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Folder Title:
[Comments, Remarks and Speeches by Kristine Gebbie] [loose]

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THE WHITE HOUSE

WASHINGTON

Statement of
Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator
at
Press Conference Announcing
National Task Force on AIDS Drug Development

As the National AIDS Policy Coordinator, I am charged with promoting the higest levels of coordination and collaboration in the nation's response to the effect of the HIV/AIDS pandemic on individuals, families, and private and government institutions. The focal point of my efforts include, research, prevention and care.

Over the past several months, representatives of the Department of Health and Human Services (DHHS) have participated in forums with academicians, AIDS advocacy groups, and the pharmaceutical industry on AIDS research improvement. Out of those sessions have come several ideas on public-private partnerships for information sharing and research that can speed the pace of discovery in our effort to stop the spread of HIV. The establishment of this new Drug Development Task Force is one example of the type of improvement anticipated by many of us.

By bringing together those conducting research on drugs to combat HIV infection from the pharmaceutical industry, the

academic community, individuals with HIV infection and those advocating on their behalf, and key agencies of the federal government, DHHS formalizes channels of communication among the partners who must be involved to successfully bring new drugs into use. Working together, these partners can identify barriers to quick action or clear communication, and can act in common to eliminate those barriers.

The mere creation of a new task force does not halt an epidemic, and if this new group were allowed to become a mere bureaucratic space-filler, it could even become counter-productive. I am confident, however, that neither of those things will occur. Instead, the steadily strengthening collaboration among all parties concerned about AIDS gives me great confidence that this is one more important step toward our collective goal of stopping AIDS.

confidential

THE WHITE HOUSE

WASHINGTON

Comments of Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator
from an Interview with The Washington Blade
July 1993

Taken from The Washington Blade, July 9, 1993

Blade: Some critics of your have told us that they're concerned that you had proposed a mandatory reporting process for those who got tested for T-cell counts, and that the reporting be done through laboratories in the state. Could you explain what you had in mind there and why you think the governor [Booth Gardner of Washington state] ultimately turned it down?

Gebbie: Well, A. the governor didn't turn it down and B. the proposal didn't come for me personally, it came from a working group of a number of people. The board of health adopted a regulation that did not include laboratory reporting of T-cell counting in the end, and that's fine.

That proposal came up when the expanded case definition [of AIDS] came in. As you know the expanded case definition is related to T-cell levels and, as with many diseases where a laboratory test is pertinent to the diagnosis, one of the possibilities was having a lab report test s directly. That's just a double check on your reporting system. That's what we do with tuberculosis testing, for example--to rely not just on the doctor buy on the lab to send the information on. Bearing in mind that AIDS patients have been reported by name at the state level all along in this epidemic, that was just a way of making sure we noted that together.

The arguments against it were that T-cell testing is done for other reasons that identifying new [AIDS] cases and therefore, more people would be reported than needed. Some believed that laboratories were not sound keepers of privacy and that they might leak the information. And then, [there was] just the general; nervousness, I think, of names going any where to anybody, that everybody looked.

I wasn't particularly forceful supporter of that proposal. I thought it was a reasonable one, but it certainly wasn't anything I was going to jump cliffs over or argue long about. I felt it deserved a fair hearing in the process and would have

anticipating and doing over time. Didn't have timetable in place, wasn't writing up a draft regulation, and wasn't running into it. But i just see that as one of the things that's coming and felt that it would useful to start the dialogue around it.

Blade: How do you feel about mandatory reporting? Do you suggest that the U.S. government require that at this time?

Gebbie: Absolutely not. No. First of all, even the phrase "mandatory" just makes everyone go like this [she flinches], including me.

I think anybody who is HIV-infected deserves to be connected with services. If he or she is already ill, he or she needs care. If the issue is support for learning to live with a disease that's going to be fatal, they need that support. If it is to understand how you got it and who you might have infected before you knew you had it, that;'s also a part of the process. I don';t care how that connection happens. Any many individual practitioners who do HIV testing do all those connections for their patients. Many community groups do those connections for people. But there are some people who are so disconnected that only a formalized system through a health department seems to work to make the connections. But I don';t want to push toward something called mandatory reporting till I also know that other things are in place, like absolute confidentiality for the name, like good non-discrimination laws in every jurisdiction, like enough capacity in the service system to respond when you get the name.

So, yes, I've been a part of raising that question, and I have said in groups I think we're moving toward that kind of reporting at some date in the future, But I am certain not in favor of it, certainly not in factor of the federal government mandating it, and I've argued that with CDC, that I don;t think they should sound like they're pushing toward mandating it to the extent that they think it's good public health practice; They need to do better evaluation of the reporting, and counseling, and testing programs that are in place now to give us a better feel for what works and what doesn't work.

For additional comments please call (202) 632-1090.

probably spoken out in favor of it at the board of health meetings had I still been office when it came along.

Blade: Do you feel that []T-cell reporting] might, as some AIDS activists have suggested, have discouraged some, nullified or canceled out any benefit it might have in making sure all the cases are reported?

Gebbie: I know they raised that question. I don't know how to answer that, and that was certainly part of the tradeoff, but I think the board of health went through ....

We don't know what the [new] wider case definition does around that. The other case definition, which really had people quite ill before they were reported, didn't seem to raise many questions. [people were ill enough that they needed medical care so the questions of reporting didn't seem quite as central there. Now we're dealing with people who are physically still feeling well and fitting under the case definition,m and I think we're all learning what that is. Washington state has a good record on confidentiality, has reasonably;y good state laws in that area. I must admit I didn't see that as a central issue. But to the extent an activist group is saying it is a problem, that does seem to be a community level concern.

Blade; Some have said that you might have had a proposal or a feeling that mandatory reporting of positive tests for HIV antibodies was something to look into. Could you clarify your position on that?

Gebbie: I do think that someday -- five years, ten years, twenty years from now-- Hiv reporting will be very much like our reporting for many other diseases. We will be far enough along in our community understanding not just of the disease, but our community understanding of human beings and their sexuality; some of the current hassles and fears will be minimized; and we will have a more extensive reporting system, especially if the earlier our treatment moves, the more it is we want to provide people with care.

The whole point of a disease reporting system is to connect people with the system. It's not to do something to them, its to serve them better, and serving not only them but those around them, including the people they may have been involved with. So I did ask the question, assuming this may come at some point, or will come at some point, what are the things we should think of? I wanted them to be looking at what needs to happen with our confidentiality laws. Do our anti-discrimination laws need redoing? Do we need different communicating mechanisms? What about computerized systems? What about the capacity of state and local health departments do anything with the information> Doesn't do any good to report a disease if we haven't got any staff there to deal with it. I simply wanted them to be having that discussion so we had our tick list of things we needed to be

THE WHITE HOUSE

WASHINGTON

Remarks of Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator
at the Meeting of the
Association of Reproductive
Health Professionals

October 20, 1993
Willard Hotel
Washington, D.C.

You used the phrase in my introduction that I am supposed to be working with the President or that the President has asked me to work towards developing a national plan for AIDS. We have one, it's called "Stop AIDS." That's the strategy, that's the plan and that's the goal, and the question is what are the strategies that we are going to use between now and then to get it to happen. And that is the vision of the future because we know we have already too many infected people. We still have an immense care burden that we will have through the end of the century and beyond even if we stop transmission today. But if stopping transmission is our vision of the future, for that to happen, it really is an issue of youth in our society.

You only have to look at the data now available about new cases of AIDS, remembering that that's a late stage in HIV infection, to know that much transmission, men and women, heterosexual and homosexual, is happening prior to adulthood. And that unless we can change patterns of sexual behavior with young people, we will not be able to stop this disease even if we invent a cure tomorrow. We know that from our work with other sexually transmitted diseases earlier in this century and even today.

To focus just a little then bit on a vision of the future in which we could change those sexual patterns, there are a couple of things that I think you can be most helpful on as we move towards the implementation of a national strategy:

The first is that we have to understand that this activity is both national and local. There are some things that can be done nationally to set the stage. Certainly at the national level we have big checkbooks that can be hauled out to pay for things, but changing human behavior at an intimate level happens at an intimate level, at a local level. It is affected by not what you saw for five minutes on the TV, and I think that many of you will be pleased and impressed with the new public service announcements coming out of CDC so the new materials, they will help. But not just those few seconds, those few minutes on national TV, but what kind of messages are being conveyed through the schools, through doctors and nurses

in every health facility, through the churches and the boys and girls clubs and the community at large in our expectations. So that we need to keep organizing and developing people concerned about the future health of teens at the local level at the same time we are developing better grass roots strategies to have an influence nationally.

The second point I want to make is critical to what our message has to be. I am more and more convinced that we will not change what we need to change, unless we as a nation, as a culture of many cultures, have an affirmative view of human sexuality as an essential thing to human life and as an essentially important and pleasurable thing as a part of human life. That as long as we couch our messages around sexuality in terms of don'ts and diseases and don't recognize it for the positive thing it is and figure out how to give those messages while giving the warning messages about the risk, we will continue to be a repressed Victorian society that misrepresents information, denies sexuality early, denies homosexual sexuality, most particularly in teens, and leaves people abandoned with no place to go.

I can help just a little bit in my job, standing on the White House lawn, talking about sex with no lightning bolts falling down on my head, but that's only a little bit. The work that the Surgeon General is doing, the work that each one of you is doing in your daily efforts will be a part of that. I invite you to remain a part of that dialogue and please share with each other and with me your ideas on how we can begin work on some of that social transformation.

Thank you.

Office of the National AIDS Policy Coordinator

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750 17th Street, N.W. Suite 1060
Washington, D.C. 20500

Phone: (202)632-1090 #5048
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Deliver To: Kristine Gebbie or
John Gurrola

Sent From:

___ Kristine Gebbie, RN, MN, National AIDS Policy Coordinator

___ Carlos Velez

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Thank you.

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speeches

THE WHITE HOUSE

WASHINGTON

Comments of
Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator
before the

University of Michigan Public Health Students' Association
December 2, 1993
Ann Arbor, Michigan

WAD - guilt / activities -

The second decade of AIDS

I. The epidemic twelve years later
   A. numbers infected
   B. demographics--impact on women, minorities
   C. community responses--good and bad
      1. care
      2. prevention

II. Policy directions
   A. Research
   B. Care
   C. Prevention

III. The policy challenge
   A. reshaping a national consciousness
      1. on substance abuse
      2. on sexuality

Clergy

Speech

THE WHITE HOUSE

WASHINGTON

Comments of
Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator
before the

Healing AIDS: HIV Primary Care Conference
University of Michigan
Ann Arbor, Michigan
December 2, 1993

HIV Primary Care in the Clinton Health Care Reform Era

Objectives

To review the principles of the Clinton health reform plan

To identify the primary care needs of HIV infected individuals

To discuss the issues in moving toward a reformed system without putting HIV infected individuals at a disadvantage

Discussion

I. Health reform basic principles
1. security
2. simplicity
3. savings
4. quality
5. responsibility

II. Health reform benefit package
1. primary care
2. diagnostics
3. prescription drugs
4. home care
5. mental health & substance abuse
6. public health system improvement
7. infrastructure development
8. targeted projects

III. Care needs of HIV infected persons
1. get coverage
a. comprehensive benefits package
1. drugs
2. home care
3. substance abuse prescriptions
4. choice

2. equitable continuous coverage
a. lifetime limit
b. not treatment specific
c. no cancellation

3. early diagnosis

4. planned care

5. appropriate specialty referrals & support

6. participation in research trials

7. supportive services

8. getting from here to there
a. defining outcomes and quality control
b. chronic disease
c. data management and access
d. confidentiality

IV. Currently insured--plan development and selection

V. Currently uninsured--finding and enrolling them

VI. Role of essential providers
A. risk adjustment for providers

VII. Role of Ryan White funding

THE WHITE HOUSE

WASHINGTON

Comments by
Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

before

HIV/AIDS Prevention Education for
Diverse Communities of Women Conference

Brooklyn, NY
March 9, 1994

1. Why worry about HIV and Women
   - A. Continuing growth of cases in young women
   - B. Impact of Infection on women
     1. On their own health
     2. On their children
     3. On their families

2. Why this area is missed
   - A. Focus on men
     1. Gay men
     2. Injection behavior
   - B. Tendency to denial
     1. On the part of society
     2. On the part of caregivers
     3. On the part of women themselves

3. What it takes to get a prevention message through

A. That the risk is real

B That there is something which can be done

C. That the individual can do it/is worth it

4. The issue of making messages pertinent/receivable

A. The images must be relevant

B. The messages must get where people are

C. The messages must fit into priorities

5. Ownership of the issues

File - speeches

THE WHITE HOUSE

WASHINGTON

Comments of
Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator
before the

School of Public Health
Department of Public Health Policy and Administration
University of Michigan
Ann Arbor, Michigan
December 3, 1993

AIDS Policy: What the Federal Government Can (and Cannot) Do

I. Focus of Federal AIDS Policy
   A. Research
      1. Breadth of basic research
      2. Targeting the investment

   B. Care
      1. Health reform
      2. Ryan White CARE Act

   C. Prevention
      1. Health reform
      2. Community planning
      3. Explicit messages
      4. The substance abuse connection

II. The Role of the Body Politic in Public Health
   A. In what is offered as policy options
   B. In what is selected/delivered

III. Reshaping a national focus
   A. The public framework
   B. Connecting public and private sector
   C. Shifting the federal investment

Randy –
misstated #

? Relative Risk

Reporting
Mandatory Testing
? surrogate markers
Cannot infringe on choice ?

THE WHITE HOUSE

WASHINGTON

December 30, 1993

MEMORANDUM

TO: Andrew Barrer
Terry Beswick
Buck Buckingham

FROM: W. Steve Lee W. Steve Lee

SUBJECT: KG's speech to First National Conference on Human Retroviruses and Related Infections

ACTION REQUIRED: Review text and develop distribution list

DATE REQUIRED: January 4, 1994

Please review the text of Kristine's speech to the First National Conference on Human Retroviruses and Related Infections (as transcribed by Terry and edited by KG) to see if there are any glaring mistakes. If so, please bring them to my attention. Also, provide me with a list of individuals that should get a copy and they will be sent a copy with a cover letter from KG. Thanks.

Attachment

THE WHITE HOUSE

WASHINGTON

Remarks of
Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator
at the
First National Conference on
Human Retroviruses and Related Infections

Washington, D.C.
December 12, 1993

On Research, Policy, and Process:
The Impact of AIDS

Thank you. This is what people who are trying to haul elephants wear in this country, I guess. I didn't get one of those little suits like were shown in the slides. My apologies for having transportation difficulties and causing the rearrangement of presentations this evening. It was a good review for me, however, to hear most of the previous presentation, I appreciate that.

There are two problems I confront in coming to this audience tonight, one of which I knew ahead of time and the other which I didn't. I happen to prefer speaking where I can see faces as I talk. And what I didn't realize was this arrangement what I see is just a few shapes in the front row and then nothing. I am going to assume that at least three or four of you have stayed and that you are out there watching the screen or watching me here.

The other is that this is a conference focusing on the epidemic at a fairly discreet level of the virus, looking at the science of developing a better understanding of the virus, and its effect on the human body. Looking not only at this virus, but other related ones. This is not my area of expertise.

Predominantly I have tended to look at larger health and illness care systems and at human responses to those systems either as individuals or as families. And I become nervous that I don't use words that are quite polysyllabic enough for some of you, for an audience such as this. I will, however, try to give you some perspective on what I think the impact of the HIV epidemic has been on research policy and process in this country and what are some of the remaining challenges in developing that policy and process.

As many people do when speaking about this epidemic, I think of individuals who have been directly affected by it, some of whom

are no longer with us, and in preparation for this particular presentation was reminded Jesse Dobson, a member of the advocacy community, who has also been an active member of a number of the groups looking at the science process and a particularly active participant in and founder of the gatherings in this country that crosses many of the lines the institutions trying to find the future directions of AIDS research, no longer is with us. An example of what this epidemic is costing us.

This is an important conference, and I am pleased to be here at its beginning. I will do a version of informed consent with you. Some of you may have heard me do this before. One of the things this epidemic has taught me and many of us is something about the complexities of our language and the subtleties with which the words that seem plain and simple to any one of us, become complex and even hurtful to others among us. They may be heard as uncaring, as ignorant, as categorizing, stigmatizing. It is not my intention to use any words that do that, but rather my intention to try out some words as I now see how they fit together. I would invite you to give me your feedback if my choice of words causes you to be discomfited or if you think some further observations would help me elaborate a better on the points I am trying to make.

One of the things that I think a lot of us in the health and illness field fantasize is that science and policy are closely related and that relationship is of the following type: first, science finds brilliant answers and then policy tidily applies it to eliminate some human ill. As we know with this epidemic, those relationships are not tidy. They don't come in that order, and we are constantly interacting to try to use the best of what we know of science and what we <u>believe</u> about what we know and how we <u>feel</u> about what we know, to do something within our system that might be useful.

And that policy can happen at many levels, the policy in a laboratory about what will be studied; the policy in a clinical setting about what kinds of staff will be employed or what kinds of patients will and will not be cared for; the policy of an academic institution on what it will focus on as its specialty areas; the policy of a government about where it wants to go. As was mentioned by the previous speaker, I think that at the beginning of this epidemic, it was the dominant policy in this country to hope that the epidemic would go away and we wouldn't have to have policy at all.

Pieces of the federal government bureaucracy had polices within

the prevention agencies, within research agencies, but overall it was a struggle. And we are still struggling to find out what a policy looks like when we try to pull it all together other than policy at the very broad level called stop the epidemic.

I think our ability to stop the epidemic, to develop wise policy and particularly wise research policy (to talk specifically about that area) is influenced by our mythologies. Each of us approach any situation with a well developed mythology both about ourselves and about those with whom we come in contact. Those mythologies draw on experiences and stereotypes. We learned them from our mentors in our own disciplines or in our worlds, we learn them from our families and from our friends. We don't always think about them consciously, but they shape what we do and how we do it. And they shape our concerns. They clearly shape our ability to hear one another.

If we were brought up into one of the healing professions, before the era of informed consent, we may have very paternalistic and maternalistic mythology about our appropriate relationships with our patients and "nurse knows best," "doctor knows best," "please take your pills dear," "will you go home now and come back on my schedule," were things that many of us thought were o.k., because that was the way we were brought into our profession. That is not the way our world expects us to behave today and our younger generation of practitioners is being brought up with some different mythologies.

We are generally far more sensitive to the flaws in the mythology about us, than we are in the flaws of the mythology that we hold for other people. And so when we recite a mythology or an image of someone else that may be negative about that group, we may not hear the negatives because that's what we accept as a reality, whereas a slight flaw in someone else's mythology applied to us may be reacted to as being outrageous and absolutely insupportable.

In looking at research policy, I identify four major players, one of them I will subdivide, so really five groups. And I think our research policy, our ability to develop it and understand it and make it work right is, in fact, deeply affected by these mythologies that we hold about one another. And the groups that I will identify in these mythologies are: the government, and that's the one I subdivide into both the regulatory bureaucracy and the scientific research bureaucracy, academia, the pharmaceutical industry and advocacy groups. For each of these I can identify both a positive mythology, which is the one everyone

of us would like to hold about ourselves, and the more negative mythology which maybe is what is circulating in the rest of the world about us.

In the positive mythology of all of the above, the government research center is the great center in which the brightest young minds are trained and developed and supported to go forward. The government regulatory bureaucracy is acting firmly on the public's behalf, always searching for truth and protecting people from flaws and dangers. Academia is full of purists in search of truth, free to go wherever they want to go because of academic freedom. The pharmaceutical industry attracts private capital and has money and resources to bring to bear on all complex problems. And advocacy groups bring life and energy, open the doors that have been closed and show the world how things really work, urging them forward to a good end. That describes all of us perfectly.

On the other hand, on down days, the government research centers are in an incestuous relationship with an establishment that only wants to look at the way things have always been, never at anything new. The government regulators are a stumbling block so caught up in their mills of paperwork and their piles of regulations that they cannot hear the people crying outside. Academia is full of grubbers after tenure, using grants and publications as their weapons and not wanting to get into anything too controversial. The pharmaceutical industry is nothing but entrepreneurial profiteers seeking money wherever they can find it. And the advocacy community goes after fads and fancies, has not a brain among them to really understand the science of the disease. None of that applies to anyone in this room, of course.

There are bits and pieces of truth in each of those exaggerated statements I made. None of us are perfect, none of us works for perfect institutions. Each of us occasionally gets caught in doing things the old way, in clinging to paper and regulation, in looking at an outcome that may benefit only us and not others around us, in jumping on a bandwagon of what seems the common thing to do today or the best thing today or the most popular thing today. But I think all of us also has a side that is looking for the right answer, the best way, the most helpful way, responding to the cries of those who are hurting and fearing their own early death.

Somehow, we must come to tables together in which we leave at the door our own exaggerated versions of our own truths and our own

exaggerated images of others' problems, and openly share both the positive and the negative that we each bring in order to build on what we have together. We are struggling with that process in all AIDS policy and in certainly in AIDS research policy in this country.

We do have a policy. That policy is based on an assumption that we can and will find reasonable answers to complex human questions, that we can find scientific answers to a disease such as the infection caused by the human immunodeficiency virus. And we have in fact gone aggressively after those answers, looking at the epidemiology of the disease, the causal agent, understanding its pathophysiology, the natural history of the disease in people, looking for treatments and cures of all kinds, and seeking to understand what will work for prevention, both behaviorally and biochemically.

With that as a framework for a policy, we, therefore, believe that it is worthwhile for this federal government to invest money in AIDS research, large money, and money that has grown under this administration considerably larger than it has spent before. That money is spent on research, not only within the confines of federally managed agencies, but is spread across the country in research grants that go to a wide range of agencies, institutions and individuals.

That commitment is a firm one, it is related to a commitment to biomedical research in general, and I do not see that it will be changing. But that's a very high level of research policy, and doesn't particularly talk about what the difference that HIV might have made in research policy and research process.

In regard to the research process, our policies are based on several important things. One of them is a deep seated respect for what is known as the scientific process. That process of seeking answers that has evolved in bench science in several disciplines, that is regularly applied to medical science in almost all of its aspects and that many of us have struggled to apply to the social sciences, because they don't fit quite so tidily in the time frames and measurement modes that we are used to using.

The research process that we respect is built on what we call peer review, something that assumes that knowledgeable scientists are in the best position to critique what each other does and to verify that we are not being sold a bill of goods by someone with an ulterior motive or someone with a weak knowledge of what is

going on. It is that peer review piece that in some ways has been most attacked by the changes brought about by this epidemic.

Our research process is also deeply grounded in a respect for what I label academic freedom, with a great reluctance to direct where researchers will go, because with our experiences in the past, that the unfettered search by someone who is knowledgeable for new knowledge leads us in surprising and positive ways.

The impact of this disease on that process has included a number of things, one of which I already mentioned, and that is funding, large increases in funding for the National Institutes of Health, for other agencies of the federal government. There is some concern in some quarters that funding is causing distortions, that the funding doesn't necessarily match the relative importance of most conditions or appropriate investment in things that do cause a great deal of human harm.

One of the examples of that is the nation's prevention budget, where the single largest disease-specific proportion of money in the Centers for Disease Control and Prevention budget is now HIV. My answer to people who question any of those investments in HIV is to suggest that it may not be that we are spending too much on AIDS but too little on everything else and, therefore, the proportions look wrong. The problem is that, once you get a baseline of investment in any disease, it's hard to dramatically shift it.

AIDS investments have grown very rapidly because we are early in the course of this research effort. I do not know that we will be able to see those large increases in the future, particularly with the limits on domestic spending that we are facing.

I think the impact of this epidemic has been equally visible in the process as in the funding. We are changing the way we relate to one another and changing the ways we go about doing business. For example, we now have a disease specific Director reporting to the Director of the National Institutes of Health, or we will have when that position is filled, the Director of the Office of AIDS Research, a full-time position designed to pull together research across all the institutes.

That's an organizational change that was created by Congress with the collaboration of many parties. That in itself discomfits some concerned about policy, that Congress is dabbling in the organizational chart of a research institute, supposedly operating above politics. It gives heart to others who believe

that this disease is so important it cannot be managed without that kind of central direction and enthusiasm. Whichever is right or wrong, it is at least different, and getting a strong, creative, well-schooled research scientist into that position will have a lasting future effect on where we go with research policy and process in this country.

For many, the most visible change has been the role of the advocacy community. From being a group which is seen primarily standing outside the doors very angry, very hurt, very loud, that community has become a partner in many pieces of the research process. A partner to the extent that I have sat in meetings where members of that community argue with one another that some of them have become too much like government bureaucrats and academic scientists, have been coopted inside the system and can no longer qualify as being considered really "real advocates." Their answer is that what they have learned is that coming inside and becoming a part of the process is how you get things done, that you understand better some of the complexities and that, merely making loud noise outside does not do enough.

Perhaps we have two mythologies going within the advocacy community and I have to add to my list of myths as I continue to look at this. But that role has changed and representing those affected by the disease, people I am calling advocates, now sit on grant review committees, sit with scientists as they plan what they might want to do next, critique the scientific journals as fast as they come out, share information rapidly around the community and has led to a patient population in many cities which is more knowledgeable than the average practitioner about what the latest shift in understanding of this epidemic is. And they therefore, ask very sophisticated questions about subtle shifts in treatment regimes or anticipated research studies that may be done in the community.

That continued push by those not certified as members of the research community but watching it carefully from an informed, and enlightened and energized self-interest continues to push us all. The process of regulation and review has been changed, speeded up, the process is overlapping to the point where, at least as I can follow, into our drug review establishment in this country, time from application to production of a fully licensed product might be cut in half or less from what it one time took. And that process is now available, that improved process can be applied to other conditions.

That's one area where people are nervous about overreacting and

pulling back too far, that drug regulation has arisen over generations in specific response to what were felt as outrageous events in which many people were damaged, made ill, born with deformities, and people are afraid of pulling back, but have become, in large measure because of the advocacy community, also afraid of holding back, of causing unnecessary grief to those who fear death immediately and are willing to take great risks with their own lives.

I would add that one of the areas of concern that has been presented to me recently is that of how we view in that regulatory process and review process the role of women as individuals who are willing to participate in research processes, who want to speed up the introduction of new drugs or understanding of the disease. They feel that they are inhibited because others see them not as individuals in their own right but as carriers of babies and potential carriers of future babies and deny these women the right to participate in studies that might be risky not because of what might happen to that woman but of what might happen to that unborn child or an as not yet conceived child. Understanding that intricacy and how we bring that to bear in the regulatory process is an upcoming challenge.

The lines among these communities that I outline for you are becoming blurred and the most recent specific example of that is the newly chartered drug development task force, National task Force on AIDS Drug Development, created by the Department of Health and Human Services, which will bring together at the table representatives of all the communities I listed to aggressively look together, not serially and not in antagonism to each other but together, at that process by which a potential new drug goes from being the idea of a molecule in the brain of a scientist to a product that can be prescribed for individuals in the community. That's a first, it's something that's been tried informally that's been emerging, but is now formally recognized in the structures of this government.

I think there are many more changes yet to happen. I think there are many more ongoing at the local level that I won't even attempt to describe at this hour, that involve individual research projects and individual relationship with grant programs. I want to move to describe what is one of the most difficult definitional problems in understanding how we may yet need to change the research policy and process around this epidemic, and that's with the thing that is called by many a Manhattan Project.

This is something that many folks have asked for. Many people have looked at our history, and said there was a time when the nation was really energized, it was during a war and they wanted to build a bomb and they took the necessary scientists, gave them practically a blank checkbook, locked them up in secret places in the desert and said "build it." And they did.

People, many of them infected with this virus, feel that the same type of process might work to stop this virus. And the name Manhattan Project has caught on and my boss the President has talked about a commitment to a Manhattan-like Project to fight this disease. But the part of the problem is that as I talk to people about what they mean by it, it's not entirely clear that they even understand what the first Manhattan Project was, how it operated, what it did what it did, what a legacy it left us, some of which is a negative legacy.

It's not clear whether they mean one single research project that would answer a cure for AIDS. I can't understand that as being a single research project. I understand what we need to fight this disease as an overlapping series of projects focused on several pieces of where we want to go, both to stop the virus and to assist the immune system, to deal with our understanding of how human behavior overlaps with this infection and would continue to be important whether we were trying to get people to adhere to a treatment regime or to change their behavior in a preventive way. Does it mean a single boss of the project? If it does that, does it mean a single boss within government or somebody that transcends government into the private sector, and if so, what pieces of it?

For some people, it almost seems to mean one laboratory, one laboratory where and how big would it have to be to contain all the questions that we already heard tonight and many, many more?

What I know, is that we have in the policy of this country, based on our understanding of the research process, a commitment to putting our resources to stop this disease. That does mean redesigning how we do research, it means crossing the line of what were traditional relationships between those who funded research and those who conducted it, between those who thought of ideas and those who critique them, between those who developed new ideas and those that bring them to commercial products, between those who develop products and those who use them to protect their own lives.

That as we build those relationships in new directions, we must

stay focused on that end result of stopping this epidemic. We must do so in a way that fully respects the questions as we now understand them, but does not lock us in in such a way that we cannot shift if we understand the question to be a little different in three months, in six months, in nine months or a year. It must be a way that fully energizes both those who know they are working on a specific AIDS project and those who are working in basic sciences, both behavioral and biological, whose work is not labeled HIV infection, but in fact may be relevant to what we need to know, if we keep our eyes and our ears and our minds open.

This is not a discussion that comes to a smashing conclusion in which I will flash up a slide and say here is the answer to AIDS policy and process. What I've tried to summarize for you is what I see as the major influences on how we develop that process because of our relationships with one another, and something about how this epidemic has had an impact on what we are doing to fight this epidemic or to do research in general.

As I said at the beginning, I invite your comments. I have used some caricatures of people that may apply to some of us in this room and may make some of us uncomfortable. I kind of hope they have because discomfort usually makes me look at myself and understand myself a little better. And I hope that this discussion will help each of us to understand our role in that research process better.

I have ended with a question in an area where many people believe that there is an absolute answer: there is or there isn't a thing called a Manhattan Project and it does or does not look this way and either you are or aren't committed to it. And I do have an answer that I am committed to what I understand is a good research project to get AIDS and it doesn't quite match what I hear that label word saying for many people, but I am not quite sure of that either.

I look forward, as I try to make this AIDS Policy Office on behalf of the U.S. government a workable office, invite your comment on how research fits into the overall attack on this epidemic. And particularly invite you comment on how this description of the process may help or hinder where we go, how your piece of it might be expanded or shifted if I understood better what you are trying to do or if we all understood better how we all fit together. I believe whatever the scientific question, however fast we find the answer to this disease, it is by interaction that we can continue to strengthen, continue to

develop a strong policy that will indeed help us to stop the virus.

Thank you very much.

January 19, 1994

MEMORANDUM

TO: Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

FROM: Bob Jackson, Science Fellow W Stimbee for

SUBJECT: Heroin Trends Assessment -- Comments on report

I found the Heroin Trends Assessment report on heroin trends very interesting. I hope the following comments are helpful.

Point 1
An attempt is made to suggest that there are a large number of "new users" involved in the current heroin problem and that these new users are drawn from the "ranks of crack and cocaine addicts" and that these "new users" provide the "catalyst for drug epidemics." This concept is very confused. If the new heroin users are being drawn from the ranks of the already addicted then they don't represent new drug users but only new heroin users and hence do not represent a new pool of addicted people. In fact, it merely confirms what we already know about addiction; that addicts have drugs-of-choice, but other factors (supply problems, fear of AIDS, marriage to a partner who has a different drug-of-choice, etc.) can alter drug-of-use but that does not alter their fundamental drug dependency.

Point 2
Intranasal use of heroin has increased from near 20% in estimates done in the late-1980s to near 50% in recent studies in the northeast United States. There are two primary reasons for the increase: 1) fear of HIV/AIDS, and 2) availability of a pure enough product to make intra-nasal use satisfactory. The drug dependent community may be addicted but they are not stupid, blind, or indifferent. They are very aware of the risk of exposure with intravenous use and have chosen to use heroin intranasally. It is more expensive to use intranasally (it takes 2-3 times as much to obtain an equivalent high), but given the choice many of these folks have made an affirmative risk-reduction decision. The AIDS factor is discussed in the body of

the report, though the consultants down-played the importance of AIDS as a factor even though the majority of those questioned said it was important. The report suggests that we can expect all intranasal users to progress to intravenous. This is not a normal progression, as it is depicted in the report. From my own front-line experience treating addicts, they are far less likely to move to intravenous use than is suggested in the report. Moreover, intranasal users are far more likely to be HIV negative, to know it, and to wish to stay that way. This group, in particular, is very unlikely to change routes of administration.

Point 3
The combination of heroin and cocaine is spoken of as if it were some new discovery. This combination has been around as long as these two drugs have been available together -- it is known in the drug community as "speedballing." It has been well known as the "Cadillac" of highs -- supposedly the combination most closely simulates an exaggerated orgasm which can be prolonged until the body becomes exhausted. The supposed upswing in their combined use is simply a measure of the resources of drugs and money available to the users, not a new vogue.

Point 4
The apparent increases in the amount of relatively pure heroin being used is not an undiluted reflection of increased numbers of heroin addicts. A significant portion of the increased amount is simply a reflection of the increased amount of heroin necessary to give an equivalent high when used intranasally. If there has been an increase of 30% in the number of heroin users who are intranasal, and if it takes 3 times the amount of heroin when used that way, you have accounted for almost a 100% increase in heroin use with no increase in numbers of people involved whatsoever.

Point 5
There is no mention of needle exchange programs in the report that I can find even though the consultants interviewed and did their studies in 5 cities, 3 of which have had active and long term needle exchange programs, an intriguing gap in the information.

Please let me know if you have questions.

THE WHITE HOUSE

WASHINGTON

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

Speech before

The Portland City Club
April 15, 1994

"HIV -- Oregon and the Nation"

The last time I spoke about HIV and AIDS to the City Club was in 1988. The disease continues to be a problem, but some things have changed. At that time, there had been 323 cases of AIDS diagnosed in Oregon; at the end of 1993, there had been 2525. In 1988, 3% of the cases were in heterosexual drug users; today, about 10% of the cases are from that route of transmission.

In Oregon, as in the nation, AIDS kills a generation that should live. In Multnomah County it is the leading cause of death of young men between the ages of 25 and 44; statewide, it is the second leading cause of death. While it has not achieved that level in women, it is steadily rising.

And despite interest and action, the rate of infection grows in a number of groups. In 1988, about 4% of injecting drug users tested in public sites were HIV+; today that number is about 18% in Oregon.

The major problem with this infection continues to be denial and division. We persist in talking about various "infected groups" as if they were mutually exclusive, and unrelated to one another. The list often includes homosexual men, drug users, hemophiliacs, women, people of color. It is certainly true that hemophiliacs are not women, nor are gay men. But with those exceptions, all intersections of the listed groups are possible: there are women who are drug users and there are gay men of color. The intersecting circles of interaction in our society mean that all of those exposed to or at risk of HIV infection are indeed a part of our community, our family, and we must be concerned.

So what are our national policies to deal with this epidemic? They are in three areas: research; services; prevention.

In research, we are committed to seeking until we find the answers. This means a national commitment to the full range of biological, biophysical, physiological, psychological and sociological sciences as they apply to this disease and our experience of it. It means doing both basic and applied studies in all of these areas. For example, we need to study both how the immune system works in general, AND how to restore it after it is damaged by this particular virus. We need to study how young people learn sexual roles AND how to help with choices in the face of this epidemic.

There is no single, technical "fix" out there which will resolve this disease easily: we are going to be helping people live with a chronic disease, for a long time, and that will take a lot of information we do not yet have.

The goal in services is that anyone who is infected with this virus is diagnosed early, and has access to a full range of services that will allow him or her to live as long and full a lifetime as possible. Health reform is at the heart of this policy: without non-discriminatory, non-cancelable coverage it is impossible to build the kind of services needed. People with HIV infection are too often un-insured or under-insured, or lose their coverage just when they need it most.

But coverage for payment is not enough. We also need to build a network of services which are based on good planning and management of resources so that anyone with a chronic condition, including those living with HIV, get the care needed in a timely manner, in the most appropriate setting for his or her circumstances and health status.

The funding called Ryan White must also be continued, not only to assure a safety net during transition to a reformed system, but continuously, to provide those needed services which are not part of insured benefit packages. These services, which include transportation, child care, housing, food and the like, must be planned and organized by each community, to fit the resources and needs of the population.

Somewhere between services and prevention comes substance abuse prevention and services. Preventing and treating substance abuse IS HIV prevention. This not only applied to any form of injecting substances, but to any abuse which clouds judgement and can leave individuals in risky circumstances. The administration is committed to increasing resources for substance abuse treatment, and has asked for over 300 million additional dollars

in the FY95 budget.

Finally, prevention of any further cases of HIV, using the best available knowledge, is a central part of the national policy. It is simple to describe the behavior changes which must be achieved: no one should ever share injecting equipment, ever, for any purpose. No one should engage in sexual activity outside of a mutually monogamous, lifetime relationship, unless a latex condom is used consistently and correctly for each sexual act. Those two behavior changes are simple to state, but very hard to achieve in practice. It is especially difficult because we have trouble talking about sexual behavior, and do not really understand what it takes to help a young person develop a sexual identity, understand his or her sexual orientation, and then make decisions about what, if any, sexual activities are appropriate.

In considering these policies, I am struck over and over by the local nature of the decisions needed to translate any of these policies into effective actions against HIV infection and AIDS. No matter what is done in Washington, no matter how firm the commitment of the President and the administration (and the commitment is firm), your actions in the community will make the real difference for people.

A few examples. No matter how much money is available for HIV-related research, it is a university's decision whether to reward leadership in AIDS research, or to hide it by failure to recognize those who do it, or placing it in the most obscure corner of the campus without signs on the door. It is a community decision to make it easier for those who are or might be infected to acknowledge their infection, by making testing readily available AND by committing to non-discrimination in all settings. It is a community decision to give all young people the information they need to save their lives, and to support that decision firmly, not only by a school curriculum which includes comprehensive health information, but by church, service and civic club commitment to give parents and young people the support and value information to turn the facts into meaningful life decisions.

One example of how a community could support efforts to stop this disease would be through workplace HIV prevention education. The federal government has made this commitment: all 3 million civilian employees of the federal government will be getting such education. We are doing it for three reasons. We value the personal health of our employees, and want them to have the information; we know we have HIV+ employees, and we want our

supervisors to know how to manage them appropriately within the Americans with Disabilities Act; and we hope that information on the epidemic will trigger at least some individuals to reconsider how their programs can become a part of the overall prevention effort.

This community could make it a community norm that all workplaces be places of HIV information. There are some interesting resources out there. For example, there is a group of "Racers against AIDS" -- car dealerships or garages might team up with this group in developing programs. And what about the hairdressers and barbers? This is a group we once looked to for their role in mental health and crisis intervention. They are certainly in a position to talk to people about important subjects. Have we made certain that they have facts and resources to pass along?

Two other examples and possibilities. One is the expectation that community leaders are not just attending to this issue quietly, but that they are paying attention to critical public decisions, such as school board consideration of comprehensive health, sexuality and HIV education. These are often tough decisions, and the school decision makers need to know that the community leaders are there with them. And then there is the HIV planning table: first the local planning for Ryan White service dollars, and now the new planning for HIV prevention.

Oregon has been a leader in community involvement in health issues, as is evidenced by the development of the Oregon Plan and the debates on access to health care. Is the same standard of openness and involvement of all affected being applied in the HIV area? It must be, if we are to be successful.

We can stop HIV, if we connect with the reality that what we know in our heads does not automatically equal right behavior. It takes much more that the ability to pass a factual test about HIV for individuals to make healthy behavior choices for a lifetime. We need honest and open commitment, honest and open communication among ourselves if we are going to be successful. Something I said to you in 1988 still seems to be essential:

> One of my strongest beliefs is that our response to this epidemic will be measured not by how fast we found the virus or a vaccine, but in large part by the degree to which we acknowledge our community and our mutual responsibility... only collective attention to our own behavior will be

effective in stopping this epidemic.

If we can do that, we can, indeed, stop AIDS.

THE WHITE HOUSE

WASHINGTON

Testimony of

Kristine Gebbie, R.N., M.N.

National AIDS Policy Coordinator

Executive Office of the President

Before the

House Committee on Energy and Commerce

Subcommittee on Health and the Environment

January 24, 1994

Mr. Chairman and members of the Committee, thank you very much for this opportunity to share with you what the President's plan will do to help vulnerable populations -- those with HIV/AIDS, people with disabilities, Native Americans, migrant workers and others.

Their special circumstances, illnesses, and disabilities amplify their needs and illustrate poignantly the failures of the current system to provide the security of coverage when help is needed the most.

I'd like to share with you the stories of some real people, to illustrate how devastating a chronic illness -- in this case HIV/AIDS -- can be. As you'll see, because these people could be any one of us here in this room today, there are no guarantees in the system for any of us.

> Christina, a 25 year old woman, was covered under her father's insurance policy while she was a college student. During this time, she tested positive for HIV, the virus that causes AIDS. When her father disclosed this to his self-insured company, they pursued several strategies to get Christina off company policy. Finally, the company solved its problem by firing Christina's father.
>
> Charles has coverage but he doesn't feel very good about what he has to do to keep it. Charles is a 37 year old male who was diagnosed with AIDS in 1985. At the time he was working and had no insurance because he couldn't afford the high premiums. He knew he would need some help with his medical expenses, so he turned to Social Security for help. Charles quit his job in order to apply for disability and Medicaid. Charles would like to work, but in order to have his $4,000 a month medical bills covered, he had to stay unemployed and disabled. Charles feels that he is "caught in a trap" and fears the day when "the day the house of cards will collapse."

Fortunately, the President's plan provides universal coverage for every American, and that includes all the Charles's and Christina's out there, regardless of their needs or risks.

Congress -- particularly members of this Committee -- has demonstrated great concern about the ability of underserved populations to obtain access to health care services. The President recognizes, as you do, that a Health Security Card alone cannot guarantee that all Americans will receive necessary health care services. To achieve this goal, the Health Security Act includes additional measure that will provide special protections and secure access and quality for our vulnerable populations. Let me share them with you.

Security of Comprehensive Coverage

All Americans will have the security of comprehensive health coverage -- with no exceptions. People with disabilities or chronic illnesses will no longer be subject to the precipitous loss of coverage they face today. No one can lose their coverage. Under the Health Security Act, hospital services are covered; doctor visits are covered; prescription drugs are covered. In addition, certain extended care, hospice services, and outpatient rehabilitation services are covered. These services, and others offered under the benefit package become a crucial link for the very survival of people with certain disabilities or illnesses.

Mental illness and substance abuse treatment services are guaranteed elements of the comprehensive benefits package. By 2001, this coverage is without day or visit limitations -- on the same terms as other services.

From the onset, mental illness and substance abuse treatment benefits covered by the Health Security Plan (within certain guidelines and criteria) include: screening and assessment; inpatient and residential treatment; crisis services; intensive non-residential treatment; outpatient treatment; collateral services; and case management. Benefits are provided in variety of settings, including offices and clinics, residential treatment and intensive non-residential programs.

Continuity of Care

The Health Security Act assures that all Americans will have a choice in selecting their providers and health plans. Each individual will be able to enroll in a traditional fee-for-service plan, join a network of doctors and hospitals, or join an HMO. In addition, all health plans must offer a point-of-service option -- individuals will not be restricted to the plan providers.

To further guarantee continuity of care, all individuals will have access to medical specialists for unique services they need. All health plans most sufficient arrangements with providers to assure the provision of all items and services covered by the comprehensive benefit package. In addition, plans must contract with academic health centers for services that are rare and performed in enough frequency at these sites to ensure quality. Further, states may require plans to contract with centers of excellence they identify to further guarantee appropriate access to care.

The essential community provider provision guarantee services of federally-funded clinics and other providers delivering care in difficult-to-serve areas. Qualifying providers, e.g.

those being funded by Ryan White, Community and Migrant Health Centers, programs for the Homeless, family planning, and maternal and child health, are guaranteed payments for covered services from all health plans. This program assures that vulnerable populations have continued access to practitioners with experience in meeting their needs, regardless of which health plan they choose to enroll in.

Protections Against Discrimination

The Health Security Act assures that no individual is discriminated against in obtaining comprehensive coverage. Health plans will no longer have lifetime limits on coverage. Health plans will offer an open enrollment, accepting everyone applying for coverage at that time without charging a higher premium to those with a pre-existing condition. States and alliances further assure that no one faces barriers to care based on race, ethnicity, sexual orientation, age or gender.

To protect health plans that attract disproportionate number of vulnerable individuals, the Health Security Act assures proper payment through an alliance-based risk-adjustment and reinsurance systems.

To ensure confidentiality of patients, national privacy protection standards are established. These standards forbid the linkage of individual-specific information with aggregate data on patterns of care. Privacy protection as applied to health care information will be a continuing focus of the National Health Board.

Special Services

The Health Security Act leaves in place certain programs to address additional needs of these vulnerable populations.

Ryan White and other safety net providers. Current safety-net programs like Ryan White will continue to receive funding for services beyond the guaranteed package. Transportation, outreach, case management, translation, and personal support services remain critical for vulnerable populations and will be sustained under the Health Security Act.

Medicaid. All Medicaid eligible children will be eligible for a new federal program of wrap-around services that supplements the comprehensive benefits package. States will continue to receive matching payments for wrap around services for adults who receive SSI or AFDC benefits and dual eligible. Long term care Medicaid services (e.g., nursing home, ICF/MR, home health, personal care, etc.) continue to be available for all Medicaid eligible as under current law. In addition, all states will be required to take Medicaid expenditures into account in determining financial eligibility for Medicaid coverage of nursing home care. Also, Medicaid patients in institutions will be able to keep $50 per month for their personal needs, up from a minimum of $30 per month.

Transitional Insurance Reform

As you know, the reform will take a few years to fully implement. During the interim it is critical that we protect existing insurance coverage for employers and families. We must

assure that insurers do not drop the most vulnerable in anticipation of a system in which they are forced to compete based on price and quality, rather than their ability to attract the healthy and avoid the sick.

The Health Security Act, therefore, includes a series of transitional insurance reforms that guard against the most egregious abuses by health insurers prior to the creation of a fully reformed market and the formation of health alliances. These reforms include:

- Health insurers are prohibited from terminating or failing to renew coverage for a group or individual, except in cases of non-payment of premiums, fraud, or misrepresentation in an application for coverage or claim for benefits.
- Insurers are required to provide coverage for new employees of an employer that purchases insurance, regardless of health status.
- Premium increases cannot be varied according to the health status of the group or individual.
- Exclusions for pre-existing conditions are limited, and individuals who are continuously insured are not required to meet a new waiting period for pre-existing conditions when switching coverage.
- Self-insured health plans may not arbitrarily reduce benefits for high cost illnesses.
- The National Transitional Health Insurance Risk Pool is established to provide coverage to individuals who are unable to obtain private coverage because of their health status.
- Insurers are required to obtain prior approval for excessive premium increases.

These transitional insurance reform by no means represent comprehensive reform, as ultimately envisioned by the Health Security Act. They will, however, protect against the most extreme abuses we see in the insurance market today, and they will ensure an orderly transition

to a system that guarantees health security for all Americans and effective control of health costs.

Other Special Programs

School-Age Youth. The Health Security Act will address the problems of one of our Nation's most vulnerable groups: adolescents and young adults. The current health care system has failed to provide our youth with the information and services they need to avoid risky behaviors and make healthy decisions. Adolescents are also often reluctant to seek help, ignorant about what help is needed or where to get it, and concerned about confidentiality. These barriers contribute to the substantial problems with substance abuse, unwanted pregnancy, and HIV/AIDS among this age group.

The Health Security Act will reach out to school-age youth and adolescents in two ways. The Comprehensive School Health Education initiative will establish a national framework within which States can create school health education programs that improve the health and well being of students, grades K through 12, by addressing locally relevant priorities and reducing behavior patterns associated with preventable morbidity and mortality. This program will be targeted to areas with high needs, including poverty, births to adolescents, and sexually-transmitted diseases among school-aged youth.

The School-Related Services program will support the provision of health services -- including psychosocial services and counseling in disease prevention, health promotion, and

individualized risk behavior -- in school-based or school-linked sites. Grants will be made to states for the development and implementation of state-wide projects targeted at high-risk youth ages 10-19. In states that do not take this initiative, grants will be available to local community partnerships including public schools, experienced providers, and community organization

Severely Disabled Persons. The plan also includes a major expansion of home and community based services for individuals with severe disabilities. This new long term care program will offer significantly increased federal funding to help states to offer a wide array of personal assistance and related supports to people at home, in the community. Eligibility for this program is not limited by age, type of disability, or income. When this program is fully phased in, approximately $38.5 billion new federal dollars will be available to help people who have significant needs for assistance with activities of daily living to live more independent lives.

Migrant Workers. Migrant Workers are guaranteed a new level of health security under the Act. With their health security card, legal residents employed as migrant workers will be able to easily transfer their coverage from one geographic area to another. In fact, the portability will be assured by regional alliances whose job it is to keep track of employer payments and enrollment for all workers.

The Public Health Service Initiatives in the Act also provide a supportive framework for the benefit package coverage that is assured. The Community and Migrant Health Center Program is maintained, and as you know, Mr. Chairman, Migrant Health Centers are an

important source of primary health care for many migrant workers throughout the nation. These Migrant Health Centers are also protected as Essential Community Providers for at least the first five years of health care reform. The PHS Initiatives also contain a new grant program to assist providers in offering support services that will make their services more accessible, including transportation, outreach, and translation services. These services will be very important in helping providers offer more culturally appropriate services for migrant workers.

Indian health. American Indians/Alaska Natives receive special treatment under the Health Security Act in recognition of the historic obligations of the government-to-government relations that exist between the Federal government and Indian tribes.

Under the Act, Indians will receive an improved benefit package and new choices of providers. Indians may choose to enroll either with an Indian health program or with a health plan offered by an alliance. The health programs of the Indian Health Service will be maintained and expanded so that they will be able to offer the full range of the comprehensive benefit package services by 1999. All Indians, whether they enroll with an Indian health plan or an alliance health plan will remain eligible for supplemental services, such as environmental health, outreach, transportation, etc. The PHS Initiatives will reaffirm the emphasis on these important services.

Conclusion

Mr. Chairman, Members of the Committee: 37 million Americans, including many people who have special needs, go without health coverage. Far too many people most in need of services, such as those with HIV infection, are uninsured, or lose their insurance just when they need it most. We can either address the problem head on -- organize health care delivery and financing, so that system works for all Americans -- or deny the problem and let the system grow more and more unfair, expensive, and out of control. We must join forces and solve this problem. We must work together to create a rational system where those who need health care the most have security of care.