please list specific questions you want answered; statistics you desire; articles, reports, and the like; issues you want covered; and names of specific speakers from which you would like to hear. (You have done this in the past in preparation for similar presentations, so are familiar with how this works.) Please FAX (360 586-6033) or mail in your response to us as soon as possible. Thank you for your input in shaping these upcoming dialogues.

① Information on current RCW/WAC regarding reporting of all infectious disease
② Legal opinion (not medical) as to HIV positivity as a disease.

Other:

Dwight Bushu, A.R.N.P., Washington State Nurses Association (WSNA) Vice President and psychiatric nurse practitioner with Behavioral Health Resources, Olympia, explained he was appearing on behalf of President Jan Bussert. He noted that the Priority Health Goals outlined in the draft *1998 WSPHR* overlap those established by WSNA in its 1998 legislative platform. WSNA actively supports the need for good prenatal care and smoking and alcohol use cessation during pregnancy. WSNA is active in the Immunization Action Coalition. Nurses play an important role in both treatment and prevention, working directly with the public on issues such as good handwashing practices. Mr. Bushu noted nurses have higher injury and illness rates than construction workers. These are often caused by latex allergy and poor indoor air quality. WSNA also supports nuclear disarmament and other activities that promote peace. Reducing use of tobacco and alcohol helps prevent many chronic diseases. WSNA supported legislation 2 years ago to classify assault on health care personnel as a Class C felony, as well as another bill which would have required health care facilities to have violence prevention plans in place. WSNA is well-known for lobbying efforts on the issue of access to health care, funding for basic health needs, and fully financing a rational health care system.

Ms. Barnard complimented WSNA for their work in helping to avert a nurses strike in Spokane. Sylvia Beck, Board Executive Director, thanked WSNA on behalf of the Board for their help in preparing the *1998 WSPHR*. She appreciated Mr. Bushu's comments on handwashing, since that was a major focus of the Board's NPHW activities. Responding to Carl Osaki, R.S., M.S.P.H., Mr. Bushu agreed greater attention should be paid to encouraging nurse awareness of environmental factors that impact disease outcomes. There is need for continuing education, especially as nurses are often focused only on their specialty areas. A holistic approach to nursing care is needed. There are opportunities to disseminate information. Responding to Ms. Beck, Mr. Bushu said WSNA's newsletter would be happy to accept articles on the subject. Mr. Reid thanked Mayor Sutton and Mr. Bushu for their warm welcomes.

APPROVAL OF AGENDA

ACTION: Approval of Agenda. Motion/Second: Pageler/Reid. Carried unanimously.

ADOPTION OF MARCH 11, 1998 MINUTES

ACTION: Approval of March 11, 1998 Minutes. Motion/Second: Corkrum/Locke. Carried unanimously.

FOLLOWUP ON INFORMATION ON HIV/AIDS REPORTING (REFERENCE 12/97)

Thomas Locke, M.D., M.P.H., introduced today's followup indicating that the state AIDS Omnibus Bill was passed in 1988. Shortly thereafter, the Board wrote rules to implement the legislation. 10 years later, the Board is beginning the process of considering how to revise not only the HIV/AIDS surveillance systems, but all communicable disease WACs. There has been a paradigm shift in approaches in HIV infection and a knowledge explosion. It is now known that HIV virus replicates very early in the disease course, and there is steady immune system destruction. There is reason to believe perhaps a majority of HIV cases are transmitted in the early stages of infection. There are new therapies that may have great impact on the risk of transmission. From a public health perspective, each new case is a failure of prevention efforts. This is public health's primary mission.

There is broad consensus that the surveillance system needs revision, as what we now have is an incomplete picture of the disease. Controversy arises from how the system should be revised, which the Board will need to grapple with in months ahead. Today the Board is functioning as a forum for public health policy development, listening to all sides of an issue. Many common goals are shared among those working to prevent HIV spread, even if there are passionate disagreements about reporting methods. He urged all participants to listen well to each other. Mr. Reid emphasized that the Board needs to continue to educate itself on these matters so that it will be prepared to act later in the year.

Kelly Scott, Governor's Advisory Council on HIV/AIDS (GACHA) member, said he was appearing today as a citizen and not as a GACHA member. He introduced today's panel members and thanked the Board for the opportunity to dialogue. He stressed importance of the issue of HIV reporting for people with HIV and AIDS around the state. The issue must be approached in a rational fashion. What is critical is preventing virus spread. Assessing the impact of HIV and its spread is important to prevention.

HIV is an extremely stigmatized disease, which is why it needs to be treated differently. Having people with HIV come forward for testing and treatment can save lives. Burdens should not be placed in the way of people doing so. This is why privacy of medical records is important for the public health purpose of preventing HIV spread. The issue is not only how a surveillance system can be designed to least burden individuals in finding out their seroprevalence status. There is a larger ethical issue of how much and how necessary it is to burden people in getting the care that keeps them alive. Even if we advocate people coming forward for testing regardless of the surveillance system, we must ask whether they should be placed at risk of the uncertain actions of policymakers.

Lupé Lopez, People of Color Against AIDS Network (POCAAN) Executive Director and member and Treasurer, Board of Directors, National Minority AIDS Coalition (NMAC), said POCAAN is a statewide prevention and education agency focused on communities of color. Both POCAAN and NMAC have policy statements on the reporting issue. There is critical need to develop a national HIV surveillance system to: improve monitoring of recent trends; provide essential data to target and evaluate prevention services; and guide decisionmaking in funding allocation. However, HIV name reporting is not necessary to accomplish these goals. Use of name reporting will pose significant social risk for people of color, including women, immigrants, gay men, substance users, and young people. Name reporting will hinder, rather than promote, important public health goals by deterring individuals from seeking HIV testing in the 1st place.

Ms. Lopez said that when she asked people who do not think they are at risk for HIV if they would get tested, knowing their names would be given to the local health department/district, the answer is always no. Perception is 99% of the way people act. In communities of color, the perception is that if names are given, they will be accessed by other systems, including criminal justice, immigration, insurance, and employment. Ms. Lopez said people are generally happy with the effective AIDS surveillance system using names. But HIV is a long-running disease, and there may be lag between knowing one's status and accessing treatment.

Ms. Lopez said Washington has access to technology necessary to make a unique identifier system (UI) work. She fears name reporting will set back work done in rural communities, with women, and young people where there is not good surveillance now. An argument used to support name reporting is that it would be become easier to access services. When POCAAN discussed this, the consensus was that access was not even an issue. It takes about 4 times longer for a person of color to access services. Name reporting will not increase that access. There is need to convey the message that people should be tested. This will require behavioral change. People will be less likely to be tested if they are fearful of where the information is going.

Michael Adams, American Civil Liberties Union (ACLU) National HIV/AIDS Project Staff Attorney, New York, noted that while states have conducted AIDS case reporting since the epidemic's beginning, until recently there has been no systematic effort to press states to adopt HIV surveillance. There are several reasons for this. Historically there has been strong fear that HIV case reporting would deter people from being tested. Reason for this deterrence is the strong stigma associated with AIDS. Having HIV positive status might be viewed as a mark for a person being gay or an IV drug user. It was also thought AIDS surveillance was sufficient along with other tools to understand the epidemic. Finally, it was believed that resources would be better spent on prevention and care.

Recently, public health officials and the federal Centers for Disease Control and

Prevention (CDC) have placed new emphasis on HIV surveillance, advocating name reporting. Reasons given for need for HIV surveillance include: emergence of promising medical treatments which can extend time between HIV infection and AIDS diagnosis; inadequacy of AIDS surveillance in providing information about disease trends; need to better target funding, prevention, and service efforts. The public is being told it need not be as concerned about deterring people from being tested because of strong legal protections guaranteeing confidentiality and protecting people from discrimination.

Mr. Adams suggested there are problems with this analysis. Most people who test positive for HIV are 1st tested years after they have been infected. Reporting positive test results will not give a very accurate picture of where HIV is now. Sound data has never been very effective influencing public policy related to HIV/AIDS. This can be shown by refusal to support frank AIDS education among adolescents or needle exchange programs, even though demonstrated to be effective.

Nonetheless, ACLU recognizes that HIV case reporting may provide helpful epidemiological data. That data may be put to good use. Federal funding may eventually be tied to HIV case numbers, though not currently the case. But ACLU adamantly opposes name reporting for 2 basic reasons: 1) it is a fatally flawed and will drive substantial numbers of people away from the public health system; 2) there is a better alternative (UI) which does not carry the same risk.

Mr. Adams reiterated that the goal of HIV surveillance is get as accurate a picture as possible of the epidemic by analyzing new infectious and collecting demographic and risk data. It is not about accessing health care systems. Surveillance systems have never been able to provide people with health care access. It is not about conducting partner notification.

On its face, it does not appear that names of each new person infected are needed to count HIV cases and gather demographic and risk data. Yet, some public health officials believe name reporting is the only efficient way to conduct surveillance. Name reporting is familiar to them, as it is used for other STDs and communicable diseases. However, the "1-size-fits-all" approach is not appropriate in the HIV/AIDS context.

Mr. Adams referred to a report in the Board Reading Packet summarizing scientific studies demonstrating name reporting will deter large numbers of people from being tested for HIV. This is because individuals fear their privacy will not be protected. In a recent University of California at San Francisco study, 19% of respondents said fear of name reporting was 1 of the reasons they had not been tested. Fear of name reporting was especially strong among groups most at risk for HIV, i.e. gay men, people of color, IV drug users. Driving people away from the public health system will reduce their chances of surviving the epidemic and will also distort epidemiological data.

Supporters of name reporting provide 3 responses to this problem: confidentiality protections; anti-discrimination laws to blunt effects of confidentiality breaches; and anonymous testing. Mr. Adams said these solutions are insufficient. Many people needing testing simply do not believe confidentiality will be maintained regardless of laws and promises. Populations most at risk for HIV are often skeptical of government and do not believe confidentiality protections will be respected. There is some basis for this belief as there have been well-publicized breaches of confidentiality. More important is public perception which is based on people's experience with government agencies and what they learn through the media. History shows promises made about confidentiality today can be broken tomorrow, especially when legislators are looking for politically expedient solutions to problems. He cited an example from Illinois which had an AIDS registry with state-of-the-art confidentiality protections. After a scare about a person exposed to a health care worker's HIV, the legislator passed a law to cross-check the AIDS registry against the registry of licensed health care workers. Then patients who had been treated by these individuals would be tracked down and advised that they might have been exposed.

Mr. Adams suggested anti-discrimination laws might not protect people in the event of confidentiality breaches. There has been a recent round of federal court decisions saying federal civil rights protections for people with disabilities do not protect people with HIV unless they are sick. If they are asymptomatic, there is no legal protection. This issue is currently before the U.S. Supreme Court.

Mr. Adams noted there are no guarantees that anonymous testing will be continued after name reporting is required, despite the best intention of public officials. 10 states with name reporting have subsequently eliminated anonymous testing. There is logic to this change. If the purpose of HIV surveillance is to report cases, and a state has chosen to do so by name, why maintain a testing system which does not allow for name-based reporting? New Jersey has name reporting, but also anonymous testing. 45% of those who test in New Jersey do so anonymously. This suggests that people are concerned about name reporting and calls into question accuracy of New Jersey's surveillance data. A recent study indicates that New Jersey's surveillance data are not very accurate. Even in states where anonymous testing remains, it has often been severely cut back.

ACLU and AIDS advocacy groups have been encouraging states to reject name reporting. As states examine the questions more closely, they are recognizing the potentially grave consequences of name reporting. Hawaii and Massachusetts have recently rejected name reporting proposals and opted for UIs. They are working with Maryland to implement UI based on their own requirements. A working group convened by New York's Governor just completed the nation's most indepth analysis of the question. After testimony from CDC, public health officials, community representatives, and AIDS directors from around the U.S., and reviewing the evidence, the work group rejected name reporting and recommended UI. Such a system is a formidable challenge in New York given the large case numbers. Mr. Adams suggested that if such a system can be out together in New York, it certainly can in Washington.

Mr. Adams was surprised to hear arguments before the Board previously linking name reporting to effective partner notification. On this issue ACLU completely agrees with CDC that it is completely inappropriate to link the 2. If linked, confidentiality protections are inevitably reduced. Name reporting is not necessary to conduct partner notification, as the name of the person with HIV is not used when notification occurs. Studies demonstrate that states with name reporting do not have a better partner notification system than states which do not. Mr. Adams encouraged the Board to conduct an indepth analysis before considering a name reporting system.

Mr. Scott noted that GACHA set up a taskforce to consider this question, and its report gave the best arguments for both systems. It held 5 forums around the state with a cross section of opinion. The full Council voted 14-4 in favor of a UI system. Mr. Scott encouraged the Board to review the GACHA report and recommendation.

Mr. Scott emphasized he has confidence in public health officials' assurance of confidentiality, anonymity, and good faith. However, since 1991, the Legislature repeatedly had bills proposed to restrict the practice of health care workers with HIV based on no scientific evidence. Legislators respond to the public's mood, and it is through them that confidentiality could become compromised. The fear is that there will be authorized, rather than unauthorized, confidentiality breaches.

Liza Solomon, Ph.D., AIDS Administration Director, Maryland Department of Health (MDOH), said her Administration deals with all aspects of HIV services, including surveillance, prevention, and Ryan White Care Act programs. Maryland implemented UI in 1994, so MDOH is familiar with what it is like to implement such a system.

Maryland has the 5th highest HIV prevalence. 17,000 AIDS cases have been reported to date, significantly more than Washington. Discussions occurred for many years within the legislature, public health, and advocacy community regarding how to move forward on HIV surveillance, for reasons cited by previous speakers. Every year between 1988-1992, a names reporting bill was introduced in the legislature

and defeated. In 1992, the public health community compromised, and legislation to create UI was enacted.

The goals of Maryland's UI system are the same as for any epidemiological system. The importance of UI is in collecting data to target programs. Data not resulting in policy change are meaningless. Data would affect decisions regarding targeted prevention programs and populations.

MDOH wanted to develop a simple system in which providers have the responsibility to create a UI number. Labs are required to report. The UI number is a 12-digit code consisting of the last 4 digits of the Social Security number (which are randomly assigned), 6 digits for birthdate, 1 digit for race/ethnicity, and 1 for gender. These last 2 make use of CDC codes. Exceptions are made to ensure individuals learn their status. Anonymous test sites are exempted from reporting, which MDOH felt to be very important. Sooner or later people will become part of the health system anyway to access care. At that point a report will be made.

All HIV positive tests and CD4 counts less than 200 are reportable. Reports are compared to the AIDS database. UIs were put on the entire AIDS database, so that numbers and types of individuals who have HIV but AIDS can be identified. A registry of unique HIV positive individuals is created. Data is analyzed by age, ethnicity, and zip code where the person was tested.

MDOH has spent much time and energy evaluating and refining their system. When Maryland's system was created, MDOH received no CDC technical assistance or funding. A study showed that in a AIDS database of 16,000 unique individuals, it was found that an error of a single digit would still provide over 99.8% uniqueness. In the field, MDOH examined all UIs from a single county which appeared more than once. In this county there were 97 UIs with more than 200 visits. By working with the local health department, it was found that when individuals went for more than 1 test, in every case they received the same UI. So the system was able to find uniqueness at least within a single health jurisdiction. 12 UIs appeared cross-jurisdictionally. By checking the records, in every case, those UIs showing more than 1 visit matched. There is confidence that the system is capable of correctly informing MDOH whether 1 individual was tested 3 times, as opposed to 3 individuals and 1 test. Work is being done to evaluate effects of incomplete UIs. Completeness has increased substantially since the system was 1st implemented.

MDOH has also done some work to check on completeness of reporting to ensure the system is really capturing the data intended. MDOH compared its data to that of the 28 states with name reporting through reports published by CDC. There is a report which shows ratios between HIV and AIDS reports. Maryland's ratio lies at the statistic mean, suggesting data is comparable to that of name reporting states. By comparing numbers of people reported through counseling and testing networks with the HIV registry, a very high level of reporting completeness (88%) is indicated.

Data gathered through the UI system provide a different picture of the HIV epidemic than that to be gained from AIDS data. In 1996, 29% of new AIDS cases, but 49% of new HIV cases were women. The HIV data show more young people being diagnosed with HIV though not with AIDS. No changes in race distribution have been found thus far and no geographic differences. This is important information for resource allocation planning.

Maryland's UI facilitates creation of a statewide statement of need which is then sent to CDC and used in regional planning. Maryland has a very active partner notification system. Such notification can happen effectively without name reporting. Access to care is not tied to the registry. According the CDC, 30% of people with AIDS are reported 1 year after diagnosis. Reporting would not be an efficient way of accessing treatment. This happens at the provider level.

Dr. Solomon reiterated that public health functions can be performed effectively with UI and without name reporting. Maryland's UI enjoys a wide range of support from the community.

Responding to Mr. Reid, Dr. Solomon said MDOH had considered adding a field for risk category, using the CDC risk hierarchy. MDOH has determined there are better ways of getting risk data, including using state-funded counseling and test forms. MDOH has risk data on 35% of all people tested in Maryland without even a need to contact providers. More than concern about subjectivity was that about confidentiality. Asking people questions about their drug use or sexual habits to place information on a form would not make many comfortable.

Replying to Dr. Locke, Dr. Solomon said providers have the responsibility for creating the code, while labs have reporting responsibilities. MDOH worked closely with the state medical and laboratory associations to ensure they were comfortable with the system and provide technical assistance. MDOH understands clinicians are burdened by any reporting system and have constraints on their time. So the UI was designed to be generated in 10 seconds. The UI is part of the informed consent form which by law must be signed before HIV testing can be done. Clinicians must have a way, which they determine themselves, of identifying their patient from a UI number. Some physicians keep their own lab list. Surveillance records are not available to insurance companies and not subject to disclosure unless paid for by the insurance companies. All HIV testing in publicly funded clinics is paid for by the state and not disclosable.

Ms. Barnard said such a UI system seemed to be an eminently sensible approach. Responding to Dr. Locke, Dr. Solomon said she did not know the % of people using the anonymous test sites. These have just been expanded in the past 6 months, and 2 new sites have been opened. Anonymous testing has always served a small % of people being tested. MDOH does get aggregate data from anonymous testing sites but without UIs. Many people 1st go through the anonymous testing system and then, after testing positive, enter the care system where they are tested again and a UI is assigned.

Replying to Mr. Osaki, Dr. Solomon said there is much cross-jurisdictional migration between states. There are many centers of excellence for HIV treatment in Maryland. The MDOH UI registry only gets data about Maryland residents. Currently, some states such as New York do not allow sharing of data with other states. Mr. Adams noted that when name reporting was adopted in South Carolina, the number of men at a particular testing site identified as gay men dropped by 50%. The largest South Carolina agency providing HIV/AIDS social services reported that 40% of people they were serving left the state to be tested where there was no name reporting. This is substantial evidence of deterrent effect of name reporting.

Responding to Bruce Miyahara, M.H.A., Dr. Solomon said UIs are used in the drug treatment system, but not for other disease-specific reporting. Mr. Miyahara said and HIV UI would make it a narrow, categorical surveillance tool. Opportunities might be lost to look at other issues related to HIV, such as hepatitis or tuberculosis. Dr. Solomon said UIs can be matched to death, Medicaid claims, drug treatment, and AIDS records. It might be desirable to convert all systems to UI. MDOH is talking with Title I and Title II councils and consortia about adopting UIs for all people in care. Mr. Scott said the Board could look at establishing the best possible UI system to maintain confidentiality while meeting other public health needs. Dr. Solomon noted that MDOH found names not to be a very unique identifier. Mr. Reid thanked the panelists who provided the benefit of their extensive experience and noted the Board has much more study to engage in before taking further action.

PANEL ON TEMPORARY WORKER HOUSING

The Honorable Margarita Prentice, Washington State Senator, 11th District, thanked the Board for the opportunity for legislators to dialogue with the Board regarding temporary worker housing issues and provide information about recent developments. She noted there is a temptation to try to solve the entire issue because the problem is so serious. It is important to resist this temptation. Senator Prentice noted when she 1st came to the Legislature in 1989, a bill did not make out of the Housing Committee because, while addressing temporary worker needs, it did not solve the problem of the entire farmworker community. Representative Heavey made

cherry growing communities outside of the cherry camps. Without camps available, workers often live "on the river bank", that is, in isolated rural areas without safe sources of drinking water or any sanitation facilities. The health risks both to workers and to the larger community associated with such conditions include the spread of infectious disease. Workers camping in isolated areas may also be the targets of violence, vandalism, and theft.

A number of cherry growers have camps which could be equipped for licensure with respect to basic safety and health standards. State and local authorities believe some of the growers would seek licensure if emergency rules could be implemented in time for the 1998 cherry harvest season. Licensed camps would provide alternative housing for migrant workers. Licensed camps would provide additional housing for migrant workers.

The above-described conditions constitute good cause to find threat to the public health, safety, or welfare. The amendment is narrowly tailored to alleviate these conditions on a temporary basis. Because the cherry harvest is imminent, observing requirements for notice and the opportunity for public comment would be contrary to the public interest.

Motion/Second: Locke/Barnard. Carried unanimously.

Ms. Pacharzina again asked the Board to define the substance of a proposed rule on the timeframe for phase-in, so that there might be deliberations. Without it, deliberations required under the Administrative Procedures Act will have to take place after a timeframe is proposal. Mr. Osaki said he did not have a problem with setting a potential compliance date, but does not agree with idea of percentages of housing compliance to be met each year. Ms. Pageler agreed. There are swings of climate from year to year. Cyclical industries may require more than 2 years to adjust to new requirements. She suggested need for 3 full seasons after this 1 to have some certainty for financing purposes. Mr. Miyahara suggested the importance of the Board doing more fact-finding in the field before setting an official transition timeframe. Adopting the emergency rule stabilizes the situation for now. New permanent rules for stick-built shelters will not be ready until end of 1998. Ms. Barnard suggested the Board spend 2 days in 2 different months to actually go through the camps. Mr. Reid said Board staff will explore options for such visits.

PRIORITY HEALTH GOAL: REDUCE THE INCIDENCE AND PREVENTABLE CONSEQUENCES OF INFECTIOUS DISEASES -- HIV REPORTING TASK FORCE REPORT -- UPDATE

Duane Thurman, Governor's Policy Office, serves as liaison to GACHA. He briefed the Board on what has occurred since GACHA submitted its report on HIV reporting to the Governor earlier this year. HB2914, which would have created a taskforce to make recommendations to the Board on a new HIV surveillance system, did not pass. However, the Governor has decided to create a taskforce similar to that described in HB2914. A framework will be worked out within 10 days that will provide for a broadbased stakeholder group to make recommendations regarding HIV reporting. A presentation to the Board will be made this fall. He invited the Board to provide input. The intention would be to present the Board with a pilot project or rules with an implementation plan, a key part of which would be to ensure federal guidelines and criteria are met in order to ensure federal Centers for Disease Control and Prevention funding.

Responding to Ms. Beck, Mr. Thurman said he thought a letter would be issued in the next 2 weeks informing everyone of plans, and encouraged Board members and staff who had questions to call him. Mr. Reid emphasized the need to be responsive in order to take advantage of any available federal monies. Mr. Thurman assured Mr. Reid he would work closely with both the Board and DOH.

Dr. Locke reminded the Board that public health officials and local health officers are interested in the HIV reporting issue, as it touches on something they do everyday. He said the real test of a surveillance system is how well it meets established public health goals. Mr. Thurman responded that the taskforce

currently being proposed by the Governor will probably not resolve the issue of a name reporting system as opposed to a UI system. There may be a 3rd approach. It is important to find a way that adequately addresses funding, as well as use of technology and other resources. Dr. Locke added that the Board's authority in this area is very broad, dealing not just with designating reportable diseases and how they are to be reported, but all aspects of communicable disease control, including partner notification. Mr. Reid thanked Mr. Thurman for his comments.

PRIORITY HEALTH GOAL: ASSURE ACCESS TO POPULATION-BASED AND PERSONAL PHYSICAL AND MENTAL HEALTH SERVICES, INCLUDING HEALTH EDUCATION, PREVENTIVE SERVICES AND ILLNESS CARE (REFERENCE 1,2/98) -- DISCUSSION

Stuart Jeanne Bramhall, M.D., President of Washington Health Providers for Health Care For All, and Washington Single Payer Action Network and the Health Care Now! Coalition (HCNC), said the groups she represents had developed a model of universal health care financing in Washington. In November 1997, they conducted a voter survey ti test the model. They also recently completed a cost financing impact study.

Chris Daw, M.P.H., HCNC, said great strides had been made in a serious effort to reduce the number of people in Washington without health insurance. Washington is currently at about 12% uninsured. Less than 8% of children are uninsured, better than the national average. Insurance reforms limiting use of pre-existing conditions as a basis for applying coverage restrictions, and Basic Health Plan (BHP) and Medicaid expansion have all contributed to improving access to health coverage. At the same time, the picture is disheartening, as Washington has probably reached a point where further progress on reducing the number of uninsured cannot be made under the current system. At 1 time, we were looking at 200,000 people to be enrolled in BHP, and the Health Care Policy Board would be working on the analytical issues involving directions in scope, financing, and delivery of health care. This past Legislative Session, it was a major effort to get just 8,000 more BHP slots, and Washington chose not take advantage of a key federal opportunity to increase the number of children who could qualify for Medicaid.

Federal efforts to increase access are also running into roadblocks. Self-paid insurance after separation from employment, as provided under the Congressional Omnibus Budget Reconciliation Act is very expensive. Insurance companies continue to gouge consumers trying to take advantage of portability provisions in the Kassebaum-Kennedy Act.

A key need is to return to reexamination of the fundamentals necessary to achieve expanded health care access at the state level. This would involve at a minimum a recommitment to universal coverage, about which there was almost a consensus several years ago. There was however no consensus regarding adjusting the way health care is financed so that costs can be controlled.

2 key problems at this point are lack of commitment to provide universal health care coverage and difficulty in addressing health care financing, especially the great inefficiencies of the U.S. health care delivery system. An international comparison is instrumental in showing what a difference health care financing systems make in terms of health care status and outcomes. In 1996, the U.S. spent 14.2% of gross domestic product (GDP) on health care, 35% more than the next ranked OECD (Organization for Economic Cooperation & Development) country. Canada spent 9.2% of GDP on health care, more than $1,500 less per capita per year. The U.S. median age is lower or about equal to that of other OECD nations. The U.S. has more invested in high technology. But the U.S. has fewer inpatient hospital beds per 1,000 population; lowest average length of hospital stay; after Japan, lowest % of hospital admissions; and yet has the highest hospital staffing ratios. A recent study in the American Journal of Public Health comparing cancer outcomes in Detroit and Toronto communities found significantly better survival rates at 1 and 5 years among the low-income population of Toronto than that of Detroit. The study merits a closer look in terms of what impact universal comprehensive coverage through a single-payer system might have on health status and health outcomes.

MR. REID: Good.

MS. BECK: Okay.

MR. REID: It's approved, with the amendment that we might hear from David.

Now the minutes of our March 11 meeting. It's been moved that they be approved. Any additions, corrections—

DR. LOCKE: I find none. I must formally surrender my crown as fault finder. They're perfect, once again.

[LAUGHTER]

MR. REID: We will make sure that there's a nit in the next one.

All in favor of approval.

[Ayes heard]

Any opposed?

It's unanimous.

Moving right along to item 5. Follow up information on HIV/AIDS reporting.

Tom, I think you're on the docket.

DR. LOCKE: Yes. It's my pleasure to introduce.

And as I was thinking about this, it strikes me that it was exactly 10 years ago, in April of 1988 that Washington State first grappled with the issue of the AIDS epidemic, and passed the omnibus AIDS bill. And shortly thereafter, the State Board of Health took up the very difficult task of writing the rules to implement this legislation.

Now we find ourselves, 10 years later, a decade later where we're beginning this process of considering how to revise, not only the HIV surveillance system, but also a more comprehensive revision of all communicable disease WACs.

And a lot has happened over this last decade. I think most people agree there's been a real paradigm shift in our approach to HIV infection. There's been an explosion of knowledge. What we once thought was a latent disease, we know now is a very active disease with

replication of the virus occurring very early in the course of the disease, and a steady kind of immune system destruction occurring.

We have reason to believe that many, perhaps the majority, of cases of HIV are transmitted in the early stages of the infection. We have new therapies for the infection, and these may have a great impact on the risk of transmission of HIV. And I think in public health we have the very sober realization that new cases are occurring all the time, and each new case is a failure of our prevention efforts. And that is, in public health—and speaking as a local public health officer—that's our primary mission. In any communicable disease, in any epidemic disease, is to prevent transmission of new infection.

I think we're at a point where there's a broad consensus that our system of surveillance needs to be revised. What we have now gives us a very incomplete picture of the epidemic. It really does not allow us to tell whether what we're doing from a prevention standpoint, is effective or not. And the controversy arises from how we should revise that system. And as Board members—as we've read through our packets, I think it's very obvious that there is an intensity to this controversy that we will need to be grappling with in the months ahead.

Eventually it falls to the State Board of Health to make this decision, as to how to revise the surveillance system.

I think what we're here to do today is really what the law that defines that powers and duties of the State Board of Health compels us to, and in fact, what we do best. And that is to be a forum for public health policy development in this state. And it's to this forum I welcome everyone who's in attendance. I assure you that the Board members will listen very attentively to all sides of the issue. And I very much urge participants to listen to each other. That's how a forum works.

And even though there are controversies, there are passionately held opposing positions, I think fundamentally, we share an enormous number of common goals, and we're working against a common adversary, and that is an epidemic disease. So I think as this issue unfolds in the months ahead, I hope our role as a forum really meets its full potential.

With that long-winded introduction, I welcome our distinguished panel. I'll let each of you introduce yourselves as you make your presentation. And I very much—we all very much—appreciate you being here and look forward to your testimony.

MR. REID: I want to underscore what Tom was saying, and also point out that there's money on the table that the State will lose if we, the Board of Health, do not act appropriately, this year.

So this is not something that we can punt. We don't need to decide today, but we need to continue our education today, and be prepared to act this year.

Who wants to go first.

MR. SCOTT: Oh, I'll lead off.

MR. REID: Please introduce yourself, for the record. You are being recorded.

[LAUGHTER]

MR. SCOTT: My name is Kelly Scott. I'm here as a citizen, also as a person with AIDS. And I'd like to thank Dr. Locke, because he made a good point, that this is an open forum, and we deeply appreciate the opportunity to provide additional input.

As you remember, both myself and the American Civil Liberties Union, in the public comment period when you last heard this issue, asked if we could return and give you more information, and perhaps a different perspective regarding what we call the UI system, or another method of doing HIV surveillance.

My name, again, is Kelly Scott. I'm here as a citizen. Beside me is Dr. Liza Solomon from Maryland. She runs their HIV surveillance in that state. On the other side of her is Lupé Lopez, the Executive Director of the People of Color Against AIDS Network, and the treasurer of the National Minority AIDS Coalition. And at the end is Michael Adams, of counsel, with the American Civil Liberties Union, National AIDS project.

And again, thank you for letting us come back to speak to you briefly.

I can't hardly stress the importance of this issue for people with AIDS. For people with HIV, and around the state. As Dr. Locke noted, it is a matter of some heat, some contention. And I think we need to approach it in a very rational fashion. And as you pointed out, with the knowledge that we do have a common enemy, and it is the virus. And what we are most importantly about is preventing the spread of that virus.

So the issue of how to assess the impact of HIV and who has HIV, is most important, as it plays out in preventing its spread.

I would like to note two issues along the lines of that, in terms of preventing the spread of HIV. HIV is an extremely stigmatized disease. That is why we treat it differently. And that is why the issue of folks medical records is of such prime importance.

It has been noted in the past that who knows you have HIV or who may become knowledgeable of that will affect whether you will come forward and seek testing. And find out whether you have HIV. And in this day where drugs can keep you alive, where drugs are indeed, keeping me alive, it is more important than ever that folks come forward, be tested,

learn their status, and if necessary, access that care. We very much want folks to do that. We don't want to place any burdens in the way of their feeling free to do that.

That is why the privacy of their own medical records is extremely important for the public health purpose of preventing the spread of HIV. I'd like to suggest, not only this issue of how can we design a surveillance system that least burdens folks in finding out their sero-status, but another issue. Another, larger ethical issue. Whether or not it burdens folks in coming forward and being tested. And let there be no mistake. Almost everyone, no matter the HIV surveillance system you design or adopt, will still promote the concept of folks learning their HIV status.

No matter what you do today, I personally would advocate for folks learning their status. Even if their name is known at the state or local level. Because it saves their lives.

For that reason, I think there is a larger ethical issue of how much, and how necessary is it, to burden people in getting that care that keeps them alive. Even if we advocate them coming forward no matter the surveillance system, how can we burden them—how can we ask them to risk the uncertain actions of public policy makers?

And to please keep that in mind. It's an ethical burden that I think we all must meet.

I'm going to stop talking, because here we have some national and local experts. We have folks who actually run the system that we'd like to give to you as a viable policy alternative. And that again, is what we're here to present. Information that we hope will lead you to actually think of alternatives to collecting names, and then a lady who actually runs such as system as a viable alternative.

Lupé?

MS. LOPEZ: Well good morning. As Kelly said, my name is Lupé Lopez, and I'm the Executive Director of People of Color Against AIDS Network. I'm not sure if you're familiar with our agency, and I'm going to give you the local perspective, since we actually are a state wide prevention and education agency.

That focus on people of color, communities of color, but also really how these populations, like for example, women in the sex industry and men in the sex industry, substance abusers, young people.

I'd just like to say a statement first, and then I will like for you guys to ask questions if you want, or at the end ask questions too.

I am also the Treasurer of the National Minority AIDS Council. And the Board of

Directors. And both POCAAN and NMAC have policy statements on this issue.

We recognize the critical need to develop a national HIV surveillance system, to improve the monitoring of recent trends and patterns in the HIV epidemic. Provide essential data to planned target. Targeted and evaluated HIV prevention services. And to guide decision making regarding the allocation of funding.

However, we believe HIV names reporting is not necessary to accomplish these goals. HIV names reporting will pose significant social risk for people of color, including women, immigrants, gay men, substance users, and young people. We feel names reporting will hinder, rather than promote, important public health goals by deterring individuals from seeking HIV testing in the first place.

And I would like to ask you a rhetorical question. And I have gone in the search for an answer to this issue. To individuals, not necessarily the ones that think they're at risk. But I would like to ask each one of you, and you have to answer, how many of you think you are at risk of HIV infection. How many of you have tested for HIV? How many of you would do so, if your name was going to your public health department? And consistently, when I ask this question of people who do not think they are at risk, their answer is always no.

I don't think I would go if I don't think I'm at risk, to get tested if I knew that my name was going to be in some system. Whatever system it is.

Now, whether we want to face it or not, perception is 99% of how people act. And in communities the perception is, that if you give your name, it will be accessed by all the other systems, including the criminal system. Including the immigration system. Including insurance. Work. All of those.

Now we are lucky in this state—in having worked in other states—we have a very effective surveillance system here, and we're not using for AIDS cases. And we're using names for AIDS cases. My experience when I have gone around the state to communities that we work with, is that most people that are accessing the AIDS services, care services, are pretty happy—and Kelly may have a different opinion from me—about the security of their names. But remember that HIV is a long disease. And from knowing your status to actually doing something about it, time goes by.

And we need to deal with the reality of what is out there. Now, we believe that in the state of Washington, a state that has access to the latest technology, it would be the perfect example of how we can use unique identifiers.

The thing you don't know about me is that my background is science. I'm a microbiologist. I understand perfectly well why for public health we should be very effective in targeting and in identifying where the new trends of this disease are coming from, the new

cases—the new infections are coming from.

And believe me, from a very selfish point of view, working with communities of color, I really would like to know exactly how many new cases are coming from women, from young people, in rural areas, and in all the other areas that we don't really have very good surveillance right now. But I am very fearful—and this is not based on just passion about this issue—it is based on the history of this epidemic. That we will lose all of those areas that we are talking about, if we go into a names reporting system.

I believe we have the potential, we have the resources, we have the expertise, to do a unique identifier system. And I think, giving the fact that this is an epidemic that is affecting our young people, our women, most of the cases in the nation are affecting—the deaths are between 25 and 44 years. This means that some of these people have been infected when they were teenagers. Youth are the future of this country. We have to do something about this. It's not going to go away.

One of the arguments about doing names reporting is accessing services. And I have to tell you that when my board of directors said that, and we started to talk about accessing services, it was not even an issue for us. It takes months—it takes about four times the effort—to get a person of color to access services than it does a mainstream person. Because of the history. And whether we like to talk about it or not, it does not matter, it's there.

We have to convince people. And from the prevention point of view, the same message goes out, whether the person is HIV positive or negative. It's a behavioral change message. And yes, we have to get people to get tested, but they won't get tested if they are fearful of where this information is going.

There's a lot of education that has to go out there. And I believe that we need to use unique identifiers.

Do you have any questions, or—

MS. BECK: Probably lots.

MS. LOPEZ: Okay.

MR. ADAMS: Thank you.

My name is Michael Adams. As Kelly mentioned, I'm staff council with the ACLU's National AIDS Project. And I appreciate the opportunity to be here this morning to speak with you.

As you all know, while states have conducted AIDS surveillance, or AIDS case reporting

since the beginning of the AIDS epidemic, until recently there's been no systematic effort to push states to adopt HIV surveillance. And there are several reasons for this:

First, there historically has been a very strong fear that HIV surveillance and case reporting would deter people from being tested for HIV, and it was very important that people be tested. And the reasons for the deterrence, I think, were well understood. There was a strong stigma associated with AIDS. There was widespread discrimination against people with AIDS, and that HIV and a positive HIV status was viewed as a marker for being possibly a gay man, or being an IV drug user. These were identities that many people were not comfortable having associated with themselves.

It was also thought that AIDS surveillance was sufficient along with the other tools that were available to understand the epidemic. And finally, there was a belief that resources were better spent on prevention and care.

Recently though, we've seen a new emphasis on HIV surveillance by public health officials and the federal Centers for Disease Control, and the surveillance system that is being pushed by the CDC and by some public health officials is a names based system. It's a name reporting system.

And there are several reasons given for the need for HIV surveillance. First, as we all know, there has been an emergence of very promising medical treatments which are a wonderful development in the epidemic. One of the results of those medical treatments is that it takes much more time for people to progress from HIV to an actual AIDS diagnosis. What that means then, is that when we look at the AIDS surveillance, it tells us less and less about where HIV infection is now. We don't understand as much as we used to understand about the trends in HIV infection, because of this gap between the time of infection and an actual AIDS diagnosis.

So what we have been told is that the profile of people with AIDS and the profile of people newly infected with HIV may be substantially different, and that therefore, we need HIV surveillance to make up for that information gap.

We've also been told that if we could better track HIV and understand where new infections are occurring, that we could also better target funding, and better target our prevention and service efforts. And we've been told that we don't need to be as concerned as we used to be about deterring people from being tested, because there are now strong legal protections that guarantee confidentiality, and that also ensure that in the event of a breach of confidentiality, that people will be protected from discrimination.

At the outset there are problems, even with the analysis that supports HIV surveillance. First of all, given that most people who test positive for HIV, are first tested when they have between 200 and 300 T-cells, i.e., years after they've been infected. Reporting positive test

results, in fact, will not give us a very accurate picture where HIV is now.

In addition—and unfortunately—good data has never been very effective at influencing public policy in the realm of HIV and AIDS. And we can witness the refusal to support frank AIDS education among adolescents, and the refusal to support needle exchange programs, even though both of those programs have been demonstrated to be extremely effective.

So there's no guarantee that with better data, we will in fact have better public policy.

Nonetheless, the ACLU recognizes that HIV case reporting may provide helpful epidemiological data. And that data may, and we hope will be, put to good use. We also recognize that federal funding may eventually be tied to HIV case numbers. Although it's important to point out that it is not tied to HIV case numbers at this point.

But, the ACLU is adamantly opposed to name reporting. And for two basic reasons: First, it is a fatally flawed system that will drive substantial numbers of people away from the public health system. And second, there is a better alternative which does not carry the same risks. Namely, a unique identifier system.

I'm not going to speak about the unique identifier system, I guess I'm going to leave that to Dr. Solomon. Instead, I want to talk to you about name reporting and about what's happening in some other states around the country.

It's important to point out the goal of HIV surveillance, which is to get as accurate a possible a picture of the epidemic by analyzing new infections and collecting demographic and risk data about those infections.

HIV surveillance is not about accessing health care services. Surveillance systems have never been able to give people access to health care systems, and it will be no different with HIV. And surveillance is not about conducting partner identification—they are two very different things.

On its face, it does not appear that you need the name of each new person infected to accomplish the goal of counting cases of HIV, getting demographic and risk data. Yet, some public health officials say that name reporting is the only efficient way of conducting surveillance. This attitude is not surprising, because name reporting is a known quantity to public health officials. It's been used with other STDs, it's been used with certain other communicable diseases. And of course, it's not unexpected that a system which is known as a system which provides comfort. There's a natural tendency to be comfortable within our solutions, but there is strong evidence that a "one size fits all" approach to surveillance is not appropriate in the context of HIV and AIDS.

So what's wrong with name reporting? From the ACLU's perspective, one of the fundamental problems is that it will deter significant numbers of people from being tested for HIV. You have, I believe, in your notebooks a report that was put out by the ACLU in October of 1997, which discusses a large number of scientific studies that demonstrate that if names reporting is adopted, large numbers of people will choose not be tested for HIV.

This is because those individuals fear that their privacy will not be protected. That information about their HIV status will be beyond their control. And that in the event of a breach of confidentiality, they will be subjected to social stigma and discrimination as a result.

You may have heard about a recent study from the University of California at San Francisco which is the most recent study on this issue. It's a study that's often cited by the federal Centers for Disease Control to downplay concerns about testing deterrence, but in fact, when you look at the study—which has not yet been published—the results actually show the opposite. The CDC often points out that only 2% of the people surveyed in the study responded that the fear of giving their name was the primary reason they'd not been tested.

Well first of all, we can't afford to lose those people, if there's any way to avoid it. But in addition to that, according to the UCSF study, the problem is in fact, much bigger than the 2%, because the study also shows that for 19% of the respondents, fear of name reporting was one of the reasons they had not been tested. And that fear of name reporting was especially strong among the groups who are most at risk for HIV, i.e., gay men, people of color, IV drug users.

This UCSF study in fact, is consistent with all of the other studies that have been done in the field, and the studies that are discussed in the ACLU report. So name reporting will drive people away from the public health system, thus reducing their chances for surviving the HIV epidemic, and at the same time, distorting the epidemiological data that's developed.

Proponents of name reporting provide three responses to the problem of testing returns: First, that we'll have confidentiality protections. Second, that we have anti-discrimination laws that blunt the affect of breaches of confidentiality. And third, that'll we'll keep anonymous testing. But these solutions are insufficient. With regard to confidentiality: Many people who need to be tested for HIV, simply don't believe that their confidentiality will be maintained, regardless of what types of laws or promises are put in place. And there are a number of reasons for this.

One is that the populations who are most at risk for HIV are populations who, for quite good reasons, are skeptical of government commendation. The gay community and communities of color have had difficult relationships with public authorities, including public health authorities over time, and they simply don't believe the confidentiality protections will be respected.

In addition, there is some basis for this belief. There have been well publicized breaches of AIDS confidentiality, and those breaches are documented in the ACLU report. Now, not all of those breaches involve AIDS surveillance systems. But the critical thing is, perception, as was mentioned already. And the perception, based on people's experience with government agencies, and based on what people read in the newspapers about the breaches that have occurred is that people can't be sure if the confidentiality of their name will be protected if its reported.

In addition, history shows us the promises made about confidentiality today can be broken tomorrow, especially when state legislators are confronting the sensationalized and isolated incidents involving HIV and are looking for a politically expedient solution. We've already had examples of this.

And I point you to the example in Illinois in 1991 with regard to Illinois' AIDS registry. Illinois had an AIDS registry which had state-of-the-art confidentiality protections. In 1991 there was a scare in a hospital where a patient who had HIV claimed that she had been exposed to HIV by a health care worker. This was all over the newspapers. The legislature rushed to produce some type of a response, even though it was not clear in fact, that there was really a problem.

And the response they came up with was to—they passed a law that said that the AIDS registry was to be taken and was to be cross-checked with the registry of licensed health care workers. And every licensed health care worker who had AIDS was to be identified, because they had the names on both lists. And they would then take those names and track down the patient who had been treated by those individuals and advise them that they might have been exposed to HIV.

This was horrific policy. This was a complete backtracking on the confidentiality promise that had been made. But it was nonetheless—

[Tape off]

[End tape 1, side 2]

[Tape 2, side 1]

[Tape on]

MR. ADAMS: --confidentiality protections in place.

I also—with regard to the argument that we have anti-discrimination laws that will protect people in the event of confidentiality breaches. I wish that were true, and in fact, as a lawyer

with the ACLU, there's been a recent rash of federal court decisions that say the federal civil rights protections for people with disabilities do not protect people with HIV, unless they are sick. If they are asymptomatic, there is no legal protection.

That question is presently before the U.S. Supreme Court. It's unclear how they will rule, but it's unlikely they will resolve the question in its entirety. Which means that those types of subtle legal protections that people talk about, which should exist, don't exist.

And third, with regard to the question of won't all of these problems be solved if we just keep anonymous testing. Well, the reality is there are no guarantees that anonymous testing will remain after name reporting is adopted, despite the best intention of public health officials. Ten states that have adopted name reporting have subsequently eliminated anonymous testing. And although this is terrible policy, there is a certain logic to it. If the purpose of HIV surveillance is to report cases, and if a state has chosen to report cases by name, why maintain a testing system that does not allow for name based reporting.

For example, New Jersey has name reporting, but also has anonymous testing. 45% of those who test in New Jersey, test anonymously. Which tells us, number one, that people are concerned about testing in a name based system, but also you have to ask, "How accurate can New Jersey's surveillance data be, given that 45% of people test anonymously." And a recent study indicates, in fact, New Jersey's surveillance data is not very accurate.

Even in states where anonymous testing remains, it has often been severely cut back, so with access to it in name reporting states is very difficult.

As a result of serious problems with name reporting the ACLU and AIDS advocacy organizations have been encouraging states to reject names based HIV surveillance. And as states examine the questions more closely, they are recognizing the grave consequences that name reporting can bring. Hawaii and the state of Massachusetts have rejected names reporting, and have opted instead to conduct HIV surveillance through unique identifier systems, and they are in the process of developing those systems. They are working with the state of Maryland and looking at their system, but it's important to note that each state has to take a look at that question, to borrow from Maryland and other systems what are applicable, and to work within the realm of what's appropriate in that state.

The state that I am most familiar with is the state of New York, which is the state that I work in. The New York State AIDS Institute which is out of the Department of Health was ordered by the governor to convene an HIV surveillance working group to study the question of how will we do surveillance if we do it. Will it be done through names, or will it be done through unique identifiers. The working group met for three months. It was a very long, in-depth process. I'm pretty sure that probably the most in-depth analysis of the question that's gone on in this country so far.

There were seven full days of hearings. There were presentations from a large number of AIDS directors in name reporting states. There were presentations from directors in Texas and Maryland which have unique identifier systems. There were presentations by the CDC, public health officials, by community representatives. At the end of that very long and arduous, and in-depth process, the working group was required to make its recommendations to the legislature and to the governor.

And after reviewing all of the evidence before it, the working group rejected names based HIV reporting, for the reasons that I have discussed. And instead recommended to the legislature and to the governor that a unique identifier system be adopted in the state of New York.

Now that is a formidable challenge in the state of New York, given the extraordinarily large numbers of cases of HIV that exist in our state. But I will suggest to you, if it can be done in New York, it can certainly be done in Washington State.

The last thing that I'll just mention is that working group also addressed the question of partner identification. I was surprised to hear—just before coming in here—that your Board had been presented with some arguments previously, suggesting that name reporting was needed in order to conduct effective partner notification. This is a very surprising argument to me, because on this issue, we are in complete agreement with the federal Centers for Disease Control, because the CDC agrees with all AIDS advocacy organizations, that it's completely inappropriate to link HIV surveillance and partner notification. They are two very different systems, and if you attempt to link them, you inevitably reduce the confidentiality protections that must exist in a surveillance system.

The CDC opposes that link, and so we. And I should point out that name reporting is clearly not necessary to conduct partner notification. Any system of partner notification does not use the name of the person who has HIV when conducting the notification of partners, and studies have been done which demonstrate the states that have name reporting systems do no better a partner notification than states that don't. So there's no indication whatsoever that name reporting is useful for partner notification, and in any way increases the chances of effectiveness.

I encourage you to engage in in-depth analysis here, and if HIV surveillance is going to be adopted that it be done through a unique identifier system, rather than name reporting. Thank you.

MR. SCOTT: Well, Michael mentioned two things on the national scene that I'd like to draw on now—just very briefly—to Washington State. He mentioned the arduous process that the New York agents went through to consider the issue. And I would not wish the New York experience—which was no doubt uniquely New York-ish on anybody. But Washington State's Governor's Advisory Council on AIDS—from the chairman of which you'll hear later today—equally set up a task force to consider this question, and in its report gave the best

arguments from its own task force regarding names reporting and UI system.

It also held five forums around the state, so it got quite a cross-section of opinion. The Task Force report went up the full council, and the full council did indeed vote, 14 to 4, in favor basically of the UI system. And I would encourage you to review that report, and indeed that vote of the full council.

Also, Michael mentioned that assurances of confidentiality and anonymity ring a little hollow in the minds of people with HIV. And it must be said that in this state, and I have AIDS. I've had AIDS since '86. I've had HIV since '85. I've worked with many public health officials, and it must be said that I have confidence in their assurances of confidentiality, anonymity, and good faith. In fact, it's been pointed out that breaches of confidentiality are probably more likely unauthorized to occur from private providers than it would from a public health system, and I agree with this.

However, in 1991, the Burgalis hysteria—the dentist and the patient—took place. And every—I think 50% of the legislative sessions in Washington State—there's been a law proposed to restrict the practice of health care workers based on no scientific evidence whatsoever of their infectiousness in their practice. In other words, we have confidence in public health. We have confidence in public health systems for unauthorized breach, but authorized by the legislature—well, we don't have a lot of confidence in a lot of the legislatures at various times. And in fact, to their credit, it's a democratic institution that does respond to the public mood.

So that is what we fear. Not so much unauthorized disclosures from public health, but the authorized disclosures. And that's the situation in Washington State. We too, have—well, call them various, somewhat misguided—actually I'd call them wacky—laws, some even passing through the legislature.

So our impetus to not have to give the names, not drive people away from testing, is not an irrational fear. Is not a mere perception. It's a very well-grounded, rational, perception of our situation.

Dr. Solomon?

DR. SOLOMON: Thank you.

I'm Liza Solomon, I'm the Director of the Maryland State AIDS Administration. And within our department, we have all aspects of HIV services, including surveillance, prevention, and the Ryan White Care Act programs.

I appreciate having the opportunity to talk a little bit about the Maryland system. I feel like, sort of, the grandmother of UIs. Maryland actually implemented its unique identifier system in 1994. And so we do have some history of seeing what it's like to try to implement

such a system, and I do appreciate the opportunity to talk a little bit about it.

Let me just tell you a tiny bit about Maryland, because I think it's hard to know—you know, what is Washington compared to Maryland? Are we bigger or are we smaller. Maryland has the fifth highest prevalence of HIV. So even though we're a fairly small state, we actually have quite a significant epidemic in Maryland. We have 17,000 cases of AIDS reported to date. Which I do think is significantly more than Washington. And as I said, I sort of put that on the table as a start, because I think it gives you a sense of the complexity of our system, and whether it might be transferred to another state.

As I said, Maryland began implementing its UI system in 1994, and the reason we did it, actually, is that we had had discussions for many years—for many years—within our public health community, within our legislature, with the advocacy community about how do we move forward on HIV surveillance. Because we actually realized fairly early that we did need to have better data, even before the very encouraging news we've seen as a result of medical treatment. That we really were losing the ability to target prevention services, to target programs to communities at need, because we didn't have the HIV piece.

So after many years of debating this, and we had proposed legislation in the Maryland General Assembly, I went back to '88—just to give you an idea—every year since 1988, a bill was introduced to again, move a system forward for HIV surveillance.

In 1992 a names reporting bill—once again, '88, '89, '90, '91, '92—all those bills had been defeated. In 1992 we actually decided to do something fairly creative: We compromised. The advocacy community, the public health community, we all decided we needed to move forward. And we needed to move away from this paralysis of what we were going to do, how we were going to do it, and we decided we would try to create a UI system, and to see if it worked.

That was enacted in 1992, and we started implementing it in 1994.

Now, what are the goals of our system? The goals of the system are really quite simple, as the goals of any epidemiologic system. We want to monitor trends in the epidemic. We want to know if we're seeing any differences in risk groups, in geographic areas. Our state, I think similar to you, has metropolitan pockets and rural areas around it. We wanted to make sure whether we were appropriately funding areas. Maybe we were seeing different patterns in migration.

All that information we needed to know. And that's what we wanted our UI system to do. And obviously the reason we want this system is that the importance of collecting data is to target programs. I mean, data that does not result in a policy change is meaningless. So we wanted the data that we could use, that we could turn back, that we could use to make decisions. And again, the decisions we saw it affecting were things like what kind of prevention programs

should we be targeting? Should they be targeted to drug users? Should they be targeted to adolescents? Who are the individuals--the populations—that were being infected.

We wanted to know about resource decisions. We fund through the state of Maryland, virtually all the HIV care programs through local regions. We needed to decide what's the appropriate allocation formula. Should it be going to central Maryland? We needed to see where the new cases of HIV were going. And those were the kinds of decisions we saw this policy helping to impact.

Now, how does our system work? Remember, we started this in 1992. We didn't want a very high tech system. We're not the location of a very large computer company like you have here. But we wanted a fairly simple system. And the system that we developed was one in which providers have the responsibility to create a unique identifier number. And labs have the burden—legislatively—to report. So the system is a lab based reporting. And I say that because we think that's important, and we think that has helped give us data that is very useful.

Now, what is our UI system? It's basically a 12-digit code that consists of the last 4 digits of the Social Security number, which are randomly created digits. The first five have to do with where someone gets their number, and approximately what year they do. The last four are considered random digit numbers. The birthday, six digits, month, month, day, day, year, year, and then a digit for race/ethnicity, and a digit for gender. And we use the Centers for Disease Control codes. And that creates a 12-digit code.

We do have exceptions, and as Michael Adams said, we actually do think that as a public health department, our responsibility is to make sure that all individuals learn their sero-status. And we don't want to do anything that would drive people away from our system. So one of our exceptions to our unique identifier reporting system is anonymous test sites. Anonymous test sites are exempted from reporting. And we felt that that was actually very important.

Because we know that sooner or later people will hit the system. They will test at an anonymous test site, we wont' get that data. But they're going to be referred into care, and they will then eventually come into the confidential site. But for that first step forward, to learn your sero-status, for people that are very concerned about confidentiality, having anonymous test sites available is critical. So we exempted anonymous test sites.

We also exempted a few research components, but that's pretty much a very small category.

So what do we do when we get the data? We get these UI reports, and in Maryland, all HIV positive tests, and all CD4 counts less than 200 are reportable by unique identifier. The unique identifier numbers come into the state, and the first thing we do, actually, is we compare it to our AIDS database. And we've put UIs on our entire AIDS database. Because again, what we're trying to determine is the numbers and the types of individuals who have HIV that are

separate from AIDS. So we get a fuller picture of the epidemic.

So we compare the HIV reports by UI to the AIDS report by UI, so we create registry of unique HIV positive individuals. Because again, we are not interested in people that we already know about. We know the demographics of people with AIDS.

Once we have the separate HIV registry, that's where we start to do our analysis. What does it look like? What are the age groups affected? Because again, we have age, we have race, we have zip code—it's not part of our unique identifier, but we know where the person was tested—and we can start to provide information and look at the difference between HIV and AIDS.

Well, obviously a question that I think is most on your mind is, well, does our system work? I know, you've told me you have one, and you put one together, and you've been working on it for years. We've spent a lot of time over the past couple of years trying to look at our system, and trying to evaluate our system. Trying to refine our system. And I have to say, in the past year or two, I've had the opportunity to talk with other states as they think about other systems, and I've realized there's a wealth of information that we can share, and improvements that can be made.

As I said, in 1992 when we crafted our system, we really didn't have a lot of colleagues to work with. And sadly, we had no help from the Centers for Disease Control. We had no technical assistance. We had no money. We have never received a penny to implement our HIV surveillance system. So everything we've put together we've had to do, basically in a conversation with ourselves. Again, until fairly recently when we've had the opportunity to talk with colleagues about how could we do it differently, and how would we tweak the system a little bit more.

Well, let me tell you a little bit about our evaluation. The first thing we obviously wanted to figure out it is, is it unique? I mean, we say we have a unique identifier, and does it really demonstrate—can it really pick out unique individuals? So the first way we tried to evaluate it, is that we took our AIDS database, which we've put UI numbers on, and it's a database of about 16,000 unique individuals, and seen—and we looked at how many times would you get duplications of UI within a 16,000 record number.

What we discovered is that if you have the entire 12 digit UI, it is unique 99.8% of the time. So we found that comforting. If you have three of the four digits, three of the four fields, including the last four digits of the Social Security number—but not four, in other words you have Social Security number and either date of birth and race, or date of birth and sex, but you didn't have all four of them, you still have over 99% uniqueness.

Again, that gave us some comfort. So we felt a lot better.

And as we worked down each of the different ways of looking at uniqueness, we found it was very unique, up until the point where you didn't have the last four digits of the Social Security number. And then if you had three of the four, but one of them was not the Social Security number, you dropped to 77% uniqueness. And that gave us some idea of what's the parameters of comfort that we could have about whether a number is truly unique.

So that started our evaluation, and again, it gave us a sense that this is fairly unique, as we say, in the lab. But we wanted to find out, is it really unique in the field? Because as we know, when we implement programs, it frequently is different in the real world, than what you think it would be.

One of the ways we looked at this question is, we took one of the counties in our state, and we looked at UIs that appeared more than once. Because we wanted to know, was it two people that were given the same UI, or is it one person that had two visits? That's clearly very important. If we're going to have an accurate number of the number of HIV infected individuals so we can plan services, we need to know that it's truly unique.

So we went to one county and we pulled every single UI that appeared more than once. In this county, for instance, we had 97 unique UIs that had more than 200 visits. And we worked with the local health department to find out whether these were truly unique. And we did it, actually, by pulling—we actually didn't, but the local jurisdiction pulled the informed consent, which people have to consent to before they're tested, and checked, was it truly the same people.

What we found, was again, very interesting. In this one county, people who had more than one test—including people that were tested in the same jurisdiction, in each case they received the same UIs. In other words, it was absolutely unique. If one person came in twice—as we would expect they would be, you might want a confirmatory HIV test. You might have more than one CD4 count. They were given the same UI. So the system was able to find uniqueness.

But what was more interesting, we found cases in which somebody would test in one county, and then the same UI would appear in another county. Sometimes far away. Those were the ones we were worried about. Maybe it's not working so well. Maybe we're getting the same UI in different counties. And in that case, we had 12 UIs that appeared across jurisdictionally. So they came in county A, and then in several other counties. And in every single case, we pulled the records, and in every case, they matched. So again, we felt very confident that this particular UI system was capable of correctly informing us whether one individual was tested three times, and we could identify that it was one individual, three tests. As opposed to three individuals and one test.

We're doing other work with our analysis too. As I told you, that's telling us that if we have a full 12-digit UI, we are very confident that they are correctly giving us the numbers of

how many people appear more than once.

We are doing also work when we don't have the complete UI, because we will have opportunities in which the Social Security number is not complete. Or gender is left out. Or race is left out. And we want to make sure that that data can be used. So we've doing a lot of work with something called fuzzy matching. Which is again, doing statistical matching, we have three or four fields, checking to see whether its really the case, and then we will be able to say, "Well, if you have this variation, you can be 99% confident they're the same. Or you can only be 90% confident." We will be able to make some statistical adjustments.

We're also looking at the completeness of our UI number. As I mentioned, ideally when you have the 12 digit code, it is very unique. You can do all the analyticals you want, but we continue to do work with our providers to make sure that they put the full 12-digit code on. And certainly, in the course of the almost four years that we've been implementing it, we have seen great improvements.

When we started, the first six months we started implementing UI reporting, it was a new system, and it's always a little confusing when you start anything for the first time. And we had something like 56% completeness of the UI number. That was the first six months of implementation. In the last six months that I looked at the data, we have 77% completeness. So we have made dramatic strides in getting the full UI. And as I've told you, even without a full UI, we know that we can do a great deal of work to look at uniqueness.

We've done some work, also, to look at completeness of reporting, because again, you want to make sure that your system is really capturing, most, if not all, of the numbers you want to capture. And we've looked at it in two different ways. One is that we have compared our data to names reporting states. Now, 28 states use HIV reporting by name. And the Centers for Disease Control publishes a summary data, I believe it's every year. And one of the things that's reported is they look at the number of HIV reports, and the number of AIDS reports. Then create a ratio, and that's available for every one of the 28 states that do names reporting.

What's interesting is if you look at the national data—and again, everything but Maryland is a names reporting state—you find that it varies from .6, which means that for every AIDS case you have a half an HIV case. But two to one. It gives you a sense of what you would predict, to 1.6. So there's a lot of variation among states that are doing names reporting.

But the average for all the 28 states that are doing HIV reporting by name is .9. Maryland is .9. So it suggests to us that our data certainly is comparable to data of other names reporting states, and again, that gives us some comfort that the data that we are providing will be as good as a names based system.

We're doing some other analysis, also looking at completeness in reporting, and I don't

know how technical this board would like to be. But we are doing things like looking at people who reported through our counseling and testing networks, and then comparing the numbers of reports to AIDS registry—to HIV registry. Again, to get completeness of reporting. And that data is also suggesting that we have a very high completeness of reporting. And the last numbers we looked at were 88%.

One of the things that we've also looked at, is does the HIV data that we are getting from this HIV surveillance system tell us anything different than the AIDS data that we have? Because obviously it's work, and time, and things that could have been spent doing other activities. We have found however, that the HIV data is giving us a different picture of Maryland than we would get from the AIDS data. Which has been very important for our planning activities.

And I just want to give you a couple of examples. In Maryland, if you look at 1996, about 29% of the cases of AIDS, new cases of AIDS, are in women. If I look at HIV data for again, the same year, 46% of cases of HIV are in women. So it's really providing us an opportunity to see something that we know is happening in Maryland—we had the sense, it's happening nationally—but it's giving us the ability to quantify changes in the epidemic in Maryland. So we are seeing big differences in gender when we look at HIV reporting versus AIDS reporting.

If we look at age differences, again, we're seeing significant differences in our HIV data to AIDS data. We're seeing younger people infected with HIV, as opposed to being diagnosed with AIDS. And again, it's reminding us what I think we knew about, but again, helping us then more closely target programs to that age group.

We haven't seen any differences in race. We have looked. And that may just be a function of what the epidemic is like in Maryland, but that is important for us to know, and important for us to say, "Well, there are no changes in racial distribution of AIDS cases versus HIV."

And lastly, we found that in fact, there were no geographic differences. Because we are looking at AIDS cases, and we're looking at HIV cases. That again, is very important, because we make our resource allocations based on geographic area of residents. So that would be something we would continue to look at very closely.

Well, what are some of the things that we are going be using this data for? In fact, Maryland, like all states, are required to create a state-wide statement of need. And we have provided this data to our state-wide panel. This data was included in our state-wide statement of need, and it has been sent to the CDC as a way of informing the community about what's happening. We are using it in our regional planning. We are using this data in making decisions about resource allocation for services.

So we have found it very helpful in helping to guide decision making about what will happen for monies that are going out next year, and the year after.

A couple other issues have come up, just in passing about what other things can be done with either, do we do partner notification in Maryland? What does the UI system help or hurt us for? Do we think it helps us with accessing care? And I think it is very important to look at the fact that no matter what kind of surveillance system you had, it really is not the same as what you're going to be doing for partner notification.

We have a very active partner notification program in Maryland. We believe it's an important public health prevention activity. The partner notification happens after the part at the clinic. Where the person has just been given HIV positive test results is being counseled. That's the time that you say, "Can I help you inform your partner? Do you need help? What can I do?" And with our system, that can be done regardless of whether we at the State no the names of the person.

In terms of access to care, again that's very important, but I think it is, as Michael said, very important to separate that from a disease registry. We feel, in Maryland, as I know you do in Washington, that we have a commitment to providing care for people who do not have access. But again, that must be done at the level of the provider, because registries are always outdated.

According to the Centers for Disease Control, 30% of people reported with AIDS, are reported a year after their diagnosis. Now, I don't think that's a very efficient way of getting care—

[Tape off]

[End side 1, tape 2]\

[Tape on]

DR. SOLOMON: --that provide referrals and access to treatment, again at the level of the provider.

I'll close my remarks. I can only say that the four years we have worked on this in Maryland, we certainly have learned a lot. I think we have a lot of good ideas of how we could have done it better, in hindsight.

I do feel that the data that we need in order to perform our public health functions are available through a UI based system. This system has enjoyed a great deal of support from the community. We are able to work with our public health partners, with the community in getting the data we need. Providing the data back to make decisions about where resources need to go.

And I do suggest that for states that are looking at expanding their surveillance system, it is possible to have an effective surveillance system without a names based system.

Thank you.

MR. REID: I was interested, Dr. Solomon, in one of the pieces of paper that you presented to us, a question and answer from ACLU about improvements that you were contemplating in Maryland.

And you mentioned a described risk category. What would that be?

DR. SOLOMON: Well, um—

MR. REID: And this would be the provider, I take it? Or the tester? Would describe a risk category?

DR. SOLOMON: Yes.

The way risk is determined is usually whether it's a report for AIDS or whether it's a report for HIV, is usually a surveillance professional will call the provider and ask a series of questions about the patient. What the patient's risk group is. What kind of activities they may have engaged in that put them at risk for exposure. And that's true no matter whether your system is a UI based system, or a names based system.

We had given some—we get that information in two ways, with our UI system. One is that we have risk information on all our counseling and testing forms, and that's given to us by the person who's doing the counseling, who has obviously had a discussion with the person about what activities are putting them at risk.

We also call providers back when we're trying to get additional information and get this extra bit of information.

We contemplated adding a field for risk category, using the CDC hierarchy and we were thinking of using that as part of our UI system. I have to say that since we had that original discussion, we have decided within the administration that we would not go forward with that. And that we are using other ways of getting risk data, including—as I said—we've including on all our state funded counseling and testing forms. So we have risk data on 35% of all people who are tested in the state, without needing to even make a call back.

MR. REID: Is all the other information you have in that—what is it, 12 digit unique identifier—very easily determined, do subjective evaluation?

DR. SOLOMON: Yes.

MR. REID: It's very objective. Would not a risk category be somewhat subjective?

DR. SOLOMON: Well, actually the way that risk is determined is always based on a discussion, and almost a decision model. And CDC, for instance, has a hierarchy, if you, of how you prioritize risk. It does require discussion between someone who is trained. And I think we felt that if we just asked somebody without really the leading questions that would help get at that, the data would not be good enough. And that was one of our concerns.

Our other concern, quite honestly, was confidentiality. That to say, "Oh, I'm an injection drug user, and you can put it on my form and send it forward," was not going to be something that was going to make very many people comfortable. So we decided against implementing that idea.

MR. REID: You have decided against it?

DR. SOLOMON: We have decided against it.

MR. REID: Okay.

Any questions for the panel? Tom?

DR. LOCKE: Well, first, Dr. Solomon, I'm trying to understand—you characterized your UI system as lab-based. So do the providers, do medical providers have any role in the reporting system? Do they generate the totals? Do they have any legal responsibility?

DR. SOLOMON: Yes, they have the responsibility for creating the code. So they create code. The code goes with the blood sample, or on the lab slip. It can be either way. And then the lab has reporting responsibility, and they are required to report within 48 hours.

DR. LOCKE: What has been the response of providers to this system? Has the UI system been supported by the State Medical Association, for instance? Have you done any studies of the acceptance of the system by providers?

DR. SOLOMON: When we first started implementing it, we obviously worked very closely with the professional medical association, which is called MEDCAI in Maryland, and the lab based associations, to treat, to continue to work with them and to educate them to provide technical assistance to them on developing it.

I'm not aware of any recent discussions with them, or a survey. I think we all know that clinicians are always burdened by any reporting system. And as we know from all of our AIDS reporting systems, clinicians have many constraints on their time, and whether it's asking them

to report by name, or to report by UI, is still an extra burden. And it does, obviously, take time from other important functions.

So the idea with creating the UI was that we tried to create a UI that could be generated in literally 10 seconds. And in our informed consent form for HIV testing, which by law has to be signed before HIV testing can be done, we've now added the UI as part of that, again, trying to minimize the time it takes a provider to do that.

But as I said, we did envision this as something that would take—ideally—10 to 15 seconds, and would be no more burdensome than a names reporting system.

DR. LOCKE: Well, another question. You mention that you're investigating some of the UIs, you pull records for those. Am I understanding you correctly that there are lists that are kept by the providers and the labs? That are in effect, a translation table between the name and the UI?

DR. SOLOMON: Actually, not between the labs. We require clinicians to have a way of identifying their patient from the UI number. And we don't prescribe how it's done, although we certainly give some guidance for many ways it could be done. And it can be done from anything from UI to medical record number. Or many clinicians actually keep a list of all labs that they send out. And since we know the date of the specimen, they may not even keep a separate list. If we say, "We'd like you to look up a positive test for someone that was drawn on January 1," as I said, many clinicians keep their own lab list so they know what has not come in.

So again, we don't prescribe how it needs to be done. What we do require is that there be some way that they can get information about the patient.

DR. LOCKE: So there is an identifying record that is available to insurance companies, and the courts, and—

DR. SOLOMON: No. Not insurance companies. These are surveillance records. Nothing in them is available—

DR. LOCKE: I mean the provider's medical records. Are actually subject to disclosure to insurance companies and the courts.

DR. SOLOMON: Well, they're only subject to insurance companies if they are paid for by the insurance company. And since we pay for all HIV testing through all the publicly funded clinics, and we also pay for any test that anyone wants to send to the State Lab, no, they would not be subject to that.

MS. BARNARD: Tom, I think if I could ask you a question, because I know you're

involved in the technical aspects of it, and for me, listening to this, it just makes all the sense in the world. I don't know why there's a problem with it.

I'm looking at the time. And it's 9:50, 10:50, I think there's other people in the audience that wish to address us. And I'm wondering how we're going to—

MS. BECK: No, this the panel that's—

MS. BARNARD: Nobody else is speaking?

MS. BECK: This is the panel that's providing information today.

MS. BARNARD: So we aren't going to have anybody else speak to us today?

MS. BECK: No, there's no testimony today.

MS. BARNARD: So what, then would it be scheduled again, so we can hear from other people disagree with this?

MS. BECK: We'll be hearing on it educationally, throughout the year.

MS. BARNARD: Did you understand that, doctor? You're not here to speak today? Okay, I had understood that she had come over speak today, so excuse me. Go right ahead.

MS. BECK: But I think she's joining us for lunch.

[LAUGHTER]

MS. BARNARD: Good, I hope so.

MS. BECK: It's public health week.

DR. LOCKE: And yes, your point is very well taken, Sherry, that we have very limited time for a very complex issue, and I anticipate this will stretch out over months.

I don't want to monopolize the questions, but I had one other though.

You mentioned the anonymous testing type. And what has been your experience with that? With the UI system and anonymous sites, do you know what percentage of people are using the anonymous sites? And not using the confidential UI?

DR. SOLOMON: I'm sorry to say that I don't have the most up-to-date data on that, and I can certainly make sure that I provide this board with it.

We have expanded our anonymous test sites, actually within the past six months, and opened two more anonymous testing sites.

Anonymous testing has always been a small percent of the numbers of people being tested, a small but dedicated group that really wants to have anonymous testing. We do get aggregate data from the anonymous test sites without numbers of people that they screen, and some very basic data on race and sex. But we do not, necessarily, get a UI numbers.

Our sense is that again, someone may come through the anonymous testing system, get that first positive test, and prepare themselves to enter the next part, which is the care system, at which point they will probably have another HIV positive test for the record. For most clinicians really want the test site. And then we will be able to capture data on demographics of that individual. But the entree to anonymous is not reportable.

MR. OSAKI: I have a question regarding cross-jurisdictional issues. Excuse my geography just for a moment here. But as I understand it, Virginia is a names reporting state?

DR. SOLOMON: Uh---yep.

MR. OSAKI: Okay. The question is—do you have any figures on people that are avoiding reporting in Virginia that are coming to Maryland to report, as an adjoining state, an avoidance issue of reporting?

I guess the question is, do you keep it by residence as well?

DR. SOLOMON: Actually, people who are not residents of Maryland, we don't require reporting. So in other words, we're only interested in reporting for Maryland's residents, so we would not have that data. We don't know how many people are crossing boundaries to—I don't want to use the word "escape" but to—

MR. OSAKI: Are there other states outside, that adjoin Maryland, as well, that are names reporting states? Is West Virginia a state that adjoins Maryland?

DR. SOLOMON: West Virginia is a names reporting state. D.C. is not a names reporting state. Delaware is not. Just trying to think of my geography here.

MR. OSAKI: So do you know, whether or not people from those adjoining states are coming into Maryland to get treatment or help—

DR. SOLOMON: Well, there's certainly a lot of cross-jurisdictional migration because there are many centers of excellence for HIV treatment in Maryland. So we do have people—and given the geography—actually in West Virginia we have one of their county's in

our Title II EMA. So we do have people that cross over from Virginia and from Pennsylvania for care.

MR. OSAKI: Are you sure there's a continuity of care. When you have this cross-jurisdictional issue, does this create a barrier in terms of the names reporting versus—do you need the identifier reporting patient or person?

DR. SOLOMON: Well, remember in our system, we only have—we only get data from Maryland residents. So I'm not sure that would influence their care. Again, the surveillance system is very different from the care system. I mean the care that someone gets, the relationship they have with their provider, really opens in some ways, a completely different world than in a surveillance system. So I would think that the relationship that a person has with their provider for care would be affected by the surveillance system in that jurisdiction.

So they may not be aware of whether Maryland is a UI reporting state. They would get their care within that system. I can't see it in any way influencing it or being a barrier by the fact that there are different systems.

One thing that is important—and I'm sorry Michael—with cross-jurisdictional issues, some states do not allow any sharing of data across states, and New York is one of them, actually, that will not give any information about people with AIDS living in—I might have a Maryland residence, and I may do an AIDS case report, and the person may be in New York, and I may ask the New York health department for information. They will not furnish any information. So in fact, I wonder whether a UI based system across many states would allow sharing of data.

So we're not double-counting people, since there are many prohibitions against sharing names.

MR. ADAMS: I was going to mention with regard to the question of crossing borders, that there is a study that was done in the state of South Carolina, Apple, South Carolina adopted name reporting as referenced in the ASILIA report, which indicates that after mandatory name reporting was adopted in South Carolina, the number of men who at the testing site identified as being gay men, dropped by 50%. And correlating to that, the largest South Carolina social service agency provided services for people with HIV and AIDS reported that in their own internal survey, that 40% of the people who they were serving, had in fact, left the state to be tested elsewhere where they could test without reporting their name.

So at least in that particular state, there was evidence of substantial deterrence to having people crossing the border.

MR. REID: Bruce?

MR. MIYAHARA: Are unique identifiers used in any other program or any other disease?

DR. SOLOMON: In Maryland or—

MR. MIYAHARA: In Maryland.

DR. SOLOMON: Well, unique identifiers have actually always been used in drug treatment. They have a separate confidential system. They're not the same UI, but they are a number based system.

I'm not really familiar with any other disease-specific reporting systems—

MR. MIYAHARA: The reason I'm asking, it just seems to me that unique identifier for HIV would tend to be sort of a narrow, categorical surveillance tool. And might you be losing opportunities to look at—from a larger public health side—other issues that might be connected to HIV, hepatitis, or TB, or something else. You would not be able to take your surveillance data on HIV and use it anywhere else, other than to get a narrow categorical surveillance, epidemiological look at HIV.

DR. SOLOMON: Well, actually we can use our HIV unique identifier, we can match to death records. We can match to Medicaid claims records. We can match to our drug treatment program—our AIDS drug treatment—our ADAPT program. And again, as I've pointed out, we've already put our unique identifier number on our AIDS registry, so we are able to look at other important data through this linking system.

MR. MIYAHARA: So you have then added the unique identifier to [inaudible].

DR. SOLOMON: Yes.

MR. MIYAHARA: Gonorrhea?

DR. SOLOMON: Um, all the, I do not believe that all the elements—I don't believe that Social Security number is a part of any STD reporting—

MR. MIYAHARA: Yeah, that's all I'm asking. It seems to me that it does not feel like—unless you convert everything, to be a comprehensive public health look, that's not critical of the unique identifier system, it's just that it's that categorical approach that we're trying to get away from in public health, and there's some sort of system of disease, a system of issues in the community, that public health is responsible to manage. And it just seems that this sort of makes it—it might make it—difficult to be a little more proactive on some wider perspective.

DR. SOLOMON: Um.

MR. MIYAHARA: It seems like a very specific use. If it were converted across the board, then it would be looking at public health broadly. But it's being kept very narrow, and it seems to be a very narrow orientation that might, in the future, compromise other public health efforts.

DR. SOLOMON: Well, we may want to convert all our systems to UI based systems.

MR. MIYAHARA: Right. Right. That's what I'm getting at.

MR. SCOTT: I was about to say, it'd be useful if the Clinton Administration, rather than opening medical records per se, would have a little bit more fair—

MR. MIYAHARA: Yeah, I'm just thinking improve prevention, and improve care. And how are we going to get there.

And some of this debate it's very frustrating, because sometimes that gets lost. People get positioned in camps. And what we're trying to do is figure out a way to get a broader—you've worked the compromise within, maybe HIV issues, and our responsibility is a lot broader also. So how do we sort of reconcile some of those—

MR. SCOTT: And in fact, there's enough data for the Board, that the legislation that for other reasons didn't make it to the Governor, to do that exact study, of the best possible UI system reflective of confidentiality, but also trying to meet your other concerns.

I'm hoping that goes forward. That the Governor does appoint, even lacking the legislation.

DR. SOLOMON: I think there are opportunities though, as you point out, that we should take advantage of. One of the discussions we're having in Maryland is for our services, we don't have unique patient data, as I would imagine you don't also in Washington. We're trying to now work with our Title I and Title II councils and consortia, to talk about adopting UI as a unique identifier for people in care. And again, trying to put a broader understanding of the whole spectrum of care.

So I think you're right, that we really should take advantage of what opportunities are there for us.

MR. MIYAHARA: The thing, if we come back to a sort of cycle then. In order to get everything connected, everything will have unique identifier. Which then, why not just use the name.

DR. SOLOMON: What was interesting was we found to be a not very unique identifier.

When we did our analysis of 16,000 records in our AIDS database, and the AIDS database is known to be a unique individual person based database, and when we put UIs on it, we found low and behold, 38 duplicates. And I actually thought—it was a very interesting exercise. You know, names are not that unique. Either people change their names when they get married. There's spelling differences. So I think we have to be careful with whatever system we use that we don't think one is more perfect than another by default without really looking at our data.

MR. MIYAHARA: I'm afraid I'm going to have to ring the bell.

I certainly want to thank the panelists, especially those from the East Coast who came to give us the benefit of their experience. And we'll certainly be getting back to you. And once again, this is not the end of what we're going to be up to.

[Tape 2, side 2]

MR. REID: I know we have at least two members of the legislature that have been waiting patiently.

Senator Prentice and Representative Parlette.

Senator Prentice?

Never want to keep a member waiting.

[Laughter]

I'm sure you found much of interest in the last panel. You are certainly a panel in which we are interested in. And it's on the subject—we aren't going to punt today, we're gonna have to move and we welcome you here with your colleague from the House. Do you want to start, Senator?

SENATOR PRENTICE: Yes, thank you.

For the record, I'm Senator Margarita Prentice, representing the 11th district, the south end of Seattle.

And I've brought along with me, beginning over there, Dave Cheal, who is the staff counsel for the committee, and who's actually done the nuts and bolts work. And if there are any technical questions, I certainly like to have him along, because—

MR. REID: He's no stranger to this body.

SENATOR PRENTICE: Oh, that's very good to know. Representative Linda Parlette,

MR. REID: Welcome back. We're now on Item 9, which also has to do with HIV reporting. It has to do specifically with the HIV Reporting Task Force report, and from Governor Locke's operation we have Duane Thurman, who will give us a briefing.

MR. THURMAN: Okay, for the record, my name is Duane Thurman, and I'm the Governor's liaison to the Advisory Council on HIV/AIDS. Judith Billings was here and had to leave. She apologizes for that. She was going to give a run-down on the report, which I believe the Board received about the same time the Governor did earlier this year. I'm here basically to bring you up to date after that report. Judith says she's perfectly willing to come back to discuss the issues that were raised there.

We've been working kind of frantically since the session was over, and we've finished signing bills. One of the bills that was up for consideration when the GACHA report came out involved the task force that would study a pilot program--pilot project to implement a statewide HIV surveillance program. That bill, House Bill 2914, didn't make it out of the House, and so that issue remains unresolved.

At this point, I just wanted to announce to the Board that the Governor's decided that he will go forward with a similar task force, basically set up very close to what was in 2914, although there may be some differences. I have remarkably little in terms of specifics, but I think that in the next week-and-a-half we should have a framework, and any input that you would have in terms of suggestions--I can assure you that it will be a broad-based stakeholder-represented force. It needs to be up and running very quickly. We need to get back to the Board of Health late in the year. I believe September first would be the deadline.

In terms of its actual mission, it's to do something to decide this issue. We don't want to repeat the work that the Advisory Council's already done, and the intention would be to present the Board with a pilot project or rules or something of that sort with a call for implementation, and the key here is to ensure that the project they come up with meets federal guidelines and criteria so that we can get funding from the Centers for Disease Control. So that's basically what you have left of Item 9, but I would encourage you to invite Judith back as the chair to go over that report.

MS. BECK: And you think we'll see something in writing within a week, like a draft or something?

MR. THURMAN: Yeah, I will--I think that there'll probably be a letter coming out to everybody in the next, let's say, two weeks, and any questions you have, or concerns, just give me a call. But we're not going to move ahead without letting you know what's going on. I just want to--

MR. REID: We would certainly want to be responsive, and we would not want to be responsible for losing any federal money that we might grab.

MR. THURMAN: I hope to work closely with the Department of Health and the Board of Health, and see through this difficult issue. It is another difficult one. I hope you spend some time on it today.

MR. REID: Tom?

DR. LOCKE: Well, could I add that the public health officials and the health officers, especially, are very interested in this issue, and it touches on something we do every day. We would very much appreciate the opportunity to comment, and especially on the goals of the Task Force, which is the critical issue. In any sort of reporting of surveillance systems, the real test is how it meets the public health goals that we've established, and so that's what we would like to come to some agreement on.

MR. THURMAN: Yes, that was the essence of the Advisory Council's Task Force Report, and you know, they were very much divided on that. I can say that the task force that the Governor's proposing will probably not, in itself, resolve the issue as to whether it's a name-based or unique identifier system, and that is the issue that the task force is going to have to deal with, and as difficult as it is, we want to try to get the representation there. There may be a third approach. We just want to do it in a way that we're going to get some serious look at funding, and perhaps some use of technology and other resources that we might have out here. So at this point, I think we have a good group of stakeholders in general agreement, and just have a very difficult issue to resolve quickly.

MS. BARNARD: I have one question, Mr. Chairman.

MR. REID: Certainly.

MS. BARNARD: Okay, earlier when you were talking about this unique identifier and (inaudible word), you said that (inaudible word) would be making a recommendation or decision which would depend on the funding. Now we have this report. What is the task force going to do exactly?

MR. THURMAN: Well, the Governor's Advisory Council is set up to advise the Governor as to some issues, and it created a task force to try to resolve the issue of whether to use a name-based reporting system or a unique identifier.

MS. BARNARD: Right, right.

MR. THURMAN: They couldn't agree on that. The overall body made a recommendation back to the Governor. The Governor at the time was then looking and was supportive of the legislation that happened to be trickling through at the time, and we reached some resolution. Ultimately, it's my understanding that the Board of Health has the authority to ultimately put this into place, and I guess the point of this task force is to use the expertise

we already have to give it the visibility with the federal government that the Governor could bring to bat, and to present to the Board something that is worked out through stakeholder work and research, so that you can then do your jobs.

MR. REID: So we're going to watch what they're doing so that we're fairly prepared to respond quickly.

MR. THURMAN: This will be an inclusive process.

MR. REID: Any--

Tom.

DR. LOCKE: I would just add for Sheri and other's information that the Board's authority in this area is very broad. It doesn't just deal with designating reportable diseases and how they're reported, but really all aspects of communicable disease control, so partner notification--Our mandate is essentially to do whatever's necessary to control communicable diseases, so we have extraordinary discretion, and there's an entire very long WAC that deals with communicable disease issues--

MALE SPEAKER: For the public health and the public good.

MS. BARNARD: Okay, thank you, Tom. That was good.

MR. THURMAN: Okay, thanks.

MR. REID: Thank you, David (sic).

Item 10, Priority Health Goal: Assuring Access.

DR. BRAMHALL: My name is Dr. Stuart Jeanne Bramhall. I'm President of Washington Health Providers for Health Care for All, and Washington Single Payer Action Network and also the Health Care Now! Coalition, and this is Chris Daw, and we are--we've developed a model of universal health care financing in Washington State and did a voter survey in November testing this model, and also recently completed a cost financing impact study, and both of these were provided in advance of this meeting. We're very honored to be invited to present.

MS. DAW: Thank you very much. My name is Christina Daw, and I am a member of the Health Care Now! Coalition. I'm going to open up and talk a bit about the why--why we're here, why we're so crazy to talk about health care reform issues in the late '90s, and Dr. Bramhall will talk more about where we go from here in terms of vehicles that we're working on and the outreach that we're doing.

4. The Department shall provide regular reports to the Board on the issuance of individual compliance schedules beginning in January 1999.

5. Enforcement of applicable Board standards should be appropriate to the individual compliance schedules.

6. Given the regulatory certainty provided by the Board's reaffirmation of the minimum health and safety standards set forth in WAC 246-358, and direction provided above for individual compliance schedules, we do not anticipate there being need for emergency rules in 1999 or subsequent years.

The Board is providing this direction to you regarding the 1999 cherry harvest now with the understanding that growers and communities will require time to consider and implement options for the housing of migrant and seasonal workers before the 1999 harvest season. As always, the Board is receptive and prepared to deal with individual exemption requests from growers as provided for under WAC 246-358-020, making use of the already existing process set up under the Interagency Agreement on Farmworker Housing. Exemption requests must include a description of how the intent of the regulation will be met.

The Board appreciates the Department's continuing efforts to ensure safe and healthful conditions licensed under provisions of WAC 246-358 and to implement Second Substitute Senate Bill 6168, Section 2, to adopt new standards for construction of temporary worker housing. We understand further that a solution to the housing needs of the agricultural industry will require the full and creative cooperation and partnerships among local, state, and federal agencies, the Governor and Legislature, non-profit organizations, industry and labor advocates, and communities. We look forward to working with all interested parties for the health of Washington and its people.

Motion/Second: Locke/Barnard. Carried by a vote of 7-2, with one abstention. The letter was signed by Mr. Reid.

FOLLOW-UP INFORMATION ON HIV/AIDS REPORTING (REFERENCE 12/97, 4/98)

Dr. Locke introduced Doug Hamacker, Reporting Manager, HIV/STD Epidemiology Division, Texas Department of Health (TDH). Dr. Locke thought it especially appropriate at this time, given the *WSPHR* release, that the Board hear from a speaker on a topic related to the second State Priority Health Goal, Reduce the Incidence and Preventable Consequences of Infectious Disease. Dr. Locke recalled that the Board had heard about the need for HIV surveillance and various systems to carry it out. In late 1997, a Washington State Association of Local Public Health Officials (WSALPHO) representative presented the case for HIV name reporting. In April 1998, the Board heard about the State of Maryland's experience with a unique identifier (UI) system. The American Civil Liberties Union and other community groups also presented their concerns about HIV name reporting at that same meeting. Dr. Locke acknowledged the controversy surrounding the issue, but noted there is general consensus now about the need to do more than just AIDS case reporting. Given that there are strongly held views on both name and UI HIV reporting, Dr. Locke said it is appropriate for the Board to continue to serve as the public forum for airing these differences and talking about experiences with both kinds of reporting systems.

Mr. Hamacker pointed out that some of Texas' experience doing HIV surveillance, along with comparable data from Maryland, will be published in a future issue of *Morbidity and Mortality Weekly*. He shared this information as a handout to the Board. He began with a brief review of the public health structure in Texas. The state has 254 counties, 64 of which have local health departments. There is an

HIV/AIDS Reporting System, but only 10 local health departments, in addition to the state health department, have an active HIV/AIDS surveillance system. Texas reported about 47,000 AIDS cases in 1997. When Texas first began collecting data on HIV, it was done through a fairly rudimentary system of simply tabulating how many new cases each week came from each provider. It was not yielding much useful data, even when demographic information was added to the system in 1989. In 1992, TDH proposed name reporting, but community objections were so strong they developed a UI system instead, implemented in March 1994. Though the Texas UI system code was nearly identical to what Maryland had developed, the two systems were actually created completely independent of one another.

Mr. Hamacker said main requirements of the Texas UI system were that it had to be able to integrate with existing activities, and it had to allow for data collection, management, and analysis at the local level which then could be aggregated at the central office. At the same time, reorganization that combined HIV, AIDS, and STD into one group was implemented, allowing for a single surveillance system for all these diseases. TDH received about $1 million per year to support the system, and began using some of their HIV prevention money to help support the system as well. CDC contributed another $100,000, which permitted TDH to put two extra staff in each of the highest AIDS morbidity areas, Houston and Dallas.

Mr. Hamacker said they knew that creating a UI system would not support field followup for partner notification, but that it might allow epidemiologic monitoring. That is, it would provide a baseline figure of HIV incidence linkable to the AIDS database to track the progression from HIV to AIDS to death. This permits better resource allocation and understanding of the epidemic.

Texas' UI code, used instead of the client's name, was composed of the last four digits of the client's social security number, date of birth, and an indicator of race or ethnicity and gender. Additional information included was county of residence, health care provider, and test date. It was conceived as a locally driven system, requiring buy-in and cooperation of local health jurisdictions to make it work.

Three years after implementation, 32,000 reports were collected which yielded only 6,800 new, unreported HIV non-AIDS cases. The next step was to try to determine why so much data was collected and yet so few cases resulted. 10,000 reports were incomplete; 7,000 more were grossly incomplete with no social security numbers or birthdates or race information, representing more than half of the reported cases. The item most commonly missing is the social security number. 3,400 of the remaining 14,000+ cases turned out to be duplicates because positive test results are reported by both the laboratory as well as the physician. In addition, by comparing some of the HIV data to the AIDS data, for the number of AIDS cases present, TDH estimated they were missing approximately 74% of HIV cases from their UI system. Thus, trying to characterize the epidemic from their HIV UI surveillance system would have a serious bias to it. The ability to link the system to other databases, e.g. birth records, STDs, and tuberculosis, was also uneven.

A follow-back study of 765 HIV reports resulted in only 60% of those cases being traceable back to the medical provider. There was no ability to try to capture additional risk information on a majority of the HIV reports. Of those that were traced back, only 50% had race or ethnicity information, and only 40% had a true social security number. Most of the cases reported came from a public provider source.

Mr. Hamacker said three main issues became clear: 1) inability of private laboratories to report UI information required to construct the report, primarily the social security number; 2) inability of local health departments to complete incomplete reports, and thus, to do any followup on HIV positive results; 3) information from the UI system was not statistically valid or representative of the epidemic. Problems that are unique to a UI system include: a) if any piece of information is missing, e.g. date of birth or social security number, the UI cannot be created, thus the cases themselves cannot be counted; and b) even when

reports are complete, only 60% of the time can further information be obtained.

Mr. Hamacker said that HIV reporting is critical because AIDS cases have leveled off and AIDS deaths are declining, but new developments in treatment have made it necessary to identify HIV positive persons as early in their infection as possible. An accurate profile of the epidemic cannot be developed unless HIV as well as AIDS is reported. Using only AIDS data, Texas has begun to show significant changes in the profile of the epidemic with respect to different ethnic groups. Shortening the time between when a person becomes infected, gets tested, and begins treatment extends the period of time before the onset of full-blown AIDS and keeps the amount of virus in the infected person's body at a lower level. This, in turn, has exciting implications for degree of infectiousness and prevention of new infections.

As of December 1997, 27 states have begun HIV name reporting; since that time, both New Mexico and New York have also begun developing HIV name reporting systems. Texas would like to switch to name reporting, with TDH taking the lead in developing the rules for the system. Mr. Hamacker said the Texas Legislature convenes again in January 1999, and the TDH would like to develop their system before they are mandated to do so by the Legislature. He thinks it possible that there could be federal legislation mandating HIV name reporting. It would be preferable to be proactive at the state level.

TDH convened a workgroup in Fall 1997 to look at what needed to be done to improve the HIV reporting system. Starting from the premise that aggregate reporting using UIs had failed, other options were explored, mainly name reporting. They identified what a good HIV surveillance should ideally provide: infected persons would receive timely referrals and basic services; ability to monitor recent infections; ability to support planning and targeting of services; assistance to physicians in providing disease interventions; and assistance in public health investigations, including a data set that could support requests for funding.

TDH decided to merge their HIV reporting system with their existing AIDS name reporting system, thereby reducing development and infrastructure costs. Though there was a concern about confidentiality, TDH felt the AIDS reporting system had sufficient protections built into it if HIV name reporting were added to it. Mr. Hamacker stressed that a UI system does not create anonymity for the person being tested, only a system where the person's name is not seen, though the name can still be accessed. The TDH workgroup also felt that their UI system did not support public health interventions or assist with allocation of resources. The recent CDC guidance on evaluating a surveillance system stresses sensitivity, simplicity, timeliness, and flexibility, and while it stops short of recommending name reporting system, it does conclude that name reporting systems perform better based on these criteria.

TDH then convened a number of stakeholder meetings around the state to create a dialogue and solicit input on named versus UI reporting systems. Concerns from the infected community centered around the issue of confidentiality, but in Texas, as elsewhere, in general, only about 2% of people are aware of how reporting is currently done, whether it is by name or UI. The typical reasons for people to delay HIV testing are not related to the kind of reporting system used, but instead to fear of test results. TDH sees value in retaining the option for anonymous testing, which is provided for in Texas law, and will be reinforced in the rules being proposed for HIV name reporting.

Confidentiality of reported information continues to be a concern. Mr. Hamacker has been spending much of his time visiting local health departments around Texas to review their security standards. Another concern is that people who test positive for HIV disease are not guaranteed services or access to the drugs that may deter or prevent the onset of AIDS. Instead, the primary objective of an improved HIV surveillance system would be to provide the safety net of basic public health functions and services to those who need them. TDH established a community consultation group of diverse stakeholders in June 1998 to assist with this, and

assigned a coordinator to assure a single point of contact. TDH envisions an active role for their local health departments in implementing the name reporting system, recognizing their own capacity and resources.

TDH plans to evaluate the HIV name reporting system, possibly even trying to ascertain a point in time after which the system no longer needs to retain individuals by name but instead by an encrypted code. Much time is currently being spent on responding to inquiries about the new system, including putting information out on the Internet.

Mr. Hamacker emphasized that even if Texas' UI system could be made to work, it would still be a unifunctional system limited to characterizing the epidemic. It appears to underrepresent the private sector with the biggest barrier being presented by private laboratories. Given that certain patients and providers appear to be unwilling to provide or collect certain information (e.g., migrant workers and illegal aliens either have no social security numbers or do not want to provide them), the UI system offers few prospects for meeting certain performance criteria. Another barrier is increasing local participation in a unifunctional system. Despite the public health system's inability to guarantee services to all who test positive for HIV, a named reporting system would provide the ability to at least inform everyone tested of their HIV status. Such a system would also provide the ability to direct attention in a more meaningful way to those at highest risk for HIV: sexual and needle-sharing partners of those who test positive for HIV.

Responding to Ms. Reeves, Mr. Hamacker said the system does not interface with other databases via modem. Using modems would not meet TDH's strict confidentiality and security provisions. Public health remains uncertain about how to recapture those HIV infected individuals for whom protease inhibitors have proven to be ineffective, as well as those who seem to have some HIV resistance. Ms. Reeves related how the Washington State prison system has made protease inhibitors available to inmates who need them, and how they have discovered the different factors that influence a patient's drug compliance. Availability is not the only factor. Mr. Hamacker pointed out that in Texas, the UI system was not able, even in the prison system, to capture all the information needed to do followup on those inmates whose HIV test results were positive. Mr. Reid thanked Mr. Hamacker for his informative presentation.

OPEN PERIOD TO TAKE PUBLIC TESTIMONY ON ANY HEALTH ISSUES

Mr. Reid invited citizens to testify on health issues of their own choice.

Judith Billings, Ph.D., Governor's Advisory Council on HIV/AIDS (GACHA) Chair, said she also chaired GACHA's taskforce on HIV surveillance. The taskforce took six months to examine activities in other states, receive written comments, and hold community forums around the state. Dr. Billings also serves on the President's Advisory Council on HIV/AIDS, and on the boards of the Northwest AIDS Foundation (NWAF) and National AIDS Fund.

Dr. Billings noted that there is universal agreement on the need for HIV surveillance. Without it, there is little reliable data to plot changes in the epidemic, now infecting women, young people, and people of color in increasing numbers. Surveillance would help ensure prevention resources are directed in the right direction. Dr. Billings urged the Board to act expeditiously. She said there is a need for information, which she hopes can be gathered without names being kept on a list in perpetuity. She cited proposed legislation in Illinois which would have given a list of infected persons to the legislature so they could inform health care workers and others about their HIV status. Dr. Billings noted there have been no leaks from DOH of names of people with AIDS. However, when she was diagnosed, newspapers got the story even before she had told her family. People's privacy concerns are legitimate in a society where discrimination still exists.

Kim Colaprete, NWAF Statewide Community Organizer, indicated NWAF has been working

on the HIV reporting issue for sometime. There is great fear of name reporting in the community of people most at risk and most affected by HIV/AIDS. NWAF is committed to creating the best HIV surveillance system which at the same time meets the needs and takes into consideration those most affected. She noted there are now nine published studies indicating people at most risk would not be tested or would delay testing if there were name reporting. A study in Los Angeles found 23% of people said they would not seek care until sick if they knew their names would be reported. Ms. Colaprete said confidentiality is important. It is not so much the fear of public health breaching confidentiality, but other agencies gaining access to names. A name-based system would place one more barrier to keep people from seeking testing. She noted the Texas information was very different from that received from Maryland, which has been able to improve accuracy over time and track incomplete data back to providers. They also received high levels of risk-related data from their UI system. Massachusetts, Connecticut, Hawaii, and Puerto Rico are now implementing UI systems. There is a bill in the California legislature to implement such a system. Ms. Colaprete looks forward to presenting NWAF's proposal at the October meeting.

Ms. Barnard expressed surprise that Washington is one of the few states without an HIV surveillance system. Dr. Locke recommended the Board take up the issue as soon as possible. He noted lives are devastated by the epidemic and represent a failure of prevention. The nation is at best holding the line against HIV. Around the world the battle is being lost. He welcomes NWAF's proposal in October and would like to see the issue put on a fast track. Washington State Medical Association and other groups are depending on the Board to act in order to stave off legislative action. The issue belongs with the Board. Ms. Reeves noted recent research indicates unusual resistive factors to the use of protease inhibitors. People are not responding to new medications because of previous use of antivirals. This makes consideration of new preventive efforts urgent. Dr. Billings said several counties are considering taking action. A patchwork system for the state is not desirable. Mr. Albert indicated the item is on the Agenda Planning Calendar.

1998 LEGISLATIVE WRAPUP AND 1999 SESSION PREVIEW

Ms. Hayes referred to a fact sheet on Dawn Mining included in the Board Reading Packet. Because of ongoing litigation and other issues, she has alerted Hal Dygert, Senior Assistant Attorney General, that if the Board has questions, he can address them next month. Ms. Hayes noted that coming out of the 1998 Session, rules are being written and implemented. She offered to provide a written report on any item of Board interest. Mr. Osaki said the Washington Association of Local Public Health Officials is convening an all-day policy and legislative meeting on Friday.

Ms. Hayes also referred to an item on 1999 Agency Request Legislation included in the Board Packet. This contains issues DOH may be looking to put forward in 1999. They are due in the Governor's Office on September 9. The Governor will then sort out what will become Governor's Request Legislation. DOH is looking at revising the Indoor Air Act to restrict smoking in all public places.

LEGISLATIVE REQUEST FOR SUNRISE REVIEW OF HB2254 -- AUTHORIZING DISPENSING OPTICIANS TO PERFORM EYE REFRACTIONS - PRE-DECISION BRIEFING

Karen Valenzuela, Board staff, gave the pre-decision briefing on a legislative request for Sunrise Review of HB2254 to authorize opticians to perform eye refraction. This would allow licensed opticians to undergo additional education to become certified as "Certified Refracting Opticians" (CRO). CROs would be permitted to perform subjective refractive examinations. They could modify existing prescriptions for contact lenses or eyeglasses, provided the change was two or less diopters, plus or minus. Patients would have had to receive an actual examination within the past two years if a contact lens wearer, or within the past four years if an eyeglass wearer. Opticians have met with the Washington Association of Eye Physicians and Surgeons to discuss concerns with the bill. There

Kris are you voting, or are you abstaining?

MS. VAN GORKOM: I think it's directed to the Department, I should abstain.

MR. REID: You're abstaining.

Seven to two, with one abstention.

I think we have a machine here that will crank out the amended letter. And I will put my signature on it. Anyone else who wants to put their signature on it, is free to do so.

Moving right on. Where are we?

MS. BARNARD: Can we take a five minute break?

MR. REID: Maybe we need at least a five minute break.

Florence, you've earned your five minutes, but you got more.

Moving right along. We're having another presentation on HIV/AIDS. And Tom, you're going to introduce the group?

DR. LOCKE: I think it's especially appropriate that we have this presentation after the release of our *State Health Report*. And that this—what this—issue has to do with is our Number 2 priority, that is, reducing the incidence and preventable consequences of infectious disease.

This is not the first time, of course, the Board has heard about the issues involved with HIV reporting. Back last December we heard from the State Health Officials, and the in March, in Bainbridge Island, we heard of the experiences of Maryland. And I think we also heard presentations from the ACLU at that time. So we're certainly aware that there's controversy connected to this issue.

I think where there's general agreement is at this time, 15 years into the HIV epidemic, we need to rethink how we do surveillance of this infectious disease. And I think there's general consensus that we need to change from how we're doing it now, which is AIDS only reporting.

Where the controversy is, is how we do that reporting. And we've heard strongly held arguments, at this point, on both sides. Both regular reporting or what many call names reporting. And unique or encrypted identifiers. I think the Board is, as a board, we're in our public forum role at this point. And it's very appropriate that, rather than just dealing with the theoretical arguments involved in this, we actually hear the experiences from people

who are doing this in the real world.

Out there in the United States we have 28 states that have gone with named reporting. We have two states, so far, with word of perhaps others, that have tried unique identifier systems. Last March we heard from Maryland, and this month I have the pleasure of introducing Doug Hamacker, whose the Reporting Manager of the HIV/STD Epidemiology Division at the Texas Department of Health. And Doug has very kindly agreed to fly up from the inferno of Texas and share with us his experiences in, first Texas' experience with the unique identifier system, and where they've gone beyond that point.

And so with that, I'll turn things over to Doug.

MR. HAMACKER: Thank you very much. I appreciate coming up and talking to you all about our experiences with unique identifier surveillance. It's one that's—there's a couple documents that we'll hand out toward the end of the presentation that we've not only written up, but also has appeared with comparable data from Maryland in the *Morbidity and Mortality Weekly Report*, the scientific publication put out by the Centers for Disease Control.

So we'll be handing some of that out. It contains much of the data and much of the results of what I'll be presenting to you today. But again, in a slightly different format.

I have about a 30 minute presentation. In reality it's about an hour presentation. But I'm going to try not to talk with my slow Texas drawl today—

[LAUGHTER]

--try to do it as quick as I can. I've been told and guaranteed that I might have a little bit of flexibility if I do get a little bit of a long wind to me. So I'll start right off.

But before I get into the unique identifier surveillance and some of the idiosyncrasies of—did I say that?

Before I got into that, I'm learning a little bit about the public health organization of Washington. And I think I owe you the same due about our system. As it lines up, though in size it's slightly different. In reality it's fairly similar.

But we have 254 counties in the state of Texas. 64 of those have a local health department, an organized local health department. Not all of those are state participating, some of those will be singular local health departments.

HARS is an acronym that we use within the AIDS surveillance section, in that that stands for the HIV AIDS Reporting System. How many satellite sites do we have for the

collection within the 64 local health departments. How many of those have an active surveillance unit that routinely collect and transfer—in an encrypted format—their data up to us. And that stands at actually 10, and we have a centralized site within our central office.

To give you a perspective of the epidemic picture in Texas, through March of 1998, we had over 46,000 cumulative cases reported. The total for just 1997 AIDS cases reported was a little over 47,000.

MS. BARNARD: Was that 4,700?

MR. HAMACKER: Or 4,700, I'm sorry.

MS. BARNARD: That's quite a difference.

MR. HAMACKER: Yes it is.

Okay. A little history about reporting HIV infection reporting in Texas that kind of led us to where we are now. We started the slide with 1987, which is when we had a legislative mandate, one of the few diseases in our legislature that is specifically mandated as being reportable. Because for the most part, our Board of Health has that authority, to not only describe which diseases are reportable, but also they have the authority through our rules and regulations to define how those infections are to be reported.

Again, the slide starts in 1987. But in reality, we had an HIV infection reporting mechanism from the very beginning of the epidemic, and that would be called an AIDS reporting system. We did not realize at that time that the underlying issue of AIDS was actually then soon-to-be realized as HTLV-3, later to be called HIV. It was discovered in 1983 with an antibody test that came out 1985.

So many of the states—we being one of them—knew that we had a named AIDS case reporting that was universal across the nation. But we also specifically went in towards HIV. At that point it was a very controversial topic to talk about—extending your surveillance mechanism to named HIV. So what we did was we allowed to be an aggregate reporting. What I mean by aggregate, I sometimes called the chicken pox reporting, where you have tabular data, how many cases did you have from the doctor this week. And the active surveillance component of that was we'd call the doctors, or they'd send in their forms to us, and we'd have stick figure tallies of how many cases came from various providers.

It complied with the law. We did have in place a mechanism for HIV infection, so it gave us an out. We were not out of compliance, but in reality, it was not providing us useful data whatsoever. We did amend it in 1989 to try to get a little bit more demographic data, again it was a fairly useless system, aimed primarily at complying with the law, but keeping us from having to hit that controversial names issue.

Until finally in 1992, we grew tired of doing something that was just for compliance sake. We did propose named reporting. There was a very vocal outcry to that from some members of the community. The offering from that outcry was, try something different. Try something that no one else has done. Try something that should be successful. Try numeric code reporting. Don't use the person's name. Use a numeric code.

And at that point we listened. We listened to the community very long and hard, and realized that this was a system that—because it was unknown and was untried—was something that we needed to look at, and very seriously consider as being an option to our proposal.

So for the next two years we developed a unique identifier system. Again, I'm going to describe what that system is, in just a second. But we began the U I reporting in March 1994. Coincidentally—and a lot of folks will really have troubles believing this—the U I system that we developed, the code—code for code—coincided with what Maryland produced. It was not—even though I knew the Maryland staff that were in place at that time, I knew them very well—it was a complete, independent creation of the unique identifier code that each one of us created.

When we created the unique identifier surveillance system, there were a couple of assumptions that we necessarily did have to make. Number one, it had to integrate into our existing activities. I'll go into some of the cost issues in just a second. We knew that it had to integrate into our existing activities.

Because we are such a large and diverse state, we do have decentralization of our activities. The local health authority actually has the bite of the public health laws in Texas. We knew that the data collection had to be at the local level, and we needed to create the ability for the locals to collect and manage their data, analyze their data, and use their data for their local uses, as well as provide that data into the central office, so that we as a state-wide aggregate could also use it.

Some of the cost issues that we looked at, for the most part, in 1994 we reorganized our bureau to where HIV, AIDS, and STD surveillance all were combined into one group. We also got rid of our traditional AIDS division and the STD division. We merged those two divisions, and then broke the divisions out according to common activities. For instance, field operations—those that would go out and monitor contracts. Surveillance, which was my bailiwick. I was able to, at that point, have centralized systems—integrated systems—for STD, HIV, and AIDS as well.

So we knew that TEH staff already were comprehensibly on the surveillance of STDS, and currently we were receiving about one million dollars in an annual budget to support our surveillance mechanism. That is the surveillance mechanism, in and of itself,

that does not include, for instance for the DIS, or the Disease Intervention Specialists out in the field, the clinicians, etcetera within the STD clinics. It does not include that. It includes the cost of collecting the data at the local level, and transferring it on into us.

During that year we also did go into our prevention grant—our HIV prevention grant—and said, we want to try to get better data. If we get better data we can better direct the monies that we're getting through HIV prevention grants. So can the CDC provide some funds for this activity, in order to support trying to have better data. And they did come through with $100,000. It sounds like a lot of money. In reality it comes down to two positions in two different local health departments. We placed one in the highest morbidity area in the state of Texas, which is Houston, Texas. We placed another person in the second-highest morbidity area in the state of Texas, and that is Dallas. So that bought two people.

When we created—we talked about some of the considerations. Now we sat down and looked at what did we expect the surveillance system to create. We knew that it would not allow for field follow-up. In other words, for a name to come into—er—a report to come into us, and then we follow that report back for field follow-up. In other words, some of the traditional public health responsibilities, we knew that this was not expected to support that.

We thought that it might allow epidemiologic monitoring. What I mean by that is, once you get a report in, can you link that to further databases, look to see, has that person subsequently gone from HIV to AIDS, and then from AIDS to death. Could we do some epidemiologic monitoring. We thought that it might be able to. In reality, it was conceived as a unifunctional system. And what I mean by unifunctional system is, is the ability to monitor the epidemic. To get a baseline figure of how much HIV is there in our community, in our state, and have the ability to have the epidemiologic monitoring. From that there's a couple of activities you could be able to do, resource allocation is one of those. And a better understanding of your epidemic for receiving some of the scarce funds that are out there.

So we really did conceive it as a unifunctional system to try to get a better handle on the epidemic.

What is unique identifier surveillance? Basically, instead of a person's name, you create an identifier. The last four digits of the person's social security number. Plus their date of birth, plus the indicator of race, ethnicity. Plus the indicator of what their gender is. You use that in place of the person's name. We would also include county of residence information. Provider information, so that we know who the provider was. And also date of test information.

It was very exciting, because at that point, we also knew that it could go along the lines of a traditional public health system, too. And that is, that it could be a dual reporting

system. AIDS case reporting—because there's not a single test to tell you, does this person have AIDS—is a very intensive reporting process. Because you're having to follow-up predominantly with providers, and go through their records with them, or have that provider fill out the forms for you, and submit the case to you. This can be more like a gonorrhea surveillance or a syphilis surveillance, to where the laboratories can help drive some of the data reporting responsibilities.

And again, we instituted it as a locally driven system,. which means that we at the central office weren't the powers to make this happen. We knew, like all of our other public health responsibilities, this is one that requires the buy-in and the activities of the locals that make it work.

Now, three years into the data collection, and I'm cutting it off to June of last year, what did that produce for us? In the back, I'm not sure if you all can see all of this data. We received over 32,000 reports during that three-year period. A couple of very important take-home messages on that is though that we received 32,000, it only gave us about 6,800—

[Tape off]

[End tape 5, side 1]

[Tape 5, side 2]

[Tape on]

MR. HAMACKER: --actually turned into what we believed to be new, unreported, HIV non-AIDS cases. That's a lot of data to collect for a very small amount. So then, the next thing you do, is look and see why did we drop so much data between the two.

Between the 10,000 incomplete reports and the 7,000 grossly incomplete reports, you're looking at a very large share of your data, almost have of your data is dropped, simply because—or actually a little over half of the data is dropped—because they're missing components of the unique identifier. The distinction that I'm making between the two, the 10,000 and the 7,000 is, the 7,000 cases, starting in mid-1995, laboratories were giving us as much data as they could—again, remember this can be a laboratory driven system—in order to comply with our laws. The laboratories were saying, I'll give you what I have, but I don't have all of your components of your U I, I don't have 'em folks. So I'll comply as best as I can, I'll give you what I've got.

Typically, they don't have the last four digits of the social security number. Often times they don't have the data of birth. Many times they don't have the race. So if they were missing three or all four of the components, we just pigeon-holed 'em. We didn't enter them into our database.

MR. OSAKI: I think you answered my question. I was trying to figure out what of the components actually were missing in the reporting system.

MR. HAMACKER: Right. We're going to go into some of what was routinely missing—again, social security number is the big one, because it's not one that all providers have, all providers can get, or all providers can easily provide to us.

Another very disturbing part of this, is that if you look over here. The cases that kind of made it through this end of the filter, you have 3,400 duplicates out of a total of about 14,000 complete reports. Don't forget I describe this as a dual reporting system. This is one where whenever the physician takes a blood sample from the patient and sends it in, and it's positive, the physician will receive the positive report back. Both the laboratory and the physician are responsible for reporting that case. So in essence, you should be eliminating half of the complete reports right off the bat, as incomplete. We weren't doing that. We were roughly a quarter of the reports were falling out as duplicates.

What that tells you is, is that one end or the other is doing a good job. The other side isn't possibly doing quite as good of a job. So right off the bat you can kind of start seeing for the—this is going to lead us into an evaluation. Right off the bat you can kind of see that there's some problems with the way the data is coming in. And I think this is the one that's going to address your issues. Is item completeness.

This is actually in color. The way I'm looking at it down here, you all can't see the colors.

The item completeness of the U I, this dark line right here, is how many the proportion of your cases that have all of the social security number. Or the last four digits of the social security number. Starting out in 1994 it was about 56% of the cases had the social security number. We did reach a high of almost 80% in June of '97, and then again, that fell back off. Again, that can be very dependent on if we've got a lab reporting a data dump that would bring that proportion or not.

Historically, the social security number is the least available. Gender is the most available. It's averaging about 97% of the cases do have a gender indicated on there.

But something that I kind of want to picture here is that, though we have had increases, we're looking at—if you look at some of the linear modeling, we're hitting a plateau. So some of the efforts that we've previously made in trying to get the U I better, get the item completeness better, get the startup of the system through and over with, we're still running into some problems that seem to be insurmountable.

Some of the other performance statistics that we looked at was we tried to estimate,

okay, we've got these HIV infection reports, how many didn't get reported. So what we did, is we did a simple completeness of reporting statistic. Where we went over to our AIDS cases, and pulled out all of our AIDS cases that were reported during this one year time period, which is July of '95 through June of '96, and pulled out how many western block positives were indicated for those AIDS cases. Again, this is a system that's completely independent of the U I system.

So we had about—had exactly 22 24 AIDS cases with western block dates between that time period. We constructed the U I code for all of those, we started collecting social security number on our AIDS cases at about the same time that we instituted the U I system. And we came up that only 26%, 454 total cases, were in both systems. If you had 100% completeness of reporting, or if all of your HIV cases were reported, you would expect all of these cases to be down here. What this means—kind of another way of visually seeing this—is that if this pie chart was the total HIV infection that's in your community, only the yellow portion of the pie chart, the 26% portion, is the part that our statistics show. The blue section, the 74%, isn't in our database, so at that point we were realizing that we're missing a lot of data through our U I system.

And any characterization of the epidemic that we would be using with this data has a serious bias to it.

Some other performance standards that we looked at is, how is our ability to link to other ancillary or other data sets that again, this is kind of looking at the epidemiologic monitoring capabilities. Could we link this data to other data sets. The first thing you have to do is have all components of that unique identifier in the other data set. We would do that with our death records and our medication records, but we couldn't do that for our birth records, our STD records, and our TB records.

These are very important right here, to try to find monitoring of the co-infection data. Something that we currently do with AIDS reporting data. These are very important data items because of the ability to look for potentially parinatally exposed cases, and looking for births from mothers that may be HIV positive. The STD records—again this is trying to epidemiologically link some of the data that we would be collecting through HIV and seeing how many co-infections of other STDs is characteristic within our state, and we were not able to do that with the U I.

Another interesting study that we did—and boy, this is not going to come out real good at all, so I'll just walk you through it—is that we did a follow-back study of 765 cases, or reports, of HIV that we had received via U I. And what we attempted to do is go back to the provider that reported them to see, can we obtain that medical chart again. Two reasons to do that. Number one, is there missing data—wrong or missing data—on our original report. Number two, is there additional data in the medical chart that we might need that would be epidemiologically important.

Only 60% of the cases could we locate by going back to the medical provider. So that means only 6 out of 10 were eligible for us to go back and either find more information or go back and add information that we would need subsequently.

This becomes very important whenever we say, we don't have risk information as one of our items that we're collecting via U I. Risk information is something that even within AIDS case surveillance, typically takes call backs to the provider to get the ongoing dialog with the provider in order to get that information. It's normal with AIDS case surveillance currently. 60% of the time with U Is could not pull that chart if we needed additional information, in addition to that.

When we did go back and find those cases that were missing, missing components of their U I originally, only 50% of the time could we pull up the race/ethnicity. 40% of the time could we locate the true social security number. 100% of the time for gender and DOB. Again, those are two data items that are typically fairly high within the database to begin with, so we weren't looking back for very many of those.

One last statistic that we looked at, is the performance standard of representativeness of reports. We already know that this is a fairly biased system, because of the number of cases that are having to be dropped through laboratory surveillance and the providers that can't link back at their level, some of the data. We looked and saw who was source of report for the cases during that three year time period, and it was very heavily skewed to a public provider source.

Anecdotally and looking at other states, this should be closer to about a 50/50 spread. You should be looking at, at least as many private patients as you see public patients. Again, anecdotally we've heard that as some of our discussions over lunch today with Mark. We are looking at possibly a 2:1 ratio. Two privates to every one public patient that's being identified. So, again we know that this is skewed. To what extent and statistically could we factor out some of the fudge that we see in there, it doesn't appear as though it's there.

What are the take-home messages? I'm going to break them down into three different groups. Number 1 is going to be implementation issues that we saw. And that's one that we've already talked about, the inability of private laboratories to report the U I information required to construct the report itself. Predominantly that's social security numbers. Laboratories just typically don't have social security numbers.

Another kind of anecdote on that too, HMOs typically have as their social security number, the person who carries the insurance policy. So even though we were collecting an S S N from an HMO, for instance, we weren't sure if that was the person's social security number or that was the policy holder's social security number. So again, anecdotally, we knew that there were some flaws with the use of social security number particularly.

And some providers, and clients themselves, were unwilling to report the U I. We'll get into some of those issues in a few minutes. A lot of provider buy-in to the system, what's in it for me and my client on an individual basis was a very hard issue to try to sell, because we were trying to use the heartfelt strains of for the common good of the whole state to understand the epidemic, so we can get the money out in the global sense. It worked for AIDS folks, but it's harder to sell with HIV.

And that kind of comes back to the local health department's inability to complete the incomplete reports, if a provider reported a case to them. We already were able to statistically show that the majority—or almost half of the time—they couldn't find the source record. So that kind of lead to a lot of buy-in problems from the providers themselves, and the local health authorities. It didn't help the patient that was being provided the report on, and there were no reasonable public health measures that were being afforded to the patients themselves. So they didn't really see this as being a viable utility, and there is from the very beginning, some implementation issues with folks, really not liking the system.

Problems with the U I reporting system, in general. We know that the reporting information, just macroscopically and again through some of the founded scientific statistical techniques, we saw that it's incomplete. It's fairly unreliable, and it's very unrepresentative of the epidemic.

The final thing with the U I system is that it doesn't allow us to go back and do any type of support referrals or voluntary partner notification services, back to the individual reported.

Problems unique to a U I system itself. If any component is missing, like the social security number, or the date of birth, the unique identifier can't be created, and it can't really be counted as a case. I know that there are statistical methods that some folks are trying to devise, that you do what's called a fuzzy matching technique, where you say, okay, if I've got a race, a gender, and a date of birth, but I'm missing the social security number, can I kind of maybe reliably find a patient in my database that it should or could link up to. Again, those are very theoretical. Those that have devised or are talking about those were trying to look at do they have a model that we can try to apply to our system. And see if we can fuzzy match some of those missing data.

Those that are missing any data we're not able to--again I don't want to harp on the same thing—but we can't go back and count those cases, because we can't go back and get them. Most providers don't contain in their data systems all of the elements that are required to report a U I. Predominantly again, social security number. Labs also sometimes will have problems with date of birth. Instead of date of birth they'll have age, for instance.

Again, coming back to the—going back to the—provider, even if you do have a

complete report, if you needed additional information, for instance risk information, only 40% of the time—or only 60% of the time—would you be able to get that.

Okay.

Why is HIV infection reporting critical? And why is it something we're all looking at and exploring together? And holding meetings such as this. First of all is the leveling of AIDS cases and the decline in AIDS deaths. And a lot of that has to do with developments in treatment. Our overriding condition at the TDH is that we're not satisfied with the data that U I reporting has been providing. It was conceived as a unifunctional limited utility system. Again, we provided it—or we implemented it—to provide a system to profile the epidemic. To try to get away from some of the issues that we know that are critical in our plate right now.

These factors—kind of going into them a little bit deeper—these are the AIDS cases in Texas, again, I wish this was in color. It doesn't show in color very well. This is our white. This is our African-American, Hispanic, and other. So you can start seeing some of the reporting trends using AIDS case data itself. That starting in this time period, there is some very significant change in the profile of the epidemic that we see with using AIDS case data.

We also know that treatments—this is pre-1996, but let's go ahead and call this pre-protease inhibitors. And now what protease inhibitors are doing is extending the time from the time that you're tested, to the time that your CD4 drops. And even from the time that your CD4 drops to OI development, extending the quantity and quality of the person's life during that time period.

There's also much research going on in this model right here, of what protease inhibitors are doing, critically in this time period. The ability to shorten the time from HIV infection, to the time that a person's tested, and subsequently on to protease inhibitors, you may be able to lower the setpoint of how much virus is in the person's body. There's a lot of implications at that time period that you can lower what that complete viral load is, the highest viral load that a person has, it has some very positive effects on the quantity and quality of life. It also—some of the research that I've been seeing is also suggesting that it has implications as far as the person's infectiousness during that time period, too. So again, it's a very exciting time in terms of what some of the medical field is providing for us, but it's messing up our understanding of the epidemic, because we are so heavily reliant on AIDS case data to profile that epidemic.

And the other thing that I wanted to talk about, and that was one that Dr. Locke talked about, and that is kind of the changing political winds. Why now? The political winds are changing. Oh, that one came out! That was the one I needed in color! Because it'll get us through 12 of 97. At that time we had 27 states that had named case reporting.

And those are all depicted in yellow. We also had three states that had named pediatric reporting. At that point, Texas does have named pediatric infection reporting. There is also one other state that's not depicted on here, Maryland, they do have symptomatic HIV infection reporting by name. So if you add that all up there's 27, 3, 31 states that have some form of named HIV infection reporting. That was through 12 of '97.

Since then, New Mexico and New York also have named HIV infection reporting. We know that this is something that is coming down the line. Again, for a lot of the reasons that we talked about earlier, about the changing profiles of the epidemic and the need for having earlier infection data.

But it also is kind of scary. Because what we in our bureau want to do, is have a very proactive stance in the development of those rules. We would like to be the ones that put into place the mechanism through which our reporting occurs. Again, this is a Board of Health ruling that gives us these rules. But we have very strong confidence that if we don't put into place a sound, reliable HIV infection reporting system, that the next time our Texas legislature meets, which is 1 of '99, it very easily could mandate—it's done it before, it's mandated reporting rules before—but here they may mandate the requirement to have named reporting. And then anything that was written into that legislation, we would be obligated to also provide.

It's not beyond anyone's stretch of the imagination that if it's not the Texas legislature that does it, it might be federal legislation. They have passed things like spousal notification. Routine testing of the perinatal period. We do know that the federal legislation can come in and tell us how to do things. So we know that we have the responsibility right now to put into place very proactive, common sense, effective systems.

That leaves me with my note of what have we done.

What we did—again, because we realized that the U I system couldn't be improved to a readily accepted level—we convened an internal work group in the fall of 1997 within our bureau at the Texas Department of Health to look at what we needed to do. There were a couple of premises that we made at that point. Number one: We knew that everything we had done up to date was all experimental and had all failed. We had done aggregate reporting. We had done unique identifier reporting. And we had nothing to show for it.

So there was one system that we had not tried yet, and that was named reporting. At that point, we wanted to explore options. Were there any other options that we hadn't tried? But we also knew that named reporting was going to be our gold standard, by which we needed to implement a system based on. So the first thing of our work group was, we tried to define what good HIV surveillance can provide. Again, we weren't hung up on names at that point. We just sat down and said, what's the end result of our activities? What do we want our end result to be? We knew that we wanted the patients that were reported, the

infected persons, to receive timely referrals to HIV care services. A basic provision of service. We also wanted an accurate minimum estimate. The ability to monitor recent infections, as opposed to long-term or chronic aspects of the condition. Recent infections, because again, the discussion on where protease inhibitors and the setpoints and the early stages of the infection. We wanted to be able to support planning, targeting of services.

We also wanted to assist physicians. Don't forget we had buy-in problems from physicians, that they were saying, we want you to help my patient. We knew that we needed to help the physicians in providing disease intervention services that they were asking for, which would also necessarily allow public health investigations.

The final one, the demonstration of needs. How can we have the data set. We needed a data set that could provide our ability to compete for the scarce funds.

So at that point, we went back to original premise with U I and said, we need to create an HIV infection reporting system, that again, didn't require the use of additional resources. If we merged, what if we merged HIV with AIDS? The AIDS system is already there, it's going to be low cost. And the system, the infrastructure, is currently already there, and we new that it would require little alteration to the system that we had in place right now.

But in order to do that, we again, had to grapple with is this going to be names? Or is this going to be some type of a yet-to-be defined system. We looked at—well—what do names system provide, and what has U I provided for us? Again, the work group was saying, are we sure that we want to go for a named reporting system. Does the system protect confidentiality, and that's a "yes" on both sides.

There's a misnomer that I want to clear up though, that's the word, "anonymity," as opposed to "confidentiality." Confidentiality is to where you don't share information outside of its "need to know" basis. Anonymity means that you don't know the identity of the person at all. Unique identifiers do not create anonymity. There is legislation on the Health Reform Act of 1996, calling for a medical unique identifier be created for all of us that would carry through all of our lives. It's kind of a like a super social security number, so to say. And there's a lot of issues in terms of privacy and the compromise of privacy that a unique identifier would create for a person. So please, get rid of the idea that a unique identifier creates anonymity for the person reporting, and just provides an avenue to where you don't see the person's name. If you have a database that does have the U I and a name, there is the possibility that you can get the name. It's not an anonymous system.

The other needs that we need a reporting system to do, we looked at U I, and it could not do any of those: Allow the public health interventions. Allocate resources. Again, it was an inferior system. We realized that a name reporting system—an extension of our AIDS surveillance mechanism into HIV—could do that.

Very recently—this is not going to show up very good—very recently Dr. Cox, through the CDC, used some of the data that we had provided and Maryland had provided, and looked at a number of the common, scientifically understood techniques for how to evaluate a surveillance system. Sensitivity, specificity, timeliness, simplicity, flexibility, and looked at the named system versus the U I system. The CDC has not come out at this point and bluntly said named reporting system is the way to go. Yet, at the same time, they are coming in and saying, the U I system—the named system—does have all of the performance criteria that we need a system to have, and a U I system does not.

So we realized at that point, we do need to present a proposal for named reporting. But we did not want to do something like that, that was a complete proposal, without input from our community. So we sat and figured out who are stakeholders were across the state. Typically we look at the infected and advocacy groups as are typical stakeholders. We took that and broadened it as far as we could. TDH staff—Texas Department of Health staff. Our local health department staff. Our partners in public health. Contractors through our organization and others that are HIV related. Legislators. Community planning groups and the general public, interested parties in general. We realized these all had a viable stakeholder claim in the system that we would be presenting. So we formed this. We formed a recognition of who those stakeholders were—and I think I'm running kind of over.

So at that point we convened a number of meetings across the state, in order to solicit input and tried to create dialog with members of the stakeholder groups that we had identified. Not only the advocacy groups and the infected population, but also our public health partners. We held meetings—not only in the public health forum style—but we also attended meetings that were already in existence. Just like this one. Sat down and talked about unique identifier surveillance versus named reporting system. We also sat and talked with legislators one-on-one about what they perceived the legislature would do, and how their constituents would act if we were to propose named reporting—

[Tape off]

[End tape 5, side 2]

[Tape 6, side 1]

MR. HAMACKER: --five months now a dialog and an input.

MS. BARNARD: Are your public meetings will rancorous? Are they confrontational?

MR. HAMACKER: Not really. We've had—if you took a straw vote of those for

the reporting system and those against, it'd probably turn out about 50/50. This is very different than what happened in 1992 when we proposed it. Again, it was a top-down administrative proposal before, and it was very one-sided and fairly rancorous.

I happened to be on stage at that time, and I really wasn't comfortable being there.

[LAUGHTER]

These, on the other hand, are very civilized. People—though we were asking for input about what could a viable system be, typically if there was a negative approach it was, "No names. No way." It's like, folks, we can't go anywhere with something like that. I need a good system. I have a public health that's depending on me to have a good system. No names, no way, doesn't help me out. I need help in how to make a system work.

We did get a number of concerns from our infected communities, because of this. We knew before that named reporting, the concern that named reporting made deter testing. A number of scientific studies that have gone in and looked at this issue. We've participated with the Mesh Study that was being conducted nation-wide. Our data is very consistent with the national data. One in five people—only one in five people—know what reporting statutes you have on the books, among the affected or infected population know what your reporting rules are, named versus U I, versus none at all. Within ours, and again, across the nation, only about 2% of the population stated that named reporting would be the main reason for them deterring testing.

Typically the two biggest reasons for people to not test or to delay testing was, fear of what the results would be, and fear of how to handle a positive test. So how that affects the person on a personal basis is what those studies were finding. There's also the fear that named reporting would eliminate anonymous testing. And this goes back to our desire to have a proactive stance in this. We do see the benefit of having an anonymous testing option, along with a named reporting system.

So actually, in our rules it's part of our law that HIV testing through the anonymous option. The anonymous option being provided at all public clinics, we wrote into the proposed rules also. So it's now—not only in law—but it's reinforced by the rules that we're proposing.

There's a constant concern about the confidentiality of reporting information. We took that to heart. I've been out of the office—including this week—just about every week since the beginning of July. The reason is that I'm visiting all of the reporting sites, the local health department reporting sites and looking at their security standards and trying to provide—through a leadership model—techniques that can provide very basic, general, standardized data security activities.

Another concern is that there is no guarantee of care or resources if a person gets reported. And that's what I'm going to bring up in my conclusion also, is that if a person gets reported, we cannot guarantee that they're going to get the newest protease inhibitors, and we can't guarantee that we're going to take every person and make sure that every physician visit is documented and obtained. We can't do that. We don't have the resources.

So what I'm going to offer to you is that thing that we're offering through our proposal, and that is to provide a public health safety net to provide basic public health functions to those that would be needing those.

Ongoing bureau activities. Even though that we are in the middle of proposing a named reporting system, we established a community consultation group in June of 1998. And we designated a coordinator within our bureau to make sure we had a single point of contact to that community consultation. It's a very diverse group made up of again, many of the stakeholders that we identified earlier that can come in and provide a resource to us. Not about debating whether or not names is the way to go, but how can we implement names to where it's the best and the most useful system to the community at large. Again, trying to get out of the role of being the central office, TBH, telling the locals what to do. We want the locals to understand and to recognize what their resources and what their capacity in this system could and should be.

We're also planning an evaluation of the new reporting system. With that evaluation of the new reporting system we are looking at is there a point in time that after a person has been reported, and that window of opportunity for public health interventions has surpassed, is there a time that we can no longer have the person's name. Is there a time, after the named reporting has occurred, that we could encrypt or encode that person's identity and no longer have to maintain names. So again, we're looking at that evaluation after the fact, as opposed to an experimental basis during the middle of an epidemic.

We're also responding to individual inquiries about any of the proposed changes. That sounds like a trivial feat, in reality, we've tried to make our dialog, our information, and where we're going as open as we can. A lot of this information we've put out on the internet. We've got mailing resources that anytime we make any type of a change, the affected community input request, we fax out, we mail out, and we try to solicit as much before we go, and as we're going. Again, having that open ear. What are the concerns, and let's listen to the dialog.

In conclusion, the problems of U I reporting, if it could be made to work, don't forget it would still be a very limited system that could provide a characterization of the epidemic only. It's a unifunctional system. So if it could be made to work—that's a big if—if it could be made to work, that's all it could do. We do know that its item completeness is very low. It's unacceptably low. It has very limited prospects for gaining a

better understanding of that item completeness, because you can't follow back and get that information from the provider.

We do know that it under-represents the private sector. That information is not reported consistently or reliably. Barriers continue to be private laboratories. We don't want to mandate that they have to report these items for fear that we may deter them providing the test result back to the patient. We don't want to intervene in that—in an auditing capacity.

We know that another barrier is enhancing the willingness of providers to collect and patients to divulge their information, if they have it. Migrant workers. Illegal aliens. Typically other segments of the population typically don't have, or know, or care if they've got a social security number, for instance. We also know that another barrier is increasing the local participation in a unifunctional system. So again, in conclusion we kind of realize this ain't workin', and it's best to discard it.

Without beating too much of that to death, we recognize that our public system cannot guarantee the level of medical services that we have to offer through a named reporting system. But we are looking at how can we provide safety net. That safety net is we want to make sure that everybody that tests positive knows of their positivity status. It's a very, very important public health provision that we can have. There are people that are tested and never return for their results, or don't know—they kind of expect public health. If I'm positive, they'll come and tell me. I think I heard that earlier today, that there's some expectations that public health is providing some of that safety net. So we need to put ourselves—to position ourselves—to be able to provide that.

We also need to have the ability to direct our resources to the person in our communities that's at most risk for HIV infection, and that is, the person who's either the sex partner or needle sharing partner of a person that is HIV positive.

With that, I have no idea how much I went over. But I sure do appreciate the opportunity to talk to you all.

MS. CORKRUM: Are there any questions?

MS. REEVES: You were saying that interfacing the other databases, are you all on-line with modems? Are you concerned about—

MR. HAMACKER: No. No. No. No. No. No. We are not on-line with modems. No. Connection with other databases is that we would—like death certificates. We go and obtain their data.

We have very strict and stringent confidentiality and security provisions by which

we're not using modems at that time. There are plans on how to devise some secured ways of using modems, but again, it's—believe me—any use of electronic sharing is a very, very secure and conservative data exchange.

MS. REEVES: The other question I had was, you we're talking about monitoring ways to reverse and see whether or not you needed to go back to—whether it was going to be possible to go back if you did need it, to some type of a U I system, as a way of doing it, given the information—the recent information—from the World's AIDS Conference regarding the resistive HIV with the protease inhibitor interventions. Would there be concerns about that, given the new resistant people, we're going to need to know a way where they are, and how to find them, with this new impending epidemic we have coming down on us.

MR. HAMACKER: Right. At this point we're completely blind and oblivious to that component within our community. We can't monitor for any of that condition whatsoever, as we currently stand. So would there be a need to do that? I can see that. How to implement, how to implement the strategies to look for and spawn a public health response, based on the data that you've collected, that's one thing that I didn't go into about is some of our implementation plans.

It seems real easy. I presented in probably two or three minutes, about how you just add HIV infection to the front-end of your current AIDS surveillance system. It's not quite that easy. You really don't just push a button and expect it to happen. You really need to have—and we are developing through participation and work groups with our local health departments—how can we put into place the strategies and the activities needed to further front-end the reporting. It's not quite as easy, but what you're asking right now, as far as when you do have the need for response, what are those needs for response, and at what point do they get monitored.

MS. REEVES: And one comment so that you don't feel so guilty. I have the AIDS Centers for Excellence in Prisons in Washington. So we have the ability to treat everyone. We started new protocols of people on protease inhibitors within a month after their recommendations. We found that there are a huge number of things—other than availability—to determine whether or not you can effectively use them, including personality and whether or not they would take them in their quarters. Even when they are locked up. And it's available to them. And so, you know, it's not going to be—it's not nearly the panacea—

MR. HAMACKER: I don't want to—I didn't want to use the pun about the captive population, but, unique identifier surveillance does occur throughout our prison system, our TDCJ—Texas Department of Criminal Justice. With a captive audience like that, you'd expect to have 100% of your items completed for U I surveillance. We found that it's about 75% complete, because again, it's that social security number coming back. You'd think the prison system would have readily available the social security numbers, on all of their

inmates. About 25% of the time it doesn't come through their routine reporting system. Why? I don't have all of those answers.

MS. CORKRUM: Okay, we have a couple people signed up that would like to speak to this issue.

Judith, would you like—Judith Billings.

MS. BILLINGS: Thank you very much.

I expect—for the record I am Judith Billings. Private citizen. And am currently chairing the Governor's Advisory Council on HIV/AIDS and did chair the task force within that council on HIV surveillance, and we did a six-month look, including some of these same kinds of things, community forums, written comments, all of that to make some recommendations on what ought to happen in the state of Washington.

I also sit on the President's Advisory Council on HIV/AIDS, and sit on the board of directors of both the Northwest AIDS Foundation and the National AIDS Fund, so I hear a little bit about this, a lot. And it is a good way to gain perspective from a number of different avenues.

The couple comments I want to make are very short today, because I assume that as this group moves forward with their recommendations and possible changes, hopefully changes in current surveillance WACs, that there will be other opportunities to talk more in detail.

But the one thing I think all of us agree on, without any question, is that we absolutely have to have HIV surveillance. Given the change in the nature of the epidemic, we simply have nothing reliable to go on anymore. And for myself, being a woman, and someone who has always worked with young people, it's a particular concern to me with what we do know about where the epidemic is going, rates are increasing fastest among women, among young people, and particularly among young women, and particularly among young women of color.

And so, we really need to know where we should be putting our resources and how to reach people because, the virtual vaccine we have right now is prevention. And if we don't know who to talk to, and what messages to use, can't do that effectively. But until we have a vaccine, it's the one best way to really control the spread.

The second thing is, that it is not something we can put off, given what is happening with the epidemic. It really has to be done very immediately, and I think that's the one strongest message I want to bring to you today as the State Board of Health, is please, please, don't drag you feet.

I know this is a difficult issue. I mean, after dealing with it the way we have in the depth we have over the last six to eight months, it's fraught with all kinds of things. Because you're dealing with life and death. You're dealing with discrimination in every important area of people's lives. Whether it's their most intimate relations, their jobs, their insurance, whatever it is. And so naturally, you get very strong opinions about what needs to be done.

As far as whether one goes with a unique identifier system or a named system, the thing we need is information. And if you can get that without having names that are forever on a list—and I can tell you that that is a concern to me. I don't want to see a list somewhere of everybody's names that's kept in perpetuity. You probably are all aware of what happened in Illinois a year ago, where the legislature tried to get a hold of the list of names of people who were HIV positive, both health care workers, so that they could warn patients, as well as people, so that doctors and health care folks working with people who are HIV positive would know that. Whether or not the person wished to reveal that or not. And that's the thing that for most of the folks who are concerned about confidentiality, is the scary part. Is what you get when it gets really into the political realm.

I mean I haven't heard anybody be very afraid—there's never been in this state, a leak from the state health department. And you're never going to be able to control knowledge that you don't want others to have. No matter what kind of a system you have. For myself, within two weeks of the time I was diagnosed, and before I'd even talked to my family, I got a call from the *Tacoma News Tribune*, asking me if it was true, that I had been diagnosed with AIDS. So somebody just could not resist making that suggestion to the *Trib*.

And I think that's the thing that even for some of us, there was never a question in my mind, but what I wanted to talk about the fact that I had been diagnosed with AIDS, but I wanted to do it in my terms. I didn't want somebody to come up with a gotcha.

And so those are the kinds of privacy concerns that people have. And they're very real concerns, and you know, I have said this in many venues, but we would not even be worrying about whether a name was attached to an HIV diagnosis, if we as a society were still not discriminating [inaudible].

And we have a lot of work to do there, and that's one thing we need to pay a lot of attention to.

Thank you.

MR. REID: Kim Colaprete?

MS. COLAPRETE: Good afternoon, and thank you for giving me an opportunity to speak today. My name is Kim Colaprete, and I'm the statewide community organizer for the Northwest AIDS Foundation.

And as Judith said, there's some extremely strong opinions about this issue, and I'm here to express one of those extremely strong opinions.

The Foundation has been working on this issue for quite a long time. We participated. We worked with the Governor's Advisory Council. We participated and I was present at all the state-wide forums that the Governor's Advisory Council did around the state on this issue.

And one of the big issues that came up over and over again is that there is great fear in this community, from people who are most at risk and are most affected by HIV and AIDS, around named reporting.

We feel that—although we are committed to creating the best HIV surveillance system that we can create in this state—we are also committed to finding a system that meets the needs and the considerations of those people that are most affected. Our information that we have received and studies that we have shown—published studies—there are 9 published studies and I have some copies of that information available—show that overall, people at most risk would not be tested. Would delay testing or would avoid testing if they knew their names were going to be reported.

There's also a study out of Los Angeles that shows that if people who are tested know their names will be reported, 23% of them said they would not go seek care until they were sick. And that's a great concern to us, if our goal is to get people into care early, we have to get them tested, and we have to make sure that they are protected.

Confidentiality is extremely important, and as Judith mentioned, it's not so much the fear of public health breaching confidentiality, but of some other entity: The legislature. The federal government. Being able to get access to those names.

So we feel that it's vitally important that if people are afraid to be tested, that's one more barrier that we are presenting in a name based system that keeps people from going in to seek testing, and if we don't get them in the door to be tested, then we are not going to be effective. And anything else we try to do with an HIV surveillance system.

I appreciate the difficulties that Texas has had with their unique identifier system. It's very different from the information we've received from Maryland which is quite happy with their unique identifier system. They have been able to improve accuracy over time. They've been able to track incomplete data back to providers. They've also received high levels of risk-related data from the unique identifier system. And right now there are four

other states and territories, Massachusetts, Connecticut, Hawaii, and Puerto Rico that are moving forward in implementing a unique identifier system. There's also a bill in the California legislature that will implement a unique identifier system.

So there are other states that are confident that this system can work, who are moving forward.

We are available to answer any questions, or provide any information to the Board. We have put in a request to present to this Board to present our proposal, or a proposal, for a unique identifier system in October. And I look forward to being able to hear back from the Board in regards to that request, and to present our proposal to you in October. And I thank you very much.

MR. REID: Thank you.

Was there anyone else?

Okay.

MS. BARNARD: Can I propound a question?

MR. REID: Sure.

MS. BARNARD: Well, is it, Tom, since you were the one that introduced the subject, I do believe, I was surprised to see we were one of the few states in the nation that has done—we haven't done anything. So, is it going to be before the Board in October, what is your—are you recommending that we take this up right away? Or—

DR. LOCKE: I would absolutely recommend that. I think Ms. Billings said it with extreme eloquence, is that we're talking about something that's of real immediacy. And the level that I deal with this on is meeting real people whose lives are devastated by this epidemic. Every single case we see as a failure of prevention. And that's what ultimately this Board is going to have to decide. Is what system will do the best possible job of preventing HIV, and thus making, redoubling our efforts on this epidemic.

The data we have—and it's sketchy—is that we are at best holding the line in the HIV epidemic, and we may be losing the battle. And this is in the country that has the most resources in the world. World-wide, there's no question whatsoever. We are losing the battle. So this is a very serious issue.

I think we're behind the crowd and we need to face it as expeditiously as possible. So I very much welcome the Northwest AIDS Foundation's proposal in October, and I would like to see us put this on a fast a track as we can. Within the guidelines of the law.

I think we're—one last point—I think if State Medical Association and other groups are depending on us to act on this. If we don't, if we've not taken some sort of action, hopefully decisive action, by the time the legislature convenes, I can virtually guarantee there will be another effort to try to resolve this legislatively.

And I don't think that's appropriate. I think boards of health are where this issue belongs, and the best forum to hear all the different views and considerations.

MS. REEVES: And if the World Health AIDS Report and the experience of Steven Tavered at the University of Washington is true with the clinics that's using the new protease inhibitors—and we're using a lot—we're seeing unusual resistive factors happen. With people not being able to respond to them because of previous use of antivirals, and the question is coming up is, when this group, when we do not have or cannot put together a tolerable group of protease inhibitors for them, we will be right back to 1981. What are we going to do with them, and how are we going to attract their contact, because we aren't going to be able to do anything with them also.

That is the very latest information that's come from the first results and studies of the first round of use of protease inhibitors. So it's imminent, because we are facing another imminent set of urgent questions that we're going to need to have a lot epidemiology on follow-up.

I see you shaking your head, I accurately represented that.

MS. BILLINGS: Absolutely.

You know the one other thing I would say in terms of moving ahead as expeditiously as possible, is I'm sure you're all aware that there a couple of counties in this state that have already taken on maybe doing a county system of some kind. And the last thing we need is some kind of patchwork system, instead of a consistent state-wide system that gives us the state-wide information that we need.

MR. REID: Anything else to come up on this subject?

MS. BARNARD: I'm sure we don't need a motion, but the Board wants to move ahead.

MR. ALBERT: We have it on the agenda planning calendar.

MS. BARNARD: If you have it—all right.

MR. REID: And we have time between now and the legislative session. And if we

are going to take action, it is the type of action that public notice should well be given.

MS. BARNARD: Oh, absolutely. Absolutely.

MR. REID: I'm a little fearful that we may not be able to get through with everything, Karen, and I don't want to ignore Patty and her report. So be prepared to come before us again. And if we—well—we'll cross that bridge if we don't get to it.

Patty?

MS. HAYES: Yes, sir.

I can be very quick. Provided you don't have any questions.

MS. CORKRUM: We've been pretty quiet on the questions, for you.

MS. HAYES: For the record my name is Patty Hayes, the legislative liaison for the Department of Health.

I have three items for you to go over with today. I want to kind of consolidate them. So let me start with the last one first, Mister Chair.

You have in your packets under tab 15 an update on Dawn Mining. This was a request from your Spokane meeting. When I talked to Sylvia she thought the best way to deal with this at this point is to give you a fact sheet on Dawn Mining that literally goes through kind of a year-by-year analysis for you. Because of the litigation and other issues with this, I've alerted Hal Dygert that if you had any questions on it, he'd be happy to talk more specifics next month with you.

So if you want to take a look at that report and then if there are specific questions, I would respectfully just ask that you delay those 'til Hal is here, since he's been involved with the litigation on that.

MR. REID: If it started in 1956, it can just stay for another 30 days.

MS. HAYES: You think so?

But hopefully this will give you enough information so that you're feeling you're up to speed on where we're at to date on this.

Next, we sort of delayed my session wrap-up discussion, and it almost feels kind of a moot point. So what I would like to offer with that is all the issues that we've discussed and the information that we've disseminated over the last few months are all in the process of

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- ☒ For Your Information
- ☐ Per Our Conversation
- ☐ Read & Route to Files
- ☐ For Your Comments

Per your conversation with Sylvia Peck. Upcoming Board Meeting dates are October 14 and November 12. Perhaps you could speak for 1 hour? I am standing by to make your travel arrangements. Enjoy your vacation! (MZ)

Excerpt

their employees. Mr. Albert said he would talk with Dr. Hal Stockbridge, L&I, about this issue. Responding to Dr. Locke, Mr. Albert said there is a Strategy in the "Chronic Disease" chapter for L&I to expand resources to inspect or assist greater numbers of employers to prevent occupational disease. Replying to Mr. Osaki, Mr. Albert confirmed the Department of Agriculture (WSDA) has no new Action Strategies related to foodborne illness, though they are providing training and technical assistance dealing with fruit, fruit juice, milk, and milk products.

ACTION: To adopt the draft Action Strategies for the *1998 WSPHR* in the Board Reading Packets. Motion/Second: Locke/Corkrum. Carried unanimously.

DEPARTMENT OF HEALTH UPDATE ON SUNRISE REVIEW OF SURGICAL TECHNOLOGISTS (Reference 1 and 10/97) -- FOLLOW-UP

As requested by the Board at its October 1997 meeting, Mr. Miyahara provided an update on DOH activities related to the Sunrise Review of Surgical Technologists (STs). Mr. Miyahara noted Sunrise Review hearings are often politicized and adversarial, making it difficult to sort through issues. Regarding ST regulation, the Board recommended DOH try a different process to see if agreement could be achieved.

Representatives of the Medical and Nursing Care Quality Assurance Commission, practitioner boards, and others worked over 6-8 months and reached some common definitions so that communication could be clearer. There is now agreement that some minimal regulation of STs is needed so that their practice falls under the Uniform Disciplinary Act. DOH will send a letter recommending minimal regulation to both legislative health committee chairs.

Mr. Miyahara said the negotiated committee process had both positive and negative aspects. Follow-up meetings were needed to clear up misunderstandings surrounding the definitions. Agreement about need for regulation was reached but not the regulation level. DOH is working with legislative committee staff who understand the process. Mr. Miyahara said he would update the Board as the legislative process unfolds. The DOH committee process created a different environment to approach issues. Much has been learned along the way. Responding to Mr. Reid, Mr. Miyahara said it might be possible for the letter to the chairs to be a joint DOH/ Board one if acted upon quickly. He suggested it could be brought up again during the legislative update in the afternoon.

AIDSNET COUNCIL POLICY PAPERS ON: 1) NAMED REPORTING OF HIV INFECTION AND 2) PROVIDER ASSISTED PARTNER NOTIFICATION FOLLOWING HIV DIAGNOSIS

M. Ward Hinds, M.D., M.P.H., Snohomish Health District (SHD) Health Officer, said it was a pleasure to speak before the Board, which he had once chaired. His presentation was based on position papers in the Board Reading Packets recently developed and approved by the AIDSNET Council and Washington State Association of Local Public Health Officials (WSALPHO). The AIDSNET Council is composed of directors and coordinators of 6 regional AIDS Service Networks created in the 1988 Omnibus AIDS legislation.

It has been 17 years since the AIDS epidemic was 1st recognized in the U.S. Many changes have occurred both in ability to recognize the epidemic's course and public health's ability to prevent and treat the disease. During the last several months, the Council has re-evaluated its position on several prevention and control measures based on current research.

The Reading Packet contains 2 position papers for consideration. Both relate to existing Board regulations. The 1st is to require name HIV reporting by providers and laboratories while maintaining current laws and regulations which require access to anonymous testing in the public sector. WSALPHO supports this position. In 1984, the Board approved name reporting of AIDS cases. There is an average 10-year lag between the time when an individual becomes infected with HIV and when AIDS develops. The lag period has always been problematic in terms of trying to track the disease's course. In recent years, treatments for HIV infection have become available which are effective. These prevent a large proportion of people infected with HIV from progressing to AIDS and may also reverse effects of HIV infection on people with AIDS. This has made it more difficult to use AIDS reporting as an accurate indicator of the epidemic's trend and is likely to worsen. Without HIV reporting, Dr. Hinds said public health will have poor knowledge both about HIV prevalence and population groups being most affected and about associated behavioral risks.

Dr. Hinds stated the majority of states include HIV as a reportable condition, as has been recommended by the federal Centers for Disease Control and Prevention (CDC). Besides the need to track the epidemic more closely, it is also essential to be able to identify people with HIV infection early so they can be linked with effective treatment as soon as possible. This is particularly important for population subgroups including young children and women in childbearing years. We now have the ability to prevent in most cases transmission of HIV from pregnant women to their offspring by instituting treatment during pregnancy. It is important for public health authorities to know when pregnant women are infected so they can work with providers to ensure treatment.

The AIDSNET Council also recommends public health work with HIV-infected persons to sensitively and appropriately identify sexual and needle-sharing partners and provide HIV counseling, testing, and referral to care services. Barriers to provider reporting of HIV-infection persons and their partners in regulations, policies, or procedures should be eliminated. Currently, there are barriers to partner notification being undertaken by professionally training public health staff. Private providers cannot give names of infected persons or their partners to public health authorities unless the infected individuals refuse to notify partners themselves, or indicate they are unable to do so. By removing these barriers, public health would assume major responsibility for partner notification.

The goal is to maximize knowledge about people who are HIV-infected as early as possible to make sure they are aware of effective treatments for themselves and prevent further infection from occurring. Recent research suggests people in relatively early stages of HIV infection are potentially the most infectious, as they have the highest viral loads. Behavioral changes can interrupt the transmission cycle.

Dr. Hinds is aware these positions are controversial and must be carefully considered by the Board. It has been suggested that instead of name reporting, unique identifiers might be used to accomplish some of the same objectives. The AIDSNET Council is unconvinced that unique identifier would accomplish the objectives fully or as efficiently as name reporting. Texas and Maryland have had mixed results with unique identifiers and considerable difficulties in getting their systems to work. Name reporting is important if public health authorities are to make individuals aware of treatment options and contact partners.

Ms. Reeves asked whether name reporting would be in conflict with federal law, which requires those who voluntarily submit to testing in correctional settings not have their HIV status revealed. Dr. Hinds said he suspects such a conflict does not exist. Partner notification as conducted by public health officials never reveals the source of potential exposure. He reiterated that the Council also recommends anonymous test sites still be maintained by local health jurisdictions. These serve an important purpose in making contact and providing education to people at risk of infection. 98-99% of people who seek anonymous testing are not infected. Once infected persons enter care, anonymity would no longer apply.

Dr. Locke praised Dr. Hinds' presentation. From local health officers' perspectives, these are critically important strategies for the next stage of controlling HIV infection. Strategies of name reporting and provider-assisted partner notification are linked. He underscored the importance of early treatment as a way of preventing disease spread. Worldwide, 9 out of 10 infected people do not know it and would not find out unless they were told they were exposed and were appropriately tested. Local health officials are sensitive to confidentiality issues. Systems have been set up to protect privacy rights. The goals of optimal health care and prevention of new cases are mutual. AIDSNETS' position is supported by the Washington State Medical Association, CDC, and other national groups.

Responding to Mr. Reid, Mr. Miyahara said DOH has started the rulemaking process. Mr. Reid said the Board is just in the information-gathering stage. Replying to Mr. Osaki, Mr. Reid said the Legislature has power to take action on the issue if they choose but the Board must approach the issue as a public health matter. Responding to Ms. Beck, Mr. Miyahara said Board discussions about a potential rule would likely take place next Spring, though there is no emergency and no need to rush. The issue is a question of balancing the potential of better prevention and care against legitimate concern for confidentiality and other issues. Ms. Reeves suggested better education of communities regarding how care would improve might help the argument for name reporting and partner notification. Dr. Hinds appreciated Dr. Locke's comments related to confidentiality. There is distrust regarding the government's ability to maintain confidentiality, even though the state has an excellent record. Mr. Reid thanked Dr. Hinds for providing valuable information.

FOLLOW-UP ON LETTER OF INQUIRY FROM JOHN NORDQUIST, CHAIR, SNOHOMISH HEALTH DISTRICT BOARD OF HEALTH, WAC 246-217, TESTING AND LICENSING FOOD SERVICE WORKERS

Mr. Reid directed the Board's attention to letters in the Reading Packets from SHD related to food safety and foodhandler permits. Bill White, DOH Office of Community and Environmental Health Programs Director, cited additional materials on the issue in the Packet from the November meeting, which indicate the main concern is with lack of consistency in training and examination of food workers. The Food Safety and Enhancement Advisory Committee (FSEAC), a joint workgroup of DOH and WSDA, put together a number of different strategies and recommendations for dealing with this issue several years ago. Ms. Beck indicated there is reference to the FSEAC report in a past Board Annual Report which condenses it well. Mr. White said most of his presentation today would deal with revisiting those recommendations. Food workers do not receive uniform information at the time they are instructed and examined for their permits. In 1996, Environmental Health Directors (EHD), in collaboration with DOH, developed some food program standards and also addressed the issue of training, recommending interactive training as part of every local food program. Neither RCW nor WAC contains specific guidance on training, only on conducting examinations (RCW 69.06 and WAC 246-217). As a result, about 1/2 of foodhandlers go through some sort of classroom instruction prior to receiving their permits. DOH is not in a position to judge or validate the

18,000 beds. In adult family homes, over a 6-year period, the number of beds rose from 2,000 to about 9,000.

After reviewing the Report, the Legislature placed a moratorium on any further development of adult family homes, but not on boarding homes, which continue to increase in number. LTCO believes the boarding home system is overbuilt. 2 major consequences are that since lower revenues than expected are received when facilities are half-empty, operators lack the resources to provide services they thought they would. While willing to take higher level acuity cases just to boost their revenues, they are not always able to serve these residents. Issues with adult family homes are similar.

Mr. Hyre pointed out that he thought some of the Action Strategies in the *1998 WSPHR* draft for DSHS to apply to adult family homes, such as strengthening licensing standards, greater authority to deny or revoke licenses, increasing the number of case managers, could equally be applied by DOH to boarding homes. DOH has traditionally had only 4 people to inspect boarding homes all over the state, a very low number for 14,000 residents, especially as the level of care and issues like nurse delegation intensify. Last year, the number of inspectors was increased to 8, but the number of residents increased to 18,000. This compares with the 28 DSHS staff available to inspect and perform complaint investigations for the 9,000 adult family home residents. Boarding home residents need the same protection level, and Mr. Hyre urged the Board to support enhanced resources for DOH to accomplish this. He further suggested enhanced resources should come out of the General Fund-State, as they do for nursing and adult family homes.

Mr. Hyre addressed the need to test nursing home administrators. A recent Health Care Financing Administration study found Washington State 3rd behind Michigan and California in assuring quality of care in nursing homes. Nursing home administrators should be required to take a test as part of continuing quality improvement. Mr. Hyre indicated the Legislature has again asked for LTCO to report on boarding home regulatory enforcement. He will make this report available to the Board in January.

In response to Dr. Chu, Mr. Hyre said that a person who has just undergone a hip replacement procedure might be discharged to a nursing or boarding home, depending on the kind of insurance policy or coverage the person had. Discharge planning is critical but does not currently work very well. There is now an emerging industry in private pay case management which helps with discharge planning.

In response to Ms. Reeves, Mr. Hyre said it was only nursing home administrators who were required to take a test, not nursing services directors or clinical services supervisors. Ms. Reeves indicated the need for nursing directors to also be knowledgeable of laws and regulations. Mr. Hyre agreed, saying that many nurses become frustrated with the environment and end up switching over to become nursing home administrators. His report makes some recommendations about training, because when a boarding home takes only private-pay clients, the only training requirement for line staff is CPR and infection control. He has sought legislation in the past to address this, and asked for the Board's support in a renewed effort to require higher levels of staff and operator training in boarding homes.

In response to Mr. Osaki, Mr. Hyre agreed that much public education is needed regarding what can be expected of a long-term care facility, especially for family members of the long-term care resident. He said that of 5,000 complaints LTCO deals with each year, only about 1/3 come from the residents themselves, another 1/3 from family members, and 1/3 from staff. Mr. Osaki inquired about a specific situation when, during last winter's snowstorm, he fielded a call from someone saying that boarding home residents were not being kept warm. Mr. Hyre replied that boarding homes and other residential care settings are supposed to have policies and protocols for emergency situations, and that this was a kind of situation that is considered reportable to LTCO. Responding to Mr. Dygert, Mr. Hyre said it is important to remember that these facilities are not populated only by the elderly. There are many individuals with traumatic brain injury in both nursing and boarding homes, and about 1/3 of adult family home residents are developmentally disabled. Mr. Hyre requested Board support for legislation that would promote fuller disclosure from both providers and prospective residents coming into facilities, so that everyone would be clearer about what was being offered and what was really needed. He said such a bill had passed through both houses of the Legislature in 1997, but DSHS advised the Governor to veto it. Ms. Beck thanked Mr. Hyre for providing input for the *WSPHR*. Mr. Hyre appreciated the opportunity to talk with Board and hopes to do so again.

OPEN PERIOD TO TAKE PUBLIC TESTIMONY ON ANY HEALTH ISSUES

Mr. Reid invited the public to testify on health issues of their own choosing. Gérard Sheehan, Legislative Director, American Civil Liberties Union of Washington (ACLU), said his organization strongly opposes HIV name reporting for the same reasons Washington choose not to require such reporting previously. There is still discrimination and social opprobrium attached to HIV/AIDS. Mr. Sheehan shared an ACLU report which discusses the interplay between name reporting and civil liberties. There have been studies of states where name reporting has been instituted, and HIV testing rates have declined. This is why name reporting may not be advantageous from a public health perspective.

Mr. Sheehan noted case law is tending toward individuals with HIV not being protected under Americans With Disabilities Act. People with HIV are not strongly protected under disability law, and the trend is going in the opposite direction.

He noted the euphoria about the efficacy of drug treatment for HIV is wearing off. In addition, it remains that society has not chosen to fund such treatment for all those infected at a cost of $10,000-$15,000 per year for drugs which may or may not turn out to be very useful. It is too early to use the pharmacological argument to support name reporting. A confidential system of HIV testing was not adopted in the past because of dearth of pharmacological treatment. Such treatment should not now be a rationale to begin name reporting.

Mr. Sheehan suggested that Dr. Hinds' comments regarding states requiring name reporting were misleading. 27 states have adopted name reporting, but these represent only 24% of AIDS cases. Many of these states have social policies very different than Washington. California, New York, Illinois, and New York do not have name reporting. He indicated the Governor's Advisory Council on HIV/AIDS (GACHA) is deeply divided on the issue and will not recommend name reporting to the Governor.

Mr. Sheehan distributed materials about name reporting to the Board. He noted the Northwest AIDS Foundation opposes name reporting. He suggested CDC, which was the driving force behind the proposal, may now be rethinking the question. Responding to Ms. Reeves, Mr. Sheehan noted that those opposing name reporting understand that it does not create treatment, and the links between the 2 are tenuous. Studies from other states seem to indicate that name reporting deters some people from getting tested, hence defeating the purpose of the reporting system. Once one has the disease, the name is reported as treatment is received. He wonders why someone would choose to go to a test site which did name reporting if there was an option for anonymous testing. Mr. Sheehan agreed that the state does a good job of protecting confidentiality, though there are exceptions. Responding to Dr. Locke, Mr. Sheehan said ACLU favors use of unique identifiers and has some concerns about the proposed system for partner notification. Unique identifiers do not get in the way of appropriate partner notification, which should be discussed in post-test counseling.

Replying to Ms. Reeves, Mr. Sheehan said Texas and Maryland are using unique identifiers. Both have had some difficulties in making the system work. Public health officials in Maryland believe these difficulties can be surmounted and are retaining the unique identifier system. The main problem with such a system appears to be in training.

Kelly Scott, GACHA Member, has been a member of the GACHA taskforce studying these issues for the past 6 months. A taskforce report will be given to GACHA in January. He stated he was not speaking on behalf of GACHA or the taskforce today but rather reporting on their activities. Mr. Scott said the taskforce intends to take no position in its report but will provide the best thinking for name reporting and use of unique identifiers. Dr. Bob Wood, Seattle-King County Department of Public Health, and Mr. Scott are drafting the respective report sections.

Mr. Scott is a member of the statewide prevention-planning group, which prioritizes interventions for preventing AIDS spread and how funds can best be used. He reported that: AIDS Action, a Washington, D.C. lobbying arm of 2,000 community-based organizations involved in prevention and care, opposes name reporting; Connecticut has decided not to go forward with name reporting; Hawaii has sent a delegation to CDC requesting they not take a position favoring name reporting; National Association of People with AIDS, ACLU, Positive Voice Committee of the Seattle-King County Title 1 Planning Council, People with AIDS of Oregon all oppose name reporting.

Mr. Scott suggested that while public health has a good record in keeping names confidential, the real issue is misuse of data by government, which is a well-grounded fear. He cited several cases of personal disease information being misused as part of official government policy, with negative consequences for those infected. He noted that during the 1997 Session, AIDSNET Council and DOH favored legislation that would have mandated turning of HIV information to law enforcement given any well-founded suspicion that a person was behaving in a risky fashion. The bill was vetoed by the Governor. Having worked around these issues since 1991, Mr. Scott noted there have been proposals in every legislative session which make no public health sense but which are difficult to stop. Increased lifespan for someone with HIV requires greater protection for individuals so they can live productive lives without being stigmatized.

Mr. Scott indicated that a CDC-sponsored study found 20% of those responding said they might not have been tested if they thought their names would be reported. He indicated the public does not distinguish between anonymous testing and having their names reported when they seek care. In fact, most individuals at the 6 public hearings held around the state thought this unfair. If people are driven away from testing as a result of name reporting, partner notification at the time of greatest risk of infection will suffer. Furthermore, there is no new money for care, either at state or federal levels. Name reporting will not increase dollars available for treatment. Rather it will lower the percentage of those diagnosed able to access care. Research provided by the Names Reporting Taskforce found that just as many partners are identified when people are tested anonymously as

when there name reporting. Infected individuals still have to give the names of contacts. Given that there are no new funds, Mr. Scott questioned public health's desire to reach out and provide greatly expanded partner notification services. Funds could only come from gutting other community-based prevention programs and other interventions. Such a decision would not be made by the Board but by the planning groups involved in AIDS prevention and would be separate from a decision about name reporting.

Mr. Scott suggested the Board might want a 1/2 hour information session prior to rulemaking which might include Mr. Sheehan, rural representatives, and people of color who could respond to questions. There is largely a consensus that better case reporting is needed but might not result from a name reporting system.

Karen McDonell, Citizen, Gig Harbor, acknowledged the Board's interest in reducing exposure to substances that undermine health. She has been working with a number of community groups to draft a legislative 'right-to-know' bill on pesticide use in occupied buildings. Under the bill, occupants would be provided notice when pesticides were to be used indoors.

Ms. McDonell said pesticides are capable of causing injury, particularly to vulnerable populations including pregnant women, infants, and young children. They have been shown to cause cancer, birth defects, asthma, and chemical sensitivity. Many pesticides target nervous systems of pests. She believes there is growing evidence that they also cause harm to human nervous systems. Ms. McDonell cited increases in learning and behavioral disorders among children and suggested they might be linked to pesticide exposure. A 1990 federal Office of Technology Assessment attributed exposure to toxic substances as a risk factor for childhood mental disorders.

The proposed bill asked for posted notice at the point-of-entry 2 days in advance of pesticides being applied. This would provide an opportunity for pregnant women and those with young children to leave the environment during the few short hours when pesticides are most potent and dangerous. Ms. McDonell asked the Board to support this effort and endorse the idea of notifying occupants. She distributed copies of a bill abstract for Board members.

Mr. Osaki said this is a very important issue. He suggested the need to identify options in lieu of pesticides in addition to the "right-to-know". There are other ways of dealing with household pests. Ms. McDonell strongly agreed, saying she works with groups developing resources for the public on less toxic alternatives. She sees the "right-to-know" bill as a 1st step, as the public is ignorant of pesticide dangers. Once they are aware, they are more likely to seek alternatives. She suggested that from a legislative perspective this is likely to be a 2-step process. Mr. Osaki volunteered to speak with Ms. McDonell further about the issue. Ms. McDonell thanked the Board for protecting public health.

OTHER BOARD BUSINESS

Ms. Beck invited edits and suggestions regarding recommendations for the Board's Annual Report. Mr. Reid suggested members should send them to the Board Office within 10 days.

Mr. Albert indicated the Governor's Office hoped the Board would examine House Bill 2063, which would exempt nursing assistants working in state facilities from registration, as currently required. Originally, there was to be a full Sunrise Review, but DOH reported there were no funds to do so. The Board has agreed to look at the issue on a limited basis. UW's Health Policy Analysis Program will provide an analysis at an upcoming meeting.

Ms. Pageler said she serves on a committee with Ms. Corkrum to put together a plan to train new local board of health members. They hope to present a panel with case studies where political values collide with public health concerns. Sex education in schools, distribution of condoms to prostitutes, and needle exchange programs are examples.

ADJOURNMENT

Meeting was adjourned at 5:00 p.m. The next Board meeting will be held January 14, 1998 in SeaTac, Washington.

WASHINGTON STATE BOARD OF HEALTH

Warren Featherstone Reid, Chair

Excerpt

to health care, funding for basic health needs, and fully financing a rational health care system.

Ms. Barnard complimented WSNA for their work in helping to avert a nurses strike in Spokane. Sylvia Beck, Board Executive Director, thanked WSNA on behalf of the Board for their help in preparing the *1998 WSPHR*. She appreciated Mr. Bushu's comments on handwashing, since that was a major focus of the Board's NPHW activities. Responding to Carl Osaki, R.S., M.S.P.H., Mr. Bushu agreed greater attention should be paid to encouraging nurse awareness of environmental factors that impact disease outcomes. There is need for continuing education, especially as nurses are often focused only on their specialty areas. A holistic approach to nursing care is needed. There are opportunities to disseminate information. Responding to Ms. Beck, Mr. Bushu said WSNA's newsletter would be happy to accept articles on the subject. Mr. Reid thanked Mayor Sutton and Mr. Bushu for their warm welcomes.

APPROVAL OF AGENDA

ACTION: Approval of Agenda. Motion/Second: Pageler/Reid. Carried unanimously.

ADOPTION OF MARCH 11, 1998 MINUTES

ACTION: Approval of March 11, 1998 Minutes. Motion/Second: Corkrum/Locke. Carried unanimously.

FOLLOWUP ON INFORMATION ON HIV/AIDS REPORTING (REFERENCE 12/97)

Thomas Locke, M.D., M.P.H., introduced today's followup indicating that the state AIDS Omnibus Bill was passed in 1988. Shortly thereafter, the Board wrote rules to implement the legislation. 10 years later, the Board is beginning the process of considering how to revise not only the HIV/AIDS surveillance systems, but all communicable disease WACs. There has been a paradigm shift in approaches in HIV infection and a knowledge explosion. It is now known that HIV virus replicates very early in the disease course, and there is steady immune system destruction. There is reason to believe perhaps a majority of HIV cases are transmitted in the early stages of infection. There are new therapies that may have great impact on the risk of transmission. From a public health perspective, each new case is a failure of prevention efforts. This is public health's primary mission.

There is broad consensus that the surveillance system needs revision, as what we now have is an incomplete picture of the disease. Controversy arises from how the system should be revised, which the Board will need to grapple with in months ahead. Today the Board is functioning as a forum for public health policy development, listening to all sides of an issue. Many common goals are shared among those working to prevent HIV spread, even if there are passionate disagreements about reporting methods. He urged all participants to listen well to each other. Mr. Reid emphasized that the Board needs to continue to educate itself on these matters so that it will be prepared to act later in the year.

Kelly Scott, Governor's Advisory Council on HIV/AIDS (GACHA) member, said he was appearing today as a citizen and not as a GACHA member. He introduced today's panel members and thanked the Board for the opportunity to dialogue. He stressed importance of the issue of HIV reporting for people with HIV and AIDS around the state. The issue must be approached in a rational fashion. What is critical is preventing virus spread. Assessing the impact of HIV and its spread is important to prevention.

HIV is an extremely stigmatized disease, which is why it needs to be treated differently. Having people with HIV come forward for testing and treatment can save lives. Burdens should not be placed in the way of people doing so. This is why privacy of medical records is important for the public health purpose of preventing HIV spread. The issue is not only how a surveillance system can be designed to least burden individuals in finding out their seroprevalence status. There is a larger ethical issue of how much and how necessary it is to burden people in getting the care that keeps them alive. Even if we advocate people coming forward for testing regardless of the surveillance system, we must ask whether they should be placed at risk of the uncertain actions of policymakers.

Lupé Lopez, People of Color Against AIDS Network (POCAAN) Executive Director and member and Treasurer, Board of Directors, National Minority AIDS Coalition (NMAC), said POCAAN is a statewide prevention and education agency focused on communities of color. Both POCAAN and NMAC have policy statements on the reporting issue. There is critical need to develop a national HIV surveillance system to: improve monitoring of recent trends; provide essential data to target and evaluate prevention services; and guide decision making in funding allocation. However, HIV name reporting is not necessary to accomplish these goals. Use of name reporting will pose significant social risk for people of color, including women, immigrants, gay men, substance users, and young people. Name reporting will hinder, rather than promote, important public health goals by deterring individuals from seeking HIV testing in the 1st place.

Ms. Lopez said that when she asked people who do not think they are at risk for HIV if they would get tested, knowing their names would be given to the local health department/district, the answer is always no. Perception is 99% of the way people act. In communities of color, the perception is that if names are given, they will be accessed by other systems, including criminal justice, immigration, insurance, and employment. Ms. Lopez said people are generally happy with the effective AIDS surveillance system using names. But HIV is a long-running disease, and there may be lag between knowing one's status and accessing treatment.

Ms. Lopez said Washington has access to technology necessary to make a unique identifier system (UI) work. She fears name reporting will set back work done in rural communities, with women, and young people where there is not good surveillance now. An argument used to support name reporting is that it would be become easier to access services. When POCAAN discussed this, the consensus was that access was not even an issue. It takes about 4 times longer for a person of color to access services. Name reporting will not increase that access. There is need to convey the message that people should be tested. This will require behavioral change. People will be less likely to be tested if they are fearful of where the information is going.

Michael Adams, American Civil Liberties Union (ACLU) National HIV/AIDS Project Staff Attorney, New York, noted that while states have conducted AIDS case reporting since the epidemic's beginning, until recently there has been no systematic effort to press states to adopt HIV surveillance. There are several reasons for this. Historically there has been strong fear that HIV case reporting would deter people from being tested. Reason for this deterrence is the strong stigma associated with AIDS. Having HIV positive status might be viewed as a mark for a person being gay or an IV drug user. It was also thought AIDS surveillance was sufficient along with other tools to understand the epidemic. Finally, it was believed that resources would be better spent on prevention and care.

Recently, public health officials and the federal Centers for Disease Control and Prevention (CDC) have placed new emphasis on HIV surveillance, advocating name reporting. Reasons given for need for HIV surveillance include: emergence of promising medical treatments which can extend time between HIV infection and AIDS diagnosis; inadequacy of AIDS surveillance in providing information about disease trends; need to better target funding, prevention, and service efforts. The public is being told it need not be as concerned about deterring people from being tested because of strong legal protections guaranteeing confidentiality and protecting people from discrimination.

Mr. Adams suggested there are problems with this analysis. Most people who test positive for HIV are 1st tested years after they have been infected. Reporting positive test results will not give a very accurate picture of where HIV is now. Sound data has never been very effective influencing public policy related to HIV/AIDS. This can be shown by refusal to support frank AIDS education among adolescents or needle exchange programs, even though demonstrated to be effective.

Nonetheless, ACLU recognizes that HIV case reporting may provide helpful epidemiological data. That data may be put to good use. Federal funding may eventually be tied to HIV case numbers, though not currently the case. But ACLU adamantly opposes name reporting for 2 basic reasons: 1) it is a fatally flawed and will drive substantial numbers of people away from the public health system; 2) there is a better alternative (UI) which does not carry the same risk.

Mr. Adams reiterated that the goal of HIV surveillance is get as accurate a picture as possible of the epidemic by analyzing new infections and collecting demographic and risk data. It is not about accessing health care systems. Surveillance systems have never been able to provide people with health care access. It is not about conducting partner notification.

On its face, it does not appear that names of each new person infected are needed to count HIV cases and gather demographic and risk data. Yet, some public health officials believe name reporting is the only efficient way to conduct surveillance. Name reporting is familiar to them, as it is used for other STDs and communicable diseases. However, the "1-size-fits-all" approach is not appropriate in the HIV/AIDS context.

Mr. Adams referred to a report in the Board Reading Packet summarizing scientific studies demonstrating name reporting will deter large numbers of people from being tested for HIV. This is because individuals fear their privacy will not be protected. In a recent University of California at San Francisco study, 19% of respondents said fear of name reporting was 1 of the reasons they had not been tested. Fear of name reporting was especially strong among groups most at risk for HIV, i.e. gay men, people of color, IV drug users. Driving people away from the public health system will reduce their chances of surviving the epidemic and will also distort epidemiological data.

Supporters of name reporting provide 3 responses to this problem: confidentiality protections; anti-discrimination laws to blunt effects of confidentiality breaches; and anonymous testing. Mr. Adams said these solutions are insufficient. Many people needing testing simply do not believe confidentiality will be maintained regardless of laws and promises. Populations most at risk for HIV are often skeptical of government and do not believe confidentiality protections will be respected. There is some basis for this belief as there have been well-publicized breaches of confidentiality. More important is public perception which is based on people's experience with government agencies and what they learn through the media. History shows promises made about confidentiality today can be broken tomorrow, especially when legislators are looking for politically expedient solutions to problems. He cited an example from Illinois which had an AIDS registry with state-of-the-art confidentiality protections. After a scare about a person exposed to a health care worker's HIV, the legislator passed a law to cross-check the AIDS registry against the registry of licensed health care workers. Then patients who had been treated by these individuals would be tracked down and advised that they might have been exposed.

Mr. Adams suggested anti-discrimination laws might not protect people in the event of confidentiality breaches. There has been a recent round of federal court decisions saying federal civil rights protections for people with disabilities do not protect people with HIV unless they are sick. If they are asymptomatic, there is no legal protection. This issue is currently before the U.S. Supreme Court.

Mr. Adams noted there are no guarantees that anonymous testing will be continued after name reporting is required, despite the best intention of public officials. 10 states with name reporting have subsequently eliminated anonymous testing. There is logic to this change. If the purpose of HIV surveillance is to report cases, and a state has chosen to do so by name, why maintain a testing system which does not allow for name-based reporting? New Jersey has name reporting, but also anonymous testing. 45% of those who test in New Jersey do so anonymously. This suggests that people are concerned about name reporting and calls into question accuracy of New Jersey's surveillance data. A recent study indicates that New Jersey's surveillance data are not very accurate. Even in states where anonymous testing remains, it has often been severely cut back.

ACLU and AIDS advocacy groups have been encouraging states to reject name reporting. As states examine the questions more closely, they are recognizing the potentially grave consequences of name reporting. Hawaii and Massachusetts have recently rejected name reporting proposals and opted for UIs. They are working with Maryland to implement UI based on their own requirements. A working group convened by New York's Governor just completed the nation's most in-depth analysis of the question. After testimony from CDC, public health officials, community representatives, and AIDS directors from around the U.S., and reviewing the evidence, the work group rejected name reporting and recommended UI. Such a

system is a formidable challenge in New York given the large case numbers. Mr. Adams suggested that if such a system can be out together in New York, it certainly can in Washington.

Mr. Adams was surprised to hear arguments before the Board previously linking name reporting to effective partner notification. On this issue ACLU completely agrees with CDC that it is completely inappropriate to link the 2. If linked, confidentiality protections are inevitably reduced. Name reporting is not necessary to conduct partner notification, as the name of the person with HIV is not used when notification occurs. Studies demonstrate that states with name reporting do not have a better partner notification system than states which do not. Mr. Adams encouraged the Board to conduct an in-depth analysis before considering a name reporting system.

Mr. Scott noted that GACHA set up a taskforce to consider this question, and its report gave the best arguments for both systems. It held 5 forums around the state with a cross section of opinion. The full Council voted 14-4 in favor of a UI system. Mr. Scott encouraged the Board to review the GACHA report and recommendation.

Mr. Scott emphasized he has confidence in public health officials' assurance of confidentiality, anonymity, and good faith. However, since 1991, the Legislature repeatedly had bills proposed to restrict the practice of health care workers with HIV based on no scientific evidence. Legislators respond to the public's mood, and it is through them that confidentiality could become compromised. The fear is that there will be authorized, rather than unauthorized, confidentiality breaches.

Liza Solomon, Ph.D., AIDS Administration Director, Maryland Department of Health (MDOH), said her Administration deals with all aspects of HIV services, including surveillance, prevention, and Ryan White Care Act programs. Maryland implemented UI in 1994, so MDOH is familiar with what it is like to implement such a system.

Maryland has the 5th highest HIV prevalence. 17,000 AIDS cases have been reported to date, significantly more than Washington. Discussions occurred for many years within the legislature, public health, and advocacy community regarding how to move forward on HIV surveillance, for reasons cited by previous speakers. Every year between 1988-1992, a names reporting bill was introduced in the legislature and defeated. In 1992, the public health community compromised, and legislation to create UI was enacted.

The goals of Maryland's UI system are the same as for any epidemiological system. The importance of UI is in collecting data to target programs. Data not resulting in policy change are meaningless. Data would affect decisions regarding targeted prevention programs and populations.

MDOH wanted to develop a simple system in which providers have the responsibility to create a UI number. Labs are required to report. The UI number is a 12-digit code consisting of the last 4 digits of the Social Security number (which are randomly assigned), 6 digits for birthdate, 1 digit for race/ethnicity, and 1 for gender. These last 2 make use of CDC codes. Exceptions are made to ensure individuals learn their status. Anonymous test sites are exempted from reporting, which MDOH felt to be very important. Sooner or later people will become part of the health system anyway to access care. At that point a report will be made.

All HIV positive tests and CD4 counts less than 200 are reportable. Reports are compared to the AIDS database. UIs were put on the entire AIDS database, so that numbers and types of individuals who have HIV but AIDS can be identified. A registry of unique HIV positive individuals is created. Data is analyzed by age, ethnicity, and zip code where the person was tested.

MDOH has spent much time and energy evaluating and refining their system. When Maryland's system was created, MDOH received no CDC technical assistance or funding. A study showed that in an AIDS database of 16,000 unique individuals, it was found that an error of a single digit would still provide over 99.8% uniqueness. In the field, MDOH examined all UIs from a single county which appeared more than once. In this county there were 97 UIs with more than 200 visits. By working with the local health department, it was found that when individuals went

for more than 1 test, in every case they received the same UI. So the system was able to find uniqueness at least within a single health jurisdiction. 12 UIs appeared cross-jurisdictional. By checking the records, in every case, those UIs showing more than 1 visit matched. There is confidence that the system is capable of correctly informing MDOH whether 1 individual was tested 3 times, as opposed to 3 individuals and 1 test. Work is being done to evaluate effects of incomplete UIs. Completeness has increased substantially since the system was 1st implemented.

MDOH has also done some work to check on completeness of reporting to ensure the system is really capturing the data intended. MDOH compared its data to that of the 28 states with name reporting through reports published by CDC. There is a report which shows ratios between HIV and AIDS reports. Maryland's ratio lies at the statistic mean, suggesting data is comparable to that of name reporting states. By comparing numbers of people reported through counseling and testing networks with the HIV registry, a very high level of reporting completeness (88%) is indicated.

Data gathered through the UI system provide a different picture of the HIV epidemic than that to be gained from AIDS data. In 1996, 29% of new AIDS cases, but 49% of new HIV cases were women. The HIV data show more young people being diagnosed with HIV though not with AIDS. No changes in race distribution have been found thus far and no geographic differences. This is important information for resource allocation planning.

Maryland's UI facilitates creation of a statewide statement of need which is then sent to CDC and used in regional planning. Maryland has a very active partner notification system. Such notification can happen effectively without name reporting. Access to care is not tied to the registry. According the CDC, 30% of people with AIDS are reported 1 year after diagnosis. Reporting would not be an efficient way of accessing treatment. This happens at the provider level.

Dr. Solomon reiterated that public health functions can be performed effectively with UI and without name reporting. Maryland's UI enjoys a wide range of support from the community.

Responding to Mr. Reid, Dr. Solomon said MDOH had considered adding a field for risk category, using the CDC risk hierarchy. MDOH has determined there are better ways of getting risk data, including using state-funded counseling and test forms. MDOH has risk data on 35% of all people tested in Maryland without even a need to contact providers. More than concern about subjectivity was that about confidentiality. Asking people questions about their drug use or sexual habits to place information on a form would not make many comfortable.

Replying to Dr. Locke, Dr. Solomon said providers have the responsibility for creating the code, while labs have reporting responsibilities. MDOH worked closely with the state medical and laboratory associations to ensure they were comfortable with the system and provide technical assistance. MDOH understands clinicians are burdened by any reporting system and have constraints on their time. So the UI was designed to be generated in 10 seconds. The UI is part of the informed consent form which by law must be signed before HIV testing can be done. Clinicians must have a way, which they determine themselves, of identifying their patient from a UI number. Some physicians keep their own lab list. Surveillance records are not available to insurance companies and not subject to disclosure unless paid for by the insurance companies. All HIV testing in publicly funded clinics is paid for by the state and not disclosable.

Ms. Barnard said such a UI system seemed to be an eminently sensible approach. Responding to Dr. Locke, Dr. Solomon said she did not know the % of people using the anonymous test sites. These have just been expanded in the past 6 months, and 2 new sites have been opened. Anonymous testing has always served a small % of people being tested. MDOH does get aggregate data from anonymous testing sites but without UIs. Many people 1st go through the anonymous testing system and then, after testing positive, enter the care system where they are tested again and a UI is assigned.

Replying to Mr. Osaki, Dr. Solomon said there is much cross-jurisdictional migration between states. There are many centers of excellence for HIV treatment in Maryland. The MDOH UI registry only gets data about Maryland

residents. Currently, some states such as New York do not allow sharing of data with other states. Mr. Adams noted that when name reporting was adopted in South Carolina, the number of men at a particular testing site identified as gay men dropped by 50%. The largest South Carolina agency providing HIV/AIDS social services reported that 40% of people they were serving left the state to be tested where there was no name reporting. This is substantial evidence of deterrent effect of name reporting.

Responding to Bruce Miyahara, M.H.A., Dr. Solomon said UIs are used in the drug treatment system, but not for other disease-specific reporting. Mr. Miyahara said and HIV UI would make it a narrow, categorical surveillance tool. Opportunities might be lost to look at other issues related to HIV, such as hepatitis or tuberculosis. Dr. Solomon said UIs can be matched to death, Medicaid claims, drug treatment, and AIDS records. It might be desirable to convert all systems to UI. MDOH is talking with Title I and Title II councils and consortia about adopting UIs for all people in care. Mr. Scott said the Board could look at establishing the best possible UI system to maintain confidentiality while meeting other public health needs. Dr. Solomon noted that MDOH found names not to be a very unique identifier. Mr. Reid thanked the panelists who provided the benefit of their extensive experience and noted the Board has much more study to engage in before taking further action.

PANEL ON TEMPORARY WORKER HOUSING

The Honorable Margarita Prentice, Washington State Senator, 11th District, thanked the Board for the opportunity for legislators to dialogue with the Board regarding temporary worker housing issues and provide information about recent developments. She noted there is a temptation to try to solve the entire issue because the problem is so serious. It is important to resist this temptation. Senator Prentice noted when she 1st came to the Legislature in 1989, a bill did not make out of the Housing Committee because, while addressing temporary worker needs, it did not solve the problem of the entire farmworker community. Representative Heavey made similar attempts in 1991 and 1992 with little result. The Legislature tended not to act because there was such opposition, and Evergreen Legal Services would attempt solutions through lawsuits. This made each side dig in and refuse to cooperate. Senator Prentice sponsored a bill to impose many fines for violations. It also made no headway.

Senator Prentice formed a loose bipartisan coalition with Senator Deccio, with the support of the leadership, to get beyond political games. The legislative group took a number of tours and spoke with both growers and workers. Initially, grower representatives were looking toward more community-based housing, but workers said they would rather be on-farm. There have been significant changes in attitudes. The group went down to Oregon to see what worked and what did not. The coalition decided not to work on an omnibus bill, but rather to work on a discrete part with people who had shown great resistance, in this case growers. Everyone agrees the current situation is a disgrace. The goal is to be practical and realistic, not ideological. Senator Sutherland indicated his belief that the State Building Code Council (BCC) could help by developing standards which would protect workers but be less costly for growers to meet.

Senator Prentice suggested the need for the Board to go out and meet with workers and growers as part of the rule development process. She suggested focus groups might be useful. The Legislature will continue to work on the issue, especially to see what local communities can do. There is also need to look at apartment houses provided by the private sector for migrant workers, which are a disgrace. Senator Prentice asked that Legislators be kept informed of current and future Board efforts and might like to be part of trips the Board makes so that the experience will be shared.

The Honorable Barbara Lisk, Washington State Representative, 15th District and House Majority Leader, said she is also a fruit grower, with several hundred acres of apples in the Yakima Valley. She has been on many tours with Senator Prentice and has come to the conclusion that worker safety is a basic interest. She noted there is a clearly identifiable migrant worker group which is seasonal and leaves the state after the work is done. Many communities, such as the Mattawa area, have little housing available for rent. When there is no housing, workers end up living in their cars and on riverbanks. She believes the recently

WASHINGTON STATE BOARD OF HEALTH

The Washington State Board of Health was established in the State Constitutio in 1889 to protect and promote the health of Washingtonians. Its ten members ar appointed by the Governor to represent the health needs and concerns of all th people. The mission of the Board is to develop policies to promote, protect maintain, and improve the health of all Washingtonians. To fulfill this mission the Board solicits information through public forums, assesses the reports on th people's health status, establishes health-related goals and priorities in th *State Public Health Report,* and adopts administrative rules to implement statute and Board policies. The Board recommends steps to assure optimum use of publi financial and human resources to prepare Washington to meet the challenges of th twenty-first century.

Warren Featherstone Reid, J.D. (Chair) Consultant, Seattle	Representing Consumers
The Honorable Neva J. Corkrum (Vice Chair) Commissioner, District 1 Franklin County	Representing Elected County Officials
Sheri S. Barnard Consultant, Spokane	Representing Consumers
Charles R. Chu, D.P.M. Podiatrist Factoria, Puyallup, Enumclaw, Kent	Representing Health and Sanitation
Ed Gray, M.D. Northeast Tri-County Health Officer Colville	Representing Health and Sanitation
Thomas H. Locke, M.D., M.P.H. Health Officer Clallam and Jefferson County Health Departments	Representing Local Health Officers
~~Bruce Miyahara, M.H.A.~~ Secretary, Department of Health	Representing Department of Health
Carl S. Osaki, R.S., M.S.P.H. Chief of Environmental Health Seattle-King County Department of Public Health	Representing Health and Sanitation
The Honorable Margaret Pageler, J.D. Seattle City Councilmember	Representing Elected City Officials
Florence Reeves, R.N., B.S.N. Consultant, Tacoma	Representing Health and Sanitation

Sylvia I. Beck, Executive Director

PACIFIC MAGAZINE

PACIFIC PICKS

Staging it up on the road

Box and then Delivery wagons

people of influence

PAUL REDMOND. The leader of Spokane's impressive economic development efforts, he's a dedicated civic activist and visionary. In his day job, he runs Washington Water Power, Eastern Washington's largest utility and one of the state's biggest public companies.

WARREN FEATHERSTONE REID. The key behind-the-scenes figure in state health law for 40 years. He was an aide to Sen. Warren Magnuson and adviser to Gov. Booth Gardner. He helped expand federal financing of medical research and write such legislation as the federal Nurse Training Act and the state Basic Health Plan. He's the namesake of the state's Warren Featherstone Reid Award for excellence in health care.

LOUIS RICHMOND. There are those who do and there are those who promote: Richmond's a promoter extraordinaire. He "created" Northwest celebrity chefs like Kathy Casey and Monique Barbeau, and landed "news" coverage estimated to be worth $1 million for a dinner train. If you think you're hungry, he probably planted the idea.

TERRY ROGERS. His name's not well known, but as chief operating officer of King County Medical Blue Shield, the state's largest health insurer, he has a big say in deciding which medical procedures are covered, how much consumers will pay and which doctors will get the work.

KATHLEEN ROSS. The founder and tireless president of Heritage College in Toppenish and Omak, she's brought higher education to thousands of disadvantaged multicultural students who wouldn't otherwise have the opportunity. She recently won the state Medal of Merit Award for exceptional public service.

JUDY RUNSTAD. She can raise big money faster than you can say "power breakfast." Her job, land-use attorney, barely hints at her influence: She's part of the inner circle of top politicians in both parties — a trusted bridge between business and government.

GEORGE RUSSELL. He's better known elsewhere than in the Northwest, but he's one of the world's most influential money tracers. His Tacoma-based Frank Russell Company recommends investments to the managers of huge pension funds. The amount at stake, based on his advice, is said to be $500 billion. That's *billion*.

FAYE SARKOWSKY. She's a barrier breaker, a business role model who offers women guidance as they bump against the glass ceiling. She helped get the Seattle Art Museum built and influences art and commerce as a member of several boards of directors, including Children's Hospital, the Fifth Avenue Theater Foundation and Commerce Bank.

PAUL SCHELL. When the UW thought it wanted an interim president to take over for William Gerberding, the outgoing dean of architecture was one of those mentioned. Developer, innkeeper, educator, philanthropist and president of the Port of Seattle board, he's at the center of the state's money and power network.

HOWARD SCHULTZ. Until he took over, Starbucks was really just a pretty good cup of coffee. He's made it a near-religion, jangling the nerves of a double-tall nation and creating a new vocabulary in the process.

PATRICK SCOTT. Not a household name, but as the head of the last locally owned broadcast operation of any size in Seattle, he has a lot to say about what we watch on the tube and hear on the radio. Among Fisher Broadcasting's holdings are KOMO-TV and KOMO-AM, hot-talk KVI-AM, KPLZ-FM, KATU-TV in Portland, and a dozen small radio stations in Eastern Washington and Montana.

BELDING SCRIBNER. Few others have saved so many lives. Working at the UW Medical Center, he pioneered kidney transplants and kidney dialysis as a continuing treatment: there are now some 750,000 people worldwide on dialysis.

MARTIN SELIG. He's always been the developer people love to hate, but nobody's had more influence on the Seattle skyline. He built the 76-story Columbia Seafirst Center, the black "Darth Vader Building" at Fourth and Battery and other office towers, as well as many mid-rise buildings in Lower Queen Anne and the Denny Regrade.

FRANK SHRONTZ. What impact does Boeing have on the state? Right: any it wants. As CEO of the largest and most important business in the region, Shrontz can make or break the economy, from how many people are working to who pays what taxes. And his company's planes have shrunk the world.

RICK SIMONSON. Few cities anywhere are as book-crazy as Seattle. A big reason for that is Elliott Bay Book Company's manager, who founded and developed the popular and much-copied author-reading series. The success of Elliott Bay and the U. Bookstore paved the way for literary efforts like the Seattle Arts & Lectures Series, founded and directed by Sherry Prowda.

STUART SLOAN. He's at the head of the table or somewhere nearby when decisions get made at

* Our Board Chair

GARY LOCKE
Governor

STATE OF WASHINGTON
OFFICE OF THE GOVERNOR
P.O. Box 40002 • Olympia, Washington 98504-0002 • (360) 753-6780 • FAX (360) 753-4110 • TTY/TDD (360) 753-6466

FOR IMMEDIATE RELEASE — July 21, 1998

Gov. Locke cites outstanding work by citizens to protect public health

OLYMPIA — Citizens all over Washington are bringing to life the goals of the *1998 Washington State Public Health Report* released today by Gov. Gary Locke.

"Washington State strives to be a leader in protecting and promoting the health of its citizens," said Locke. He pointed out the efforts of eight people in communities all over the state who have worked to improve public health as outlined in the state's Priority Health Goals. Those goals are the basis for the report.

"These are citizens of which the people of Washington can be proud. They deserve our thanks for the fine example they set for all of us," said Locke. He said he will honor the efforts of these individuals over the coming months as he visits their home towns.

The report, which is prepared by the Washington State Board of Health, defines the challenges and the work needed to meet the state's Priority Health Goals and Action Strategies for the next two years. The eight goals outlined in the *State Public Health Report* are:

- Reduce preventable infant morbidity* and mortality.
- Reduce the incidence and preventable consequences of infectious diseases.
- Control or reduce hazards in the environment in which we live, work, and play.
- Reduce tobacco use and exposure to secondhand smoke.
- Reduce misuse of alcohol and other drugs.
- Reduce the incidence and impact of violence and preventable injuries.
- Assure access to population-based and personal physical and mental health services, including health education, preventive services, and illness care.
- Reduce the incidence and preventable consequences of chronic disease.

The State Public Health Report is used by state agencies to prepare budgets and executive request legislation. It is based on data collected from thousands of citizens, community leaders, local health jurisdictions, medical and public health professionals, and private and voluntary agencies.

— more —

The success stories of the eight people cited for outstanding work promoting the health and welfare of citizens in their communities are highlighted in the report. They are:

Jocie DeVries (Snohomish County), Executive Director, FAS Family Resource Institute, for her work to increase awareness about Fetal Alcohol Syndrome.

Joyce Claypool (Spokane), for providing HIV/AIDS education to thousands of children and adults.

The Denis Family (Kitsap County), for efforts to clean up Sinclair Inlet.

Valerie Bousquet, Pharm. D. (Vancouver), for leadership in advocating pharmacies and pharmacists play a major role in combating tobacco use.

Terry Weber (Pierce County), for showing by example that rehabilitation from lifelong addiction to drugs and alcohol can be successful and lead to healthy, purposeful living.

Theresa Cheng, D.D.S. (Issaquah), for helping abused women escape the cycle of violence.

Cindy Lowe (Sequim), for efforts to ensure delivery of quality public health services and health education to members of the Jamestown S'Klallam Tribe.

Linda McLean (Kennewick), for educating children about the importance of fitness and a healthful lifestyle.

# # #

Contact: Governor's Communications Office, 360-902-4136
Copies of the *1998 Washington State Public Health Report* are available from the Washington State Board of Health. For copies call 360-586-0399.

*"Morbidity" is a term used to signify illness, disability or a chronic health condition.

PUBLIC HEALTH
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August 6, 1998

Warren Featherstone Reid, J.D., Chair
Washington State Board of Health
P. O. Box 47990
Olympia, WA 98504-7990

Dear Mr. Chairman:

We just recently received and reviewed the *1998 Washington State Public Health Report* as issued by Governor Gary Locke. As the Governor proclaims, "Washington State strives to be a leader in protecting and promoting the health of its citizens." The accompanying news release continues by pointing out: "The report, which is prepared by the Washington State Board of Health, defines the *challenges and work needed* to meet the state's Priority Health Goals and Action Strategies for the next two years" (italics for emphasis added). Further, your cover letter does a superb job of highlighting both the important accomplishment of the statewide public health program and the significant challenges which must be addressed "to protect, promote and improve the health of Washington and its people."

The *1998 Washington State Public Health* Report is a dynamic work plan for achieving a healthier population; for organizing major health campaigns to educate citizens, mobilize communities and combat significant health risks and unhealthy behaviors; and for assuring improvements in health care access and health outcomes. We applaud the outstanding work of the Washington State Board of Health, its dedicated and excellent staff, and the many citizens, professionals and groups who contribute so much effort and good work towards the Public's health, protection and prosperity.

Sincerely,

Larry D. Jecha, M.D., M.P.H.
District Health Officer

Fred C. Jamison, M.A.
Health District Administrator

Clinton Presidential Records
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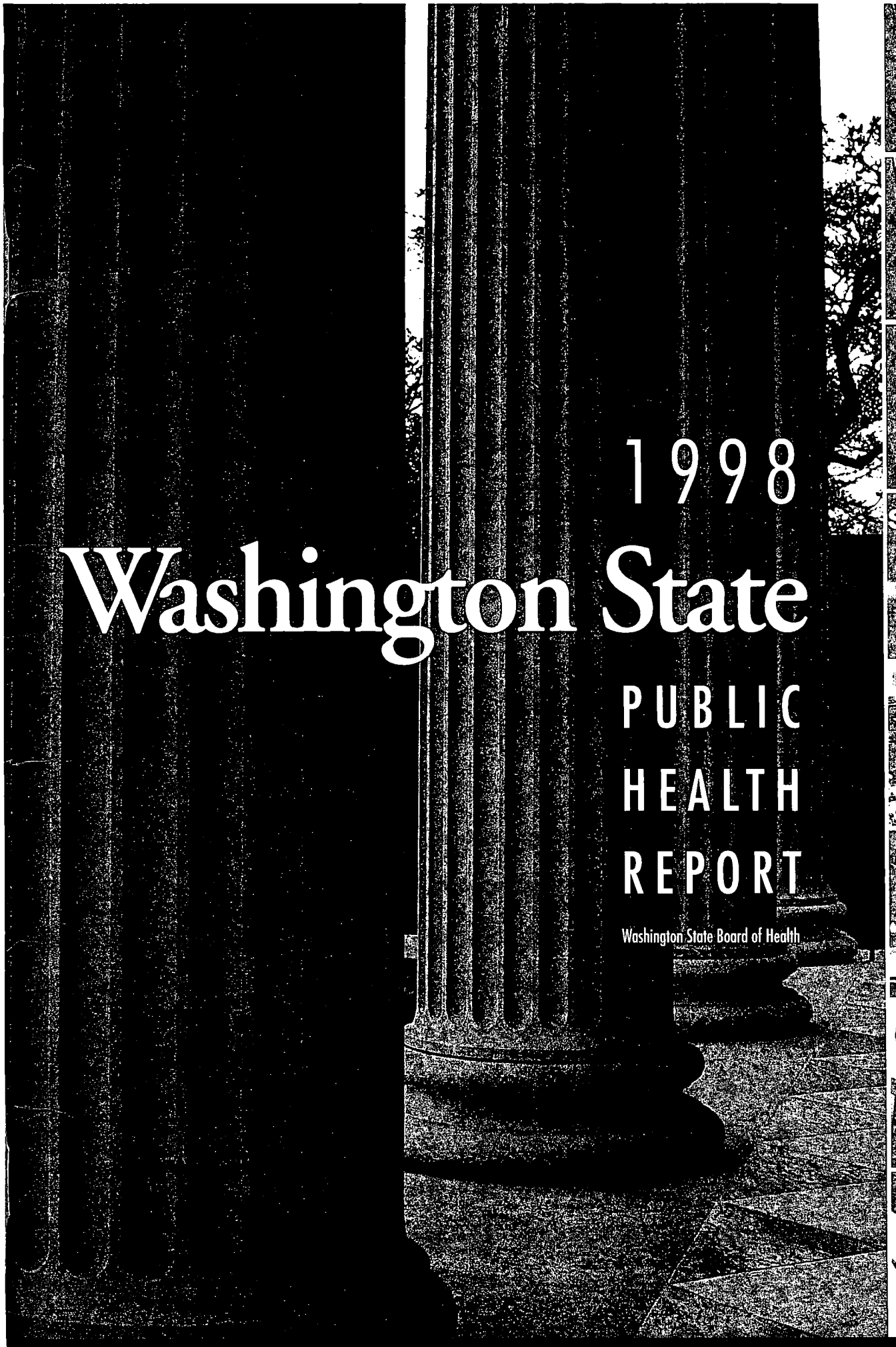
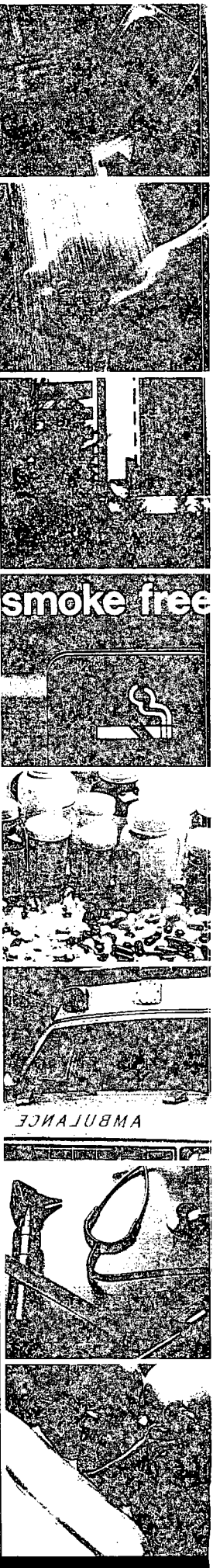


1998 Washington State PUBLIC HEALTH REPORT

Washington State Board of Health



Washington State's Health Priorities and Action Strategies for 1999-2001