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HIV OVER FIFTY: EXPLORING THE NEW THREAT

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BEFORE THE

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UNITED STATES SENATE

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HIV OVER FIFTY: EXPLORING THE NEW THREAT

THURSDAY, MAY 12, 2005

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The committee met, pursuant to notice, at 3:12 p.m., in room SH–216, Hart Senate Office Building, Hon. Gordon H. Smith (chairman of the committee) presiding.

Present: Senators Smith, Talent, and Kohl.

OPENING STATEMENT OF SENATOR GORDON H. SMITH, CHAIRMAN

The CHAIRMAN. Ladies and gentlemen, we want to welcome you, Senator Kohl and I, to this important hearing of the Aging Committee. We are grateful you are all here, and today we will be focusing on a growing problem that is too often overlooked: the increasing incidence of HIV and AIDS among persons over 50.

We are very fortunate today to have with us a number of impressive witnesses who will share their insight on the unique issues and problems faced by seniors affected with HIV. Although we often hear how the face of HIV/AIDS is changing to include women, children, and people of color, we generally do not think of it as a problem facing America's seniors. However, significant breakthroughs in the treatment of HIV, particularly the rise of highly effective antiretroviral therapies, have allowed infected persons to live longer and fuller lives. In other words, people with HIV are aging.

Today in the U.S. 28 percent of those living with HIV/AIDS are over the age of 50. Moreover, by the year 2015, the number of those over 50 who are infected with HIV/AIDS will increase to 50 percent. As we will learn today, preventing the spread of HIV/AIDS among this population poses many unique challenges. Most notably, more than 70 percent of seniors with HIV/AIDS live alone, and few are connected with family or their churches. This often makes it more difficult for communities and health care workers to identify those in need and to reach out to them.

Most also face challenges associated with managing other chronic illnesses common among the elderly, such as diabetes, high blood pressure, and heart disease, in addition to their HIV. Moreover, women, people of color, or non-English-speaking Americans generally face additional barriers to care. As the number of seniors living with HIV continues to grow, so, too, will the demand for services. We need to assure those seniors that have HIV/AIDS that

they are not alone, that they have a voice, and that they have access to the treatments and services they need.

Stereotypes and lack of awareness about this disease is another challenge in preventing the spread of HIV among seniors. Many seniors are sexually active, and their behavior can put them at risk for HIV infection. Older women in particular are at risk because they no longer are under the threat of pregnancy due to menopause. Therefore, most do not believe condoms are necessary. Further, apprehension by health care providers about discussing sexual matters with seniors and failure of HIV/AIDS public health messages to focus on this age group contribute to an overall lack of awareness and increased risk among those over 50 years of age.

Luckily, there are examples of how to reach this group. A number of Federal, State, and community programs, especially those in my State of Oregon, have made a very positive difference in helping seniors who are living with HIV/AIDS. However, I believe we can and should do more.

Today's hearing is focused on determining how well current programs work, whether they offer the tools and the resources needed to more effectively help people, and how to make their lives better.

Today's testimony will examine a number of areas specific to the elderly HIV community, including outreach and education, support programs, funding issues, and ensuring access to affordable drug treatments. Using this hearing as a starting point, I will be working with my colleagues on both sides of the dias here and the HIV/AIDS community to develop legislative proposals that result in increased public awareness about this growing threat to our Nation's seniors and provide new ideas on how to improve the programs that serve them. With the Ryan White Act scheduled for reauthorization, I believe now is a good time to address this issue.

It is my pleasure to turn the microphone now to my colleague, Ranking Member Senator Kohl.

OPENING STATEMENT OF SENATOR HERBERT H. KOHL

Senator KOHL. I thank you, Mr. Chairman, for bringing the important issue of HIV and AIDS in the senior population in front of the Aging Committee today. While much attention has been devoted to HIV and AIDS prevention for younger Americans, our growing aging population makes it necessary for us to consider how HIV and AIDS will begin to affect seniors in greater numbers. This is an issue that has been largely overlooked, so I hope this hearing will help educate older people on the prevention of HIV and AIDS.

Although the majority of HIV and AIDS diagnoses are among persons between the ages of 25 and 39, there is now a growing awareness that those 50 and older are also at risk. HIV and AIDS cases are expected to increase as people of all ages survive longer due to new drug therapies. In addition, we need to make sure seniors have the information they need to prevent new infections from occurring. This is not a population that we can afford to ignore in our HIV and AIDS prevention and treatment programs.

We look forward to hearing from our expert witnesses today who can help us better understand the challenges of educating older Americans as well as their health care providers on this subject. We also look forward to hearing suggestions for ways we can effec-

tively stem this growing health problem and treat this unique population.

So, again, we thank you, Mr. Chairman, for holding this hearing. I apologize I will not be able to stay for the entire hearing because of some other meetings I must attend this afternoon. But I look forward to working with you to move this important issue forward.

I thank you.

The CHAIRMAN. Thank you, my friend.

We have as our first panelist Dr. Robert S. Janssen, director of the Division of HIV/AIDS Prevention from the Centers for Disease Control, the CDC, here in Washington, DC, Dr. Janssen, thank you for being here, and we look forward to your testimony.

STATEMENT OF ROBERT S. JANSSEN, M.D., DIRECTOR, DIVISION OF HIV/AIDS PREVENTION, CENTERS FOR DISEASE CONTROL AND PREVENTION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, WASHINGTON, DC

Dr. JANSSEN. Thank you, Mr. Chairman. I want to thank the committee for inviting me here today to discuss HIV/AIDS among older Americans.

In large part, as you have said already, we are here because of good news. Treatment is helping people live longer and healthier lives. I am aware also of the media and interest groups reporting increased rates of HIV among people aged 50 years and older. So to address the committee's concerns related to these reports, I want to show you two types of data: data on the total number of people living with HIV and AIDS and on rates of newly diagnosed HIV. This data have been collected in 32 States with confidential name-based HIV reporting.

The total number of people who are living with HIV is, as you mentioned, increasing, as you can see on this graphic. It is increasing in both those aged 50 and older, which is the pink line, and under 50, which is the yellow line. In the 32 States in the figure in 2000, about 40,000 people aged 50 and older were living with HIV/AIDS, so here in 2000. In 2003, that number had increased to about 67,000, and this line is increasing more rapidly than among younger people. But it is increasing in both. The most likely explanation, as we have already mentioned, is treatment is more effective than it used to be. People who are infected are living longer, healthier lives.

On the other hand, we think that this is not related to new HIV transmission among this population. When you look at the second figure, the rates of newly diagnosed HIV infections among persons who are under 50 and those who are over 50, you can see those lines are flat. This is indirect evidence, at best, of HIV incidence—that is, the number of new HIV cases or HIV transmission. It is the best data we have to date, but as you can see, there are no significant changes in rates in either of these lines. You can also see that the rate of newly diagnosed HIV infection is 3 to 4 times higher among those younger than 50 than among those aged 50 and older.

The HIV/AIDS epidemic in our Nation, as you know, disproportionately affects racial and ethnic minority communities. This is also true for those aged 50 and older as well as for younger per-

sons. Rates of newly diagnosed cases of HIV or AIDS among persons aged 50 and older are 10 to 15 times higher among African Americans than among whites and 5 times higher among Hispanics than among whites.

Now, it is critical for CDC, along with State and local health departments and nongovernmental organizations, to prevent the most new infections that we can with the resources that we have available. For this reason, we focus services on those populations who are at the highest risk either of becoming infected or transmitting HIV.

Although persons aged 50 and older account for less than one-fifth of new HIV diagnoses, HIV transmission does remain a concern among this age group. Thus, it is important these individuals get information and prevention services to help protect them from acquiring and transmitting HIV. Among 141 community-based organizations from across the country that we fund, 112 or nearly 80 percent include this age group as one of their target populations. They provide prevention services, which may include targeted outreach, can include voluntary counseling and testing, partner counseling and referral services, as well as health education and risk reduction.

One of the challenges of prevention among persons 50 and older is the mistaken belief that they are not at risk, they are no longer at risk, or perhaps many people never considered themselves to be at risk for HIV or other STDs. Studies have noted that physicians do not always address sexual health with their older patients—I would say that is with any patient, but particularly with their older patients—creating a barrier to educating older adults about the risk of HIV. CDC recommends that physicians take a sexual history from their older patients and discuss their risk for HIV and STDs.

Another important strategy to prevent HIV is to increase the number of people in this country who know that they are living with HIV, because when people become aware of their infection, they take steps to protect their partners.

One way CDC strives to increase the number of people getting tested for HIV is to encourage testing in medical care settings. CDC strongly encourages all health care providers to include HIV testing, when indicated, as part of routine medical care and on the same voluntary basis as other diagnostic and screening tests. This approach is important in this age group in particular because older adults seek medical care more frequently than younger adults.

I want to add one other thing that we are doing in our Advancing HIV Prevention, a new initiative launched two years ago to expand our reach with our HIV prevention services, and that is, part of it is to work with people living with HIV, particularly working with physicians caring for patients living with HIV, to address the prevention needs of their patients. That would include STD screening and taking a sexual history every year to be able to counsel those patients who may be engaging in risky behavior. I think this is critically important as we see on that curve the number of people infected in this age group is increasing.

So, in summary, HIV/AIDS affects Americans from all age groups. All Americans need to know how to avoid infection and, if

infected, get treated and know how to avoid transmitting HIV to others.

Thank you again for this opportunity. I will be pleased to answer any of your questions.

The CHAIRMAN. Doctor, did I understand you to say that sexual activity among those over 50 is not the reason for the increasing HIV population in this age category?

Dr. JANSSEN. What our data suggest is that people living with AIDS—the number of people living with HIV or AIDS is increasing as opposed to the number of people becoming infected, so, yes, that would be right.

The CHAIRMAN. OK. I understand.

Dr. JANSSEN. So, really, as you stated, it is related to treatment.

The CHAIRMAN. OK. In places where—particularly nursing homes and things like that, is there a regular course for patients to receive health care and are these questions generally asked, you know, in terms of their sexual history and the need to remain careful, if not celibate?

Dr. JANSSEN. Well, our experience with working with health care providers for HIV is that even those providers taking care of younger adults tend not to ask those questions. I am not aware of data of people taking care of older adults and whether those questions are asked, but data in taking care of younger people in their 20's to 40's who are HIV infected, sometimes only 30 or 40 percent of those individuals may be asked those types of questions.

The CHAIRMAN. OK. I assume some States are more effective than others, as you have observed, in disseminating information about how to be careful, and protect themselves from infection. Have you seen any States that are doing a particularly good job? Is there a model that you would recommend that others follow?

Dr. JANSSEN. Well, our prevention programs are very locally based. We use a model called community planning, which includes health department folks, community members, as well as scientific experts, to look at the needs of the specific location. We have said for years from the beginning of the epidemic that HIV varies from State to State, from city to city, and even within one city it can be different because different populations are affected, and how we reach those different populations varies.

I think we have a number of good models for reaching and providing information as well as interventions that help reduce risk behavior. But I also will say that those models tend to be for younger people.

The CHAIRMAN. I guess that is the point. Is there something we can do in terms of providing information to help educate older people to make them aware that they are not out of danger if they are sexually active in any way?

Dr. JANSSEN. I think we need to do that for all people at risk, not only older Americans but younger Americans as well.

I think one of the things that I am optimistic about being able to reach this population particularly is what I mentioned. This year we will be working to revise guidelines on routine screening in medical care settings. Because older people go to the doctor more frequently, it is more likely, I think, older people will get tested.

So I am optimistic, in fact, that we will be more likely to pick up on recognized HIV infection in that older population.

In addition, a larger proportion—I do not have the data; this is an assumption. The largest proportion of people living with HIV over the age of 50 know they are infected and are likely to be in care. So the way we can reach these people is working with their clinicians to provide the prevention services that they need to do. We provided guidelines, we published guidelines two years ago, working with HRSA and NIH and the Infectious Diseases Society of America, to do just that.

We are in the process right now of developing a social marketing campaign for providers to do a better job.

The CHAIRMAN. Well, clearly, all of us—and I did before this hearing; we decided on this topic because it is such a growing concern. I have always thought of this as a problem that young people should be extra careful about. I guess the point is we need to also, as you said, provide this education for all ages. I think people, if they are over 50, somehow I think there is a perception that they are immune from it at this point. Maybe there needs to be some special emphasis given to seniors to remind them they are not beyond risk either. So anything you can do on that score is obviously very important from the data we are discussing.

Dr. JANSSEN. Well, I think the data—as I said, I think what we can do best in this area, there are two things that are being done. One, as I mentioned, 80 percent of our directly funded community-based organizations—we fund 141 community-based organizations directly. They work across the country focusing primarily on people of color. About 80 percent of them already provide services for this age group. I think what you are suggesting, which I think is a good idea, we can take a look at some of those programs specifically for this older age group and see if we can identify some best practices, and we could certainly disseminate those types of interventions.

The CHAIRMAN. Thank you very much.

Senator Kohl.

Senator KOHL. Thank you, Senator Smith.

Dr. Janssen, in Wisconsin, and all across our country, we know that Federal HIV prevention funding is not adequate to meet our current needs. Dollars are stretched thin, and States are unable to reach many of those who are at high risk. Today we are shedding light on an emerging and even a more challenging segment of the population when it comes to HIV prevention efforts.

So what can we do to include seniors in our prevention programs when funds for these programs are already stretched as thin as they are?

Dr. JANSSEN. Well, I think you have stated it very well, Senator, which is funds are stretched. Because of that, we have focused our programs to those at the very highest risk—risk for becoming infected or risk for transmitting HIV, so working not only with people who are HIV negative currently, but also working with people who are currently living with HIV. I think not only I agree that we need to do a better job among people over the age of 50, but I would say we also need to do a better job among people younger as well.

Our community planning programs try to target those highest-risk populations in those areas, and there are some areas, for example, in Florida where more work is done in the older age group than you might expect in other jurisdictions in the country.

Senator KOHL. Senator Smith was discussing with you the lack of education in preventing HIV and AIDS in the elderly population. It concerns all of us that seniors are not getting the prevention information they need. I am also concerned, however—and Senator Smith and you discussed it—that health care providers are not adequately prepared to discuss prevention with seniors or effectively diagnose HIV in older individuals.

So what steps is the CDC taking and what more can be done to ensure that health care providers are equipped to prevent and treat HIV/AIDS in our elderly population?

Dr. JANSSEN. Well, I think one of the things that we are doing is, again, providing prevention in care. There is a social marketing campaign that we are developing and that should be launched next year aimed specifically at physicians who are caring for HIV-infected patients, and that would include the over 50 group as well.

You know, as this is an aging group, we target our dollars to where the epidemic is, and, again, at those highest-risk populations. So as that group becomes a more important group, our dollars and resources will focus more and more on that group.

I think one of the things we are doing also right now, the individuals living with HIV and at risk for HIV who are older have the same demographic characteristics or risk factors as younger people. They tend to be people of color. They tend to be men who have sex with men or injecting drug users or high-risk heterosexuals, individuals with multiple sexual partners, for example. They are the same people, same characteristics, as people who are younger and at risk for HIV.

So I think we can use some of the same tools for reaching younger people for reaching older people as well. It is a little harder to reach older people. For example, young men who have sex with men are not hard to reach in particular because you can go to venues in cities where they gather. That is not so true for older people. Older people tend not to go to those types of venues.

So I think one of the things, again, that we are looking at is not only doing outreach, some of our CBOs doing outreach to these populations within their communities, but, again, working in the medical care settings because so many people over the age of 50 seek medical care.

Senator KOHL. I thank you, Dr. Janssen, and I thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Kohl.

Dr. Janssen, thank you for helping us to highlight this growing problem, and we appreciate everything you will be doing at the CDC to help us get ahead of it.

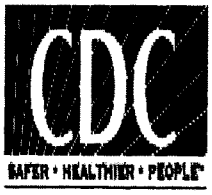
Dr. JANSSEN. Thank you very much for the opportunity.

[The prepared statement of Dr. Janssen follows:]

Testimony
Before the Special Committee on Aging
United States Senate

HIV/AIDS In Persons 50 Years of Age and Older

Statement of
Robert S. Janssen, M.D.
Director,
Division of HIV/AIDS Prevention
National Center for Infectious Diseases
Coordinating Center for Infectious Diseases
Centers for Disease Control and Prevention
U.S. Department of Health and Human Services



For Release on Delivery
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Introduction

Good afternoon Mr. Chairman and Members of the Committee. My name is Robert Janssen and I am the Director of the Divisions of HIV/AIDS Prevention of the National Center for HIV, STD, and TB Prevention at the Centers for Disease Control and Prevention (CDC). Thank you for the opportunity to discuss U.S. HIV/AIDS trends, specifically among persons 50 years and older, and CDC prevention efforts for people in this age group who are at high risk for acquiring and transmitting HIV.

We are now in the third decade of the HIV/AIDS epidemic. HIV has claimed the lives of more than 22 million people worldwide. In our nation alone, more than 500,000 people have died of AIDS. At the same time, countless Americans have been spared from infection through prevention efforts, and the lives of thousands of HIV-infected people have been extended because of advances in treatment.

The HIV/AIDS epidemic has changed significantly over the past two decades. Initially it primarily affected whites, but today the majority of those affected are people of color. Racial and ethnic minorities are now disproportionately at risk for and affected by the HIV/AIDS epidemic. In the United States, there are an estimated 850,000-950,000 people living with HIV. Twenty-five percent or 180,000 to 280,000 people do not know they are infected with HIV. It has been estimated that infections transmitted from this group account for more than half of new HIV infections each year. It is critically important that we get these individuals diagnosed and into medical treatment and HIV prevention services.

HIV/AIDS Trends

Today, the good news is that people are living longer and living healthier lives with HIV, as a result of effective treatments.

I am aware of the media and interest groups reporting increasing rates of HIV among people aged 50 years and older. To address the Committee's concerns related to such reports, I would like to share with you data on the total number of people living with HIV/AIDS and on rates of newly diagnosed cases of HIV for persons aged 50 plus and for persons younger than age 50. These data have been collected in 32 states with confidential name-based HIV reporting.

The total number of people living with HIV/AIDS is increasing. This is true for both those under 50 and those over 50. For instance, in the 32 states with name-based HIV reporting in 2000, almost 40,000 people who were over 50 were living with HIV/AIDS (see figure 1 in appendix). This number increased to almost 67,000 by 2003. Similarly, the number of people living with HIV/AIDS who are under 50 is also increasing. The most likely explanation for these trends is that with newly available treatments, people who are infected are living longer, healthier lives. We do not believe the increase in people living with HIV or AIDS is caused by an increase in new infections.

Data on newly diagnosed cases are a surrogate for new infections and serve as our best source of data on trends in infection. When you look at the rates of newly diagnosed persons who are under 50 and those who are over 50, you can see the lines are flat (see figure 2 in appendix). Neither line shows a

significant change in rates for these age groups. However, the rate of newly diagnosed HIV infection is three to four times higher among those younger than 50 years than among persons aged 50 and older. In 2003, in 32 states with confidential name-based HIV reporting, there were 27,524 HIV/AIDS cases among persons under 50 and 4,308 HIV/AIDS cases among persons 50 years of age and older. Thus, fourteen percent of new HIV/AIDS cases occurred in persons age 50 years and older.

The HIV/AIDS epidemic in our nation affects African Americans and Hispanics disproportionately. This is true for those aged 50 and older as well as for younger persons. When you look at rates of newly diagnosed cases of HIV/AIDS among persons age 50 and older by race, rates are 10 to 15 times higher among African Americans than among whites, and 5 times higher among Hispanics than among whites. The numbers of cases among American Indians, Alaska Natives, and Asian and Pacific Islanders are too small to calculate rates among those groups.

HIV Prevention Programs

It is critical for CDC, along with state and local health departments and community-based organizations to prevent the most infections possible with the resources that are available. For this reason, we focus services on those populations who are at the highest risk. To ensure that publicly funded HIV prevention programs reflect local needs and priorities, CDC began in 1993 to require that all health department grantees follow a community planning approach to HIV prevention. The community planning process requires

formation of planning groups composed of health department, community, and scientific representatives. These planning groups determine local priorities for HIV prevention resources; priorities are based on data about the local epidemic, existing community resources, and science about the most effective interventions available. Community planning is about using public resources in a way that will have the greatest public health impact.

Although persons aged 50 and older account for fewer than one-fifth of new HIV diagnoses, HIV transmission remains a concern among this age group. Thus, it is important that they get information and prevention services to help protect them from acquiring and transmitting HIV. Among 141 community-based organizations across the country funded directly by CDC, 112 or nearly 80 percent include this age group as one of their target populations. They provide prevention services to them, such as: targeted outreach, voluntary counseling and testing, partner counseling and referral, and health education and risk reduction.

One of the challenges of prevention among persons 50 and older is the mistaken belief that they are not at risk for HIV or other STDs. Studies have noted that physicians do not always address sexual health with their older patients and that their patients often have only limited knowledge about risk factors for HIV transmission. This lack of awareness on the part of health care providers is a barrier to educating older adults about the risk of HIV. CDC recommends that physicians take a sexual history from their older patients and discuss their risk for HIV and other STDs.

Another important strategy to prevent HIV is to increase the number of people in this country who get tested for HIV. As I stated earlier, one of the reasons this is so important is because research suggests more than half of new infections are transmitted by individuals who do not know they are infected. In addition, when people become aware of their infection, they usually take steps to protect their partners.

CDC strives to increase the number of people getting tested for HIV in medical settings such as publicly funded clinics, clinics run by community-based organizations, private doctor's offices, or in hospitals. To increase voluntary HIV testing in medical care settings, CDC strongly encourages all health care providers to include HIV testing, when indicated, as part of routine medical care and on the same voluntary basis as other diagnostic and screening tests. In addition, CDC encourages wider availability of testing services outside of medical settings, in community settings such as homeless shelters and mobile testing sites. We believe that widening options for and increasing the availability of testing will help more people learn their HIV status. By increasing the availability of testing in non-traditional venues and encouraging health care providers to offer testing more routinely in medical settings, more people will have the opportunity to get tested, have access to medical care, have access to ongoing prevention services to prevent transmission to partners, and decrease new infections. This is especially true for older adults, as they more frequently must seek medical care for other conditions.

HIV/AIDS Research

CDC is also working closely with our colleagues in the National Institutes of Health (NIH) to better understand the relationship between age and HIV disease progression and how this impacts HIV prevention efforts. NIH supports the Multicenter AIDS Cohort Study (MACS) and Women's Interagency HIV Study (WIHS), which are the largest observational cohort studies of HIV infection in the United States. In August 2004, the National Institute of Allergy and Infectious Diseases (NIAID), held an expert panel on aging and HIV to develop specific aging-related hypotheses in need of future study. As a result of the panel, NIH has implemented a number of studies to assess diseases affecting those who are now over 50 which may accelerate HIV progression or become more severe with HIV infection. Examples of these studies include a study of the increased risk of cardiovascular disease among aging persons on HIV therapy; and a study to evaluate the increased risk of diabetes, bone mass depletion, and stroke in aging, HIV-positive persons. In addition, the National Institute on Aging (NIA) supports survey research on HIV/AIDS and aging, in both the US and in developing nations, primarily through its Centers on the Demography of Aging. Finally, several projects are ongoing that focus on improving the overall well-being of the older AIDS population, including preventive behaviors and information dissemination among the elderly.

In summary, HIV/AIDS affects Americans from all age groups. All Americans need to know how to avoid infection, and if infected, should be aware of their infection and know how to avoid transmitting the disease to others. CDC and our federal, state, and community partners are working to this end to reduce

new infections as much as possible and link those infected into prevention and care services.

Thank you again for this opportunity. I will be pleased to answer any questions.

Appendix

Figure 1

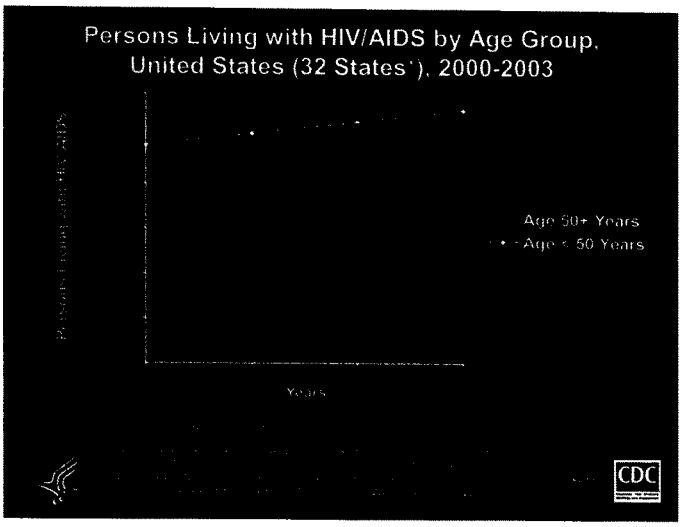
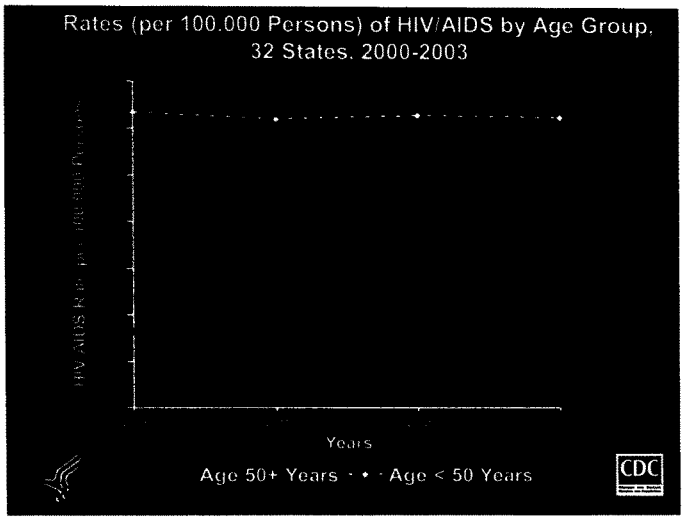


Figure 2



The CHAIRMAN. We will call now our second panel. That will consist of Mr. Thomas Bruner, executive director of the Cascade AIDS Project in Portland, OR. Tom, welcome. Also Shirley Royster, 59 years old and living with HIV in Boston, MA, welcome, Shirley.

Ms. Royster. Thank you.

The CHAIRMAN. Ms. Jeanine Reilly, who is the executive director for Broadway House for Continuing Care in New Jersey. We thank you all.

Why don't we start with you, Jeanine, and we will go down the row to my constituent.

STATEMENT OF JEANINE REILLY, EXECUTIVE DIRECTOR, BROADWAY HOUSE FOR CONTINUING CARE, NEWARK, NJ

Ms. REILLY. All right. Thank you.

The CHAIRMAN. You want to pull the microphone a little bit closer.

Ms. REILLY. Thanks. My name is Jeanine Reilly, and I am a registered nurse and a licensed nursing home administrator. I have spent my career primarily as a long-term care nurse, but in the last five years I have served as the executive director of Broadway House for Continuing Care, a 74-bed long-term care facility serving the medical, social, and psychiatric needs of people living with AIDS. Broadway House is New Jersey's only long-term care facility exclusively for people with HIV/AIDS. In fact, just a small handful of these facilities exist in our Nation. In addition, I am a board member of the National Association for HIV Over Fifty.

The CHAIRMAN. Do you get people from other parts of the country coming to stay at this facility?

Ms. REILLY. Yes, we do.

The CHAIRMAN. Where are there other comparable facilities.

Ms. REILLY. There is one in Connecticut, Leeway House; there is one in New York City in Greenwich Village; and I believe there is one in San Francisco, but I have not been able to locate it.

The CHAIRMAN. OK. That is very helpful to know.

Ms. REILLY. We have tried. There are very few facilities in the Nation.

The CHAIRMAN. That is apparent. I am surprised by what you just said. But I hope it means that the population is going down.

Ms. REILLY. It does not, no.

The CHAIRMAN. But clearly it is not. I am sorry to interrupt you, but I was very curious.

Ms. REILLY. That is OK.

In my work at Broadway House, I have seen a dramatic change in my clients over the last few years. In 2001, the average age at Broadway House was 31 years old, up from 26 in 1995. Today the average age is 44 years old. 26–31–44, this disease is aging.

According to the CDC, 11 to 15 percent of people with HIV in the United States are over the age of 50, and there are 3,000 people over the age of 60 who are living with the disease. The reasons for the increase among our seniors are positive and negative.

The positive is that the remarkable drug cocktails—protease inhibitors—are prolonging life for AIDS patients in never seen before numbers. Medications allow people to grow older with this disease, a luxury not seen in the beginning of the epidemic.

The negative is that, at least in New Jersey and Massachusetts and Florida, men and women over 50 are contracting the virus in never seen before numbers. Why? Baby boomers are not relinquishing their sexuality simply because they are getting older.

Viagra and Cialis are not only available, but really "in our face" through commercials. Every senior knows what David Letterman and Jay Leno know, and that is, if you experience an erection for more than four hours, you should seek immediate medical attention. However, the message about the threat of HIV/AIDS is not there. Often condoms are not used because the risk of pregnancy for seniors is no longer an issue, and they do not imagine their peers as being potentially HIV positive.

Sexual negotiation techniques are at this point in time a nonstarter for seniors. Asking a potential mate for his or her HIV status and insisting on the use of a condom is a difficult conversation at any age, never mind for our elders.

In nursing homes, many people are contracting the disease while in long-term care, with some researchers calling nursing homes the "new breeding ground for AIDS." It is not unusual for prostitutes to visit long-term care facilities and assisted living facilities. Widows and widowers living in nursing homes who have lived monogamously for most of their lives seek companionship with other residents, sometimes with serious health implications. Younger HIV-positive people are being admitted to long-term care because their disease complicates their health status and makes them eligible for long-term care 20 or 30 years earlier than most people are.

In short, long-term HIV/AIDS care is needed now for a new population—an older population for those working in the AIDS world, and a younger population for those working in the long-term care world. A collision of the two worlds is at hand.

In addition, the stigma of HIV in the general population is clearly evident with long-term caregivers. At all levels, there is heightened concern of infection. Whether legitimate or not, people who work in nursing homes have often felt themselves free of infectious worries because they work in geriatrics. Therefore, the surety of an HIV/AIDS diagnosis terrifies many long-term care staff members and makes a resident with the disease the "He's got AIDS" guy.

My colleagues in traditional geriatric nursing homes are caring for HIV without the necessary skill set. They are expert in caring for the significantly old, which typically means 80 years old and older, not for a 50-something with AIDS. It gets more complex and confusing when you realize that AIDS mimics aging in many ways.

This brings us to a core problem in treating those over 50 who are HIV positive: health care providers.

When an older American goes to a doctor, it is not routine to review sexual or drug history, to educate around safer sex, or to consider an HIV diagnosis, even when suggestive symptoms are present.

Medical providers are often uncomfortable discussing sex with seniors and often don't really believe their elders are still sexually active. This leads to a much later diagnosis and a much more serious prognosis, with heterosexual a rapidly growing segment of infected older people.

People over 50 have been omitted from research, from clinical trials, from prevention programs and intervention efforts when it comes to HIV and AIDS.

Mother Teresa once said, "The biggest disease is not leprosy or tuberculosis. . . but rather the feeling of being unwanted, uncared for, and deserted by everybody." HIV and AIDS often deliver this "big disease" with diagnosis. We need to do whatever we can, learn all that is possible, and educate others so that no one is ever deserted.

Thank you so much for allowing me to speak today. I appreciate it.

[The prepared statement of Ms. Reilly follows:]

Broadway House for Continuing Care
Jeanine M. Reilly, Executive Director
May 12, 2005

Good afternoon Senators:

My name is Jeanine Reilly. I am a Registered Nurse and a Licensed Nursing Home Administrator. I have spent my career primarily as a Long Term Care nurse, and the last five years as the Executive Director of Broadway House for Continuing Care, a 74-bed long-term care facility serving the medical, social and psychiatric need of people living with AIDS. Broadway House is New Jersey's only long-term care facility, exclusively for people with HIV/AIDS. In fact, just a small handful of such long-term care facilities exist in the nation. In addition, I am a Board Member of the National Association for HIV Over Fifty.

In my work at Broadway House, I have seen a dramatic change in my clients over the past few years.

- In 2001, the average age was 31, up from 26 in 1995.
- Today the average age is 44 years old.
- 26-31-44, This disease is aging!

According to the CDC, 11-15% of people with HIV/AIDS in the United States are over the age of 50, and there are 3000 people over the age of 60 with the disease. The reasons for the increase among our seniors are positive and negative.

- **The positive:** The remarkable drug cocktails, [protease inhibitors], are prolonging life for AIDS patients in numbers never seen before. Medications allow people to grow older with the disease, a luxury not seen in the beginning of the epidemic.
- **The negative:** Men and women over 50 are **contracting** the virus in numbers never seen before.

Why?? Baby Boomers are not relinquishing their sexuality just because they're aging.

- Viagra and Cialis are not only available, but really "in our face" through commercials. Every senior knows – what David Letterman and Jay Leno know – if you experience an erection for more than 4 hours, you should seek immediate medical attention…but, the message about the threat of AIDS is not out there. Often condoms are not used because the risk of pregnancy for seniors is no longer an issue, and they don't imagine their peers as potentially HIV+.
- Sexual negotiation techniques are, at this point in time, a "non-starter" for a senior. Asking a potential mate his/her HIV status, and insisting on the use of a condom, is a difficult conversation at any age, but especially hard for our elders.

And in our Nursing Homes….

Many people are contracting the disease while in long-term care – with some researchers calling nursing homes the "new breeding ground for AIDS".

- It is not unusual for prostitutes to visit assisted living and long-term care facilities.
- Widows and widowers living in nursing homes, who have lived monogamously for much of their life, seek companionship with other residents – sometimes with serious health implications.
- Younger HIV+ people are being admitted to long-term care because their disease complicates their health status, and makes the eligible twenty or thirty years earlier.

In short, long-term HIV/AIDS care is needed for a new population… an older population for those working in the AIDS world, and a younger population for those in the Long-Term Care world. A collision of the two worlds is at hand.

In addition, the stigma of HIV in the general population is clearly evident with long-term caregivers. At all levels, there is heightened concern of infection. Whether legitimate or not, many nursing home employees have assumed themselves free of infectious worries because they work in geriatrics. Therefore, the surety of an HIV/AIDS diagnosis terrifies many long-term care staff members and makes a resident with the disease the "He's got AIDS" guy.

My colleagues in traditional geriatric Nursing Homes are caring for HIV with the necessary skill set. They are expert in caring for the significantly old, which typically means those 80 years old and older, not for a fifty-something with AIDS. It gets more complex and confusing when you realize that AIDS mimics aging in many ways.

This brings us to a core problem in treating those over fifty who are HIV+……. Healthcare Providers.

When an older American goes to a doctor it is not routine to:

- Review sexual or drug history,
- To educate around safer sex,

  OR
- To consider an HIV+ diagnosis, even when symptoms are present.

Medical Providers are often uncomfortable discussing sex with seniors, and often don't believe their elders are still sexually active. This leads to a much later, much more serious diagnosis, with heterosexual women, the fastest growing segments of infected older people.

People over 50 have been omitted from research, clinical trials, prevention programs and intervention efforts when it comes to HIV/AIDS.

Mother Teresa once said, "The biggest disease is not leprosy or tuberculosis…. but rather the feeling of being unwanted, uncared for and deserted by everybody".

HIV/AIDS often delivers this "big disease" upon diagnosis. We need to do whatever we can, learn all that is possible, and educate others so that no individuals are ever deserted.

Thank you for the opportunity to speak to you today.

I will now take your questions.

The CHAIRMAN. Thank you very much, Jeanine.

We have been joined by Senator Jim Talent of Missouri. Do you have a statement you would like to make, Senator?

OPENING STATEMENT OF SENATOR JAMES M. TALENT

Senator TALENT. Yes, very briefly, Mr. Chairman. I want to thank you for this hearing. We have 10,000 reported cases of AIDS in Missouri, and a number of those folks are elders. We have contacted a gentleman named Jay Pulford. Jay is well-known within the community back in St. Louis because he has spent the last 18 years dedicating his time to helping educate people of all ages about the disease. What he said echoed what Ms. Reilly was saying. He says: No fear or stigma; we need to be honest and open and talk about this problem no differently than we would talk about cancer or diabetes; if you do not talk about it, you cannot fix the problem.

I can readily understand why that message is especially important for seniors, for whom the whole subject of sexual relations is just more difficult for them to discuss and for others to discuss with them, and who I think would be more liable to being quiet or not seeking the treatment they need because of a fear of stigma and less aware of the dangers and the importance of safe sex at their age.

So I think it is important that you are having this hearing. I have a markup in Armed Services that I have got to go to because we are going to put the bill out, but I have questions for the record. I hope that these witnesses have addressed or will address their views about concrete measures we might take to help generate more education, more understanding within that community, and perhaps working through nursing homes or other institutional providers is one way to go. But this is a much bigger danger than I think most people are aware of, and I know that is why you are having the hearing, and I want to congratulate you on doing that. I hope we can come out of this with some concrete ideas just to begin by letting people know that this is an issue and letting seniors know it is OK for them to consider an issue and to take the necessary steps for prevention or treatment.

The CHAIRMAN. Senator, we will put your questions in the record. But, Ms. Reilly, if you had to answer Senator Talent, what two or three things would you tell the Federal Government to do to help get the word out, get the help there to stem the growth of this among seniors?

Ms. REILLY. I have always wanted to be able to tell the Federal Government what to do, so this is great. [Laughter.]

The CHAIRMAN. We have all had that impulse. Now is your time.

Senator TALENT. I wish you better luck than we have had.

Ms. REILLY. I believe that there is not enough simple literature that is geared for the older person. It is geared for our kids. It is geared for young adults.

The CHAIRMAN. Where would you put that, in the nursing home?

Ms. REILLY. I would put it in nursing homes. I would put it in senior citizen housing in our towns. I would put it in churches, if they would allow us to, and in the senior citizens organizations that we have in all the local towns across America.

The CHAIRMAN. How about distributing it through Meals on Wheels and things like that where we already have a network in place?

Ms. REILLY. AARP. There are ways to do it.

Senator TALENT. The chairman and I know because we visit, as you often do—if you want to talk to a lot of seniors or visit with them about any senior subject, a subject affecting them, the lunch programs——

The CHAIRMAN. Fabulous. It would be a great distribution network.

Ms. REILLY. Yes.

Senator TALENT. It would be a great way to reach them.

Ms. REILLY. I would also suggest getting other seniors to talk about the issue of sexual activity, because except for my parents, senior citizens continue to be sexually active. [Laughter.]

They don't turn off their humanity and their sexuality just because they get older. So we need to be addressing them, and this is a peer conversation in our culture. We do not easily talk intergenerationally about sexual issues openly, but we will with our peers. I think that that is an important place to begin to reach out to all the areas where senior citizens gather.

The CHAIRMAN. Very helpful. Thank you, Ms. Reilly.

Ms. REILLY. You are very welcome. Thank you.

The CHAIRMAN. Shirley, you look great.

Ms. Royster. Thank you.

The CHAIRMAN. We are anxious to hear from you, what are your experiences and how you are coping.

STATEMENT OF SHIRLEY ROYSTER, AGE 57, LIVING WITH HIV/AIDS, BOSTON, MA

Ms. ROYSTER. I feel great, I am wonderful, and I am doing great.

The CHAIRMAN. Well, we would not have you here if you weren't wonderful. [Laughter.]

You obviously are.

Ms. ROYSTER. Thank you. My reputation precedes me, I see.

I am a person living with HIV/AIDS. I have been diagnosed with AIDS in 1996, but I have been diagnosed with HIV since 1985.

Now, I didn't have any symptoms when I was diagnosed. None. The only reason I went to go get tested was because I was getting ready to get into a very special relationship, and I knew I had risky behaviors, and I wanted to keep that person safe. Plus my friends were dying around me. A lot of people were dying in 1985. So I went and got tested. I had two little girls at home, and I didn't know what I was going to do. As a matter of fact, my doctor said to me I should not come back to her office because she did not have any information for me and she did not know what I should be doing.

The CHAIRMAN. This was in 1985?

Ms. ROYSTER. In 1985. She told me——

The CHAIRMAN. Do you hear that today, or has it changed?

Ms. ROYSTER. It has changed today. She told me to get my affairs in order. So that was then. This is now. Twenty years later, I stand before you or sit before you very healthy. I have had no major illnesses, but I do have a lot of concerns. One of my concerns is as

I age, I am going through menopause. Questions about menopause have not been answered. I don't know if there has ever been any research on women who are aging and what happens to them with HIV.

A big concern is menopause and HIV can have some of the same symptoms: the night sweats, the mood swings, all kinds of other concerns, different cancers. But there is really no information that my physician can even give me. She tells me she does not know. Being honest is probably the best thing that she can do for me right now, is just be honest. But we need that information.

The CHAIRMAN. So your recommendation is we need research on——

Ms. ROYSTER. We need research. We have to have research because if we can't—if we don't know what effects HIV has on your body as you age, we can't develop different medications, we can't develop different strategies that are different from people who are younger living with this virus.

The CHAIRMAN. Are you taking any medications now to help deal with HIV/AIDS?

Ms. ROYSTER. I am taking medication for HIV, yes, hormone treatments. Now, I am not taking adequate hormone treatments because I have an unusual Pap smear, and they cannot tell me whether the unusual Pap smear is coming because of my HIV. It is a symptom of HIV, but they can't tell whether that is it. So I can't get my hormone treatment increased until they figure it out. So I have six months to go with my own personal summer right now and other issues I am experiencing.

The CHAIRMAN. While you have not been able to get a lot of answers today, are you finding any physicians or resources that will help you to understand the answers to questions about what you are experiencing?

Ms. ROYSTER. There is one program that just opened up in Rhode Island, I believe, one program that is going to address women and HIV and menopause. That is the only one that I know of. I think it is the only one in the country. I think it just opened up this year—as a matter of fact, last month. I think I gave them an interview.

Now, you asked the question before of some of the things that we should be doing. Information is top. If people don't know, people can't address the issue. We have to have the information out there that this virus can affect anybody at any age. We have to do that.

The second thing is I agree that we have to talk to our peers about their sexual practices or any other practices. Do you know that people over 50 are still doing drugs? It is not just sex. They are still doing drugs, and drugs are rampant in their community.

We also have to develop some kind of support groups. The support groups that are needed in that age group are different from the support groups that are needed and have been going on for younger people. People like to see themselves, and so it is really uncomfortable for someone who is my age going into a room with women who are 20 and 30 years old to talk about issues.

I have a kid that is 30 years old. As a matter of fact, she is 36. So I really wouldn't be comfortable talking to——

The CHAIRMAN. You are too young for that. [Laughter.]

Ms. ROYSTER. Thank you. Flattery will get your everywhere.

The other thing I think we should do is we should talk to the medical care providers. You know, I still go to my physician, and I have to tell her about my sexual activities. She is not going to ask me. I don't think that—I don't know if she thinks that I died from my waist down when I turned 40, but I don't think she is really comfortable with that. So I have to tell her what I am doing and why I am doing it and when I am doing it, you know, whether she wants to hear it or not, because I really want her to give me some advice. If she does not have it right then, I trust that she is going to go get the information, or even if she comes and tells me she does not have it, but I want her to pay attention. I think that is one of the things that we have to also learn how to do and how we need to talk to our physicians, is that it is a partnership. Dealing with this virus is a partnership with the medical field. I think that seniors have not really been taught that. I think they just take what the physicians say at face value and not really ask questions. That education needs to happen because I think they have a lot of concerns, and they just don't know how to ask.

The last thing, I think, is resources. Now, in Massachusetts we have a program called New England AIDS and Education. Now, that program goes out and it trains physicians, it trains educators, it trains dentists, it trains different medical fields how to deal with people who have HIV. I think we need more of those types of programs. I don't know whether you know it or not, but physicians usually think they know it all. Did you know that?

The CHAIRMAN. I never noticed. [Laughter.]

Ms. ROYSTER. So I think that when we are talking about educating the health providers, I think we need to have them to know that they still can learn and that this information is important.

The CHAIRMAN. When you tell your doctor about your condition, you ask questions and they don't know now, do they try to find out?

Ms. ROYSTER. Yes, of course. Of course, and they will call me at home, too, because if they don't I'm going to call them. I'm going to ask them why they haven't responded to me. But, you know, this is me. That is not a given for everybody. So I think that we also have to—once a person finds out that they have tested positive, it is one of the most destructive kinds of information you can ever receive. First of all, you start to blame yourself. What did I do?

The second thing you start thinking about is your family. Who am I going to tell? How am I going to tell them? Will I lose my community? Who will support me in this?

It is a very scary, scary place to be, and that is why I think most people don't tell.

Senator TALENT. Ms. Royster, with the chairman's permission, because they scheduled several committees at the same time in this body—I think they believe you can defeat the laws of physics and be in two places at one time. But when you are saying these things, it is my sense that these issues which are there for anybody who gets such a report are probably many times more difficult for seniors.

Ms. ROYSTER. Many times.

Senator TALENT. Because, you know, if you are in that age group, your friends, to report that to your friends, they probably have no idea whatsoever how to respond; whereas, a 25-year-old who is raised with the presence of this disease around them, has friends who have it, and it is bad enough for them. I mean, is that fair in your mind, that first statement?

Ms. ROYSTER. It is fair.

Senator TALENT. It is much more difficult——

Ms. ROYSTER. It is fair. How do you tell your grown kids that you have HIV? "Papa, are you gay?" "Nana, are you doing drugs?" I mean, you know, these are the kinds of things that your kids will ask you, and they will need to be answered.

The CHAIRMAN. Shirley, when you were diagnosed, did you face social ostracism, how did you approach your friends, your community, your church, your circle of influence? How were you treated?

Ms. ROYSTER. I have lost friends. People stopped talking to me. Even now, in the last two years, I lost a friend that I had for 15 years because I told her I was HIV positive. She said to me—well, she stopped calling me, and she didn't respond. So I went to her house, and I said, "I gave you some information. Why aren't you responding to me?" She says, "Well, Shirley, I don't want to think of you dying." Well, she has never known me to be sick, you know, but that was her way of saying she couldn't deal with it. I never had many of those instances.

I used to work in a battered women's shelter. I used to stay sick because the kids came in with different kinds of viruses. At some point I felt really bad because I wasn't at that time strong enough to be out in the community. I knew that women who were in that shelter were putting themselves at risk, and I had information and I didn't give it to them because I was afraid of losing my job.

The CHAIRMAN. Have you found a way, as you have lived with this disease, to tell others about it in ways that keep your friends and keep a community of loved ones around you?

Ms. ROYSTER. Yes.

The CHAIRMAN. What would you say to a senior who has AIDS and hasn't told anyone? What counsel would you give them?

Ms. ROYSTER. Well, there was a program that I worked with for six years. It was called Positive Prevention—Positive Direction, sorry. What we did was we went out into the schools, we went out to the churches, we went out to anywhere that would have us to come in to tell our stories.

Now, New England AIDS and Education is one of those programs that allow people who are infected to come along with them to educate physicians. The National Organization for People Over Fifty is also one of those organizations that will give a conference. There is a conference coming up in Florida that we will go down, and they will have people who are speaking to other seniors about living with this virus.

My mission right now is to educate as many people as I can. To a senior, my first thing is to say this is not a disease that means that you are dead. This is not a disease that you can't live with.

The CHAIRMAN. Nor a disease that need drive your friends away.

Ms. ROYSTER. Nor need to drive your friends away.

The CHAIRMAN. But they need to know that, don't they?

Ms. ROYSTER. They very much need to know that, and I want to also say to you that most of the prevention funding has been cut in half. In half. I don't see how we can go out to start preventing this virus if we can't even have a program to go to educate anybody. It is just devastating. You can't begin to educate people and keep them safe if they can't get the information.

I work in a program for the archdiocese in Fall River, MA. We go into the Catholic schools to educate those kids. Those kids come from very nice homes. There is not one time that one of those kids haven't said to us, "We get drunk on weekends and pass out." It is the most scariest thing you ever want to hear, 16, 17, 18, passing out drunk. They don't even know what they are doing or who is doing something to them. We still don't have enough funding to continue to do that kind of information dissemination. We just don't have the funding.

The CHAIRMAN. I think that is the clear message from the first two witnesses. We need information out there and understanding.

Shirley, thank you. You are very courageous, and we so appreciate your willingness to come share your personal story about a growing and important issue. So we wish you well. Thank you so much.

Ms. ROYSTER. I thank you for having me.

[The prepared statement of Ms. Royster follows:]

5/9/05

I am a 57 year old Black woman. I am a mother of two daughters. I have been in a loving relationship for twenty years. And I have HIV/AIDS. I tested positive for HIV in 1985.

I didn't expect to live to get old, but the longer I lived the more hope I had. I have been able to watch my daughters grow into adults. My significant other is my soul mate and my life partner.

I am doing great. The medications work for me keeping HIV/AIDS under control. I do have some system like fatigue, night sweats, and depression, nausea and mood changes. As I got older I have many concerns about going though menopause and having AIDS.

When I started menopause I went to my doctor to ask some basic questions like about hot flashes, mood changes, irregular pap smears, fatigue and how the HIV/AIDS meds would affect me. The things I was experiencing weren't new for someone with menopause but what is different is HIV/AIDS but my doctor didn't have answers. My doctors didn't know how HIV/AIDS systems and menopause changes would enter act to the many medications I was taking.

The National Association on HIV Over Fifty is the place for me like myself to find answers and resources for issues on ageing with HIV. As I age I would like to be able to know I can get my HIV/AIDS health needs taken care of with more resources.

Submited by

Shirley Royster

The CHAIRMAN. Thomas, my Oregon constituent.

STATEMENT OF THOMAS BRUNER, EXECUTIVE DIRECTOR, CASCADE AIDS PROJECT, PORTLAND, OR

Mr. BRUNER. Absolutely. Good to see you, sir. Thank you very much for having me here today, and in preparation for being here, I did a predictable thing. I started searching data bases. I called the Oregon Department of Human Services. I directed my staff to run all sorts of queries on our data and to come up with lots of stats and charts and percentages, and I ditched all of that to come here today to tell you stories about three people—three people that I know, three people that we help, and three people who to me exemplify some of the policy and funding and service delivery challenges that all of us face around HIV and seniors.

The first person I want to tell you about is Jim, and I want to tell you about Jim because Jim, Senator, reminds me a little bit of you, except he is older. He is 61. Jim is a very articulate man. Jim is a very successful businessperson. He is not incredibly wealthy, but he is very successful by anybody's standards.

Jim was married for a long time, 30 years, and he had two kids. He worked hard, and his hard work was rewarded financially and with more responsibility as he climbed the corporate ladder. He was very engaged in his community and his church. Jim, however, underneath all of that, wrestled with depression off and on through his life, and in his 50's, Jim hit a wall. He was diagnosed with major clinical depression. He spun out of control and went down, and down, and down, and he drank a lot, and had a few affairs, and even experimented with drugs, all of which resulted in him losing his wife.

Finally, he pulled himself out of all that and has his life together. But Jim goes to the doctor, isn't feeling well, gets tested, and has HIV. Never anywhere along the way, anywhere—at his church, among his peers, in the general community at large—never did Jim see or hear information or images targeted to him for his potential risk for HIV.

So what is the lesson or the recommendation I have for the Federal Government, since you have asked, as a result of Jim? I applaud the Centers for Disease Control strategically investing the overwhelming majority of their resources where the disease is worst. However, I believe that you need to direct the Centers for Disease Control clearly to increase their programming targeting seniors at risk for HIV as well as seniors with HIV.

Now, along with that you can only squeeze so much blood out of a turnip, and along with that direction need to come resources so that the CDC can do an adequate job of that.

I also think that you need to direct all federally funded health centers serving seniors, whether they be through HHS or HUD or health clinics serving seniors, to provide HIV information to their clients, to train their staff on some of the very issues that we have talked about today, and to be able to show you how they are complying with that.

I want to tell you now about Roberta. Roberta is 70 years old. She is a very stately woman. She is a widow. She has been a widow a long time. She lost her husband a long time ago to an acci-

dent. Roberta is a woman of great faith, is very active in her church.

Roberta had two kids. One daughter got caught up in drugs, had a couple of kids, and died of AIDS. Roberta now at the age of 70 is raising her daughter's kids who are orphans because of AIDS.

Now, the challenge is that I as a service provider with none of the Federal funding that I receive can help Roberta. I am not able to use Ryan White Care Act dollars to help Roberta or her kids because there is not a person with HIV living today in that family. So I am prohibited from using any of those Federal funds——

The CHAIRMAN. Did you say the children have HIV?

Mr. BRUNER. No, they do not, but they are orphaned as a result of aids and being raised by their 70-year-old grandmother as a result of AIDS. There is no Federal funding that allows me in the Ryan White Care Act to help Roberta and her grandkids because there is not an HIV-positive person in the home. So I would like to see you direct HRSA to relax restrictions on using Ryan White Care Act dollars in order to be able to provide more services for seniors who are either caring for their adult children with HIV——

The CHAIRMAN. Or who have been collaterally victimized by AIDS.

Mr. BRUNER. Absolutely, or raising their grandchildren who are orphaned because of HIV.

The last person I want to tell you about is Andy. Andy is a wonderful guy. He is bombastic, he is gregarious, he never met a stranger, and he has got a laugh that would fill this room—loves life, loves people, very successful health care policy analyst. Andy lost his brother, his baby brother, to AIDS and later on was diagnosed with AIDS himself.

At the age of 45, his health was declining rapidly, and his doctor told him what Shirley's doctor told her: "Andy, you need to get your affairs in order." Andy trusted the medical establishment, had seen his baby brother die of AIDS, thought the same would happen to him. So he cashed out his life insurance policy at 50 cents on the dollar. He sold his house. He sold his car. He liquidated his assets. He took advantage of that to go on the trip of his dreams, his one last excursion before he died. Then he took the remainder of his money and set up trusts for all his nieces and nephews so they could go to college.

Well, now it is 12 years later, and Andy looks like Shirley. He is healthy, he is robust, and nowhere near death. He is also 59, and he is also impoverished.

Now, Andy wants——

The CHAIRMAN. Does he take a particular drug regimen to control it?

Mr. BRUNER. He does. He takes this triple combination. Andy wants to go back to work. He really wants to go back to work, and he is a man of tremendous skills and assets and talents. You would love to have him on your staff. I would love to have him on my staff. But there are two reasons that he does not. The main is he is absolutely petrified of losing his Medicaid because without it he does not have access to these life-saving medications. If he goes back to work and earns very much money, he will lose his Med-

icaid. He will never get a job that would pay enough to more than compensate for the loss of his health care.

The CHAIRMAN. What are the monthly prescription costs to him—or to Medicaid?

Mr. BRUNER. The annual cost for his triple combination cocktail therapy is about $18,000. Just that. That is no lab work. That is no doctor visits. That is not other medication. That is no medical procedure or diagnostic test that ever has to be done. But he wants to go back to work, and I want him to go back to work. It will be more cost-effective for you and I as taxpayers for him to go back to work. But he is scared because he will lose his Medicaid and be worse off.

So I want you to direct the Social Security Administration and HCFA to revise those regulations so that people with HIV who are disabled can go back to work and make a decent living while maintaining their access to Medicaid, even if on a sliding fee scale so that the more they make up to some maximum limit, they at least have the option to buy into their continued Medicaid coverage, because now——

The CHAIRMAN. If he feels good, Tom, and he can get a job maybe that has health care—but you are suggesting some scale that gets him to a point of security in terms of health care.

Mr. BRUNER. That is right.

The CHAIRMAN. So that he becomes a taxpaying citizen again.

Mr. BRUNER. Absolutely, earning wages, paying taxes, hopefully privately insured. But if he does not get a job with health insurance, which he may not, I want to see him go back to work. But this fear keeps him from going back to work.

Another thing I would like to ask you to consider doing is, you know, Senator, with Ryan White Care Act money, I can feed Andy, I can transport Andy, I can help pay Andy's rent; if Andy got sick, I could provide him with a home health nurse. You know what I can't do? I can't help him get a job. I am prohibited from using any of those Ryan White Care Act dollars to do something that would help Andy need less Ryan White Care Act funded support in the future.

The CHAIRMAN. Would HIV be considered a pre-existing condition that would disqualify him from private health care?

Mr. BRUNER. It would in some cases. Now, if Andy got a job with Multnomah County, Portland State University——

The CHAIRMAN. It would not.

Mr. BRUNER [continuing]. City of Portland, a large enough employer——

The CHAIRMAN [continuing]. Sector with health care it might.

Mr. BRUNER. It might, which——

The CHAIRMAN. I mean, really, I think your point is—I had not thought of it until you raised it, but, I mean, in circumstances like that where he can't get private care, there ought to be some allowance or provision made for people in this niche of health care need.

Mr. BRUNER. Absolutely, until we accomplish broader health care reform, which would outlaw pre-existing conditions.

The CHAIRMAN. OK.

Mr. BRUNER. So those are my list of five things that I come today to encourage you to think about that would make an enormous dif-

ference, I think, for people like Jim and like Roberta and like Andy and for people like Cascade AIDS Project working with those folks.

[The prepared statement of Mr. Bruner follows:]

Our mission: prevent HIV in youth and adults at highest risk, support men, women and children with HIV/AIDS and their families, and advocate for a strong community response to the epidemic.

Presenter: Thomas Bruner, Executive Director
Cascade AIDS Project
620 SW Fifth Avenue, Suite 300
Portland, Oregon 97204
503.223.5907, ext. 223
www.cascadeaids.org

Senate Special Committee on Aging
Hearing date: May 12, 2005, 2:30 p.m.
Room 216, Hart Senate Building

It's Not Over, and for Many Americans Over 50, HIV and AIDS Have Just Begun

I'm here today because I'm certain, that as keepers of the future, as protectors of social health, we're inevitably facing complex challenges of immense proportions related to HIV/AIDS, that as a nation, as a community of citizens, we're vastly under-prepared for.

Dialog related to AIDS and HIV's effect on people over 50 is absent in public consciousness. This disease, which is 100% preventable, doesn't discriminate by gender; does not discriminate by race; does not discriminate by geography; does not discriminate by income; and undoubtedly, as baby boomers of my generation and yours mature by overwhelming numbers, HIV and AIDS does not, and will not, discriminate by age.

The stark reminder of the human impact, that the aging population (gay and heterosexual alike), are at risk of contracting and infecting others, walked into my office last week. Jim's a client, and a 61-year old corporate executive that had been married for over 30 years. With his wife they had a son and daughter. At some point mid-marriage, Jim became depressed, and through a succession of bad luck and poor judgment, was lead to encounter a brief bout of injection drug use. Jim later tested HIV-positive and was convinced his diagnosis was a death sentence. But in Jim's case, it wasn't. The financial and emotional weight of his illness strained his family to the point of divorce.

Fast forward to when eventual fair health and hard-earned confidence prompts Jim's desire to return to dating and sexual activity. Jim's most likely to encounter women over 50, unconcerned about

pregnancy (and condom use), with little to no knowledge about safe sex practices, and unsuspecting of HIV/AIDS risks. Contrary to the basis of ethics, out of momentary passion, fear or shame, he may or may not disclose his HIV-status. Other HIV-infected women and men walk among you and me, each with their own story, and most often, unaware of their own HIV-positive status.

People live longer. Spouses die. Couples divorce. Today's person over 50 is younger, more vital, more physically active, for a longer period of time. Over 10% of new AIDS cases are in people over 50. As masses of people age across the United States, so too will the percentage of HIV and AIDS cases. Here are other critical factors to consider:

- HIV and AIDS impacting citizens over 50 isn't necessarily a new phenomenon, although the volume, social dynamics, and infection rates are. During early to mid stages of this health crisis, people didn't get older; they died. Now, medical and pharmaceutical advances mean younger and middle-aged HIV-infected individuals take the disease with them as they grow older. Today, heterosexual contact and IV drug use are the culprits of infecting people over 50. In less than 15 years, transmission in heterosexual men over 50 went up 94%, and 107% in women. Our current government system isn't equipped, educated, or adequately funded to integrate the age-demographic ramifications, or population volume this devastation's on course for.

- Unlike Cancer, heart disease, diabetes, or other ailments which increase with age, HIV and AIDS remain both 100% preventable and infectious. Disease impact exceeds great numbers beyond the single infected individual, and persists as a public health threat. As a country, we've naively at best, and blindly at worst, overlooked social dialog, education and response to preventing and addressing HIV and AIDS for those over 50.

- Increased life means increased and prolonged expenses. Medical and pharmaceutical advances come with a tremendous price. The hardcore, bottom-line economics are clearly frightening. The costs of reactive care—as opposed to prevention—upon the individual, upon families, upon our health care system, and upon our government, escalate into millions and millions of dollars; precious dollars we know aren't easy to come by.

The solutions lie in the following Federal government's immediate and earnest responses:

- As a country, and as a government charged to protect its citizens, idle time can't be afforded to address the risks of HIV and AIDS in those over 50. They're among the overlooked, blended within thousands across the United States who are infected every minute, of every hour, of every day.

- Aside from adhering to humane and compassionate social justice responses, ignoring this eminent social threat will thrust tremendous financial burden upon our economic system, particularly a fragile health care system. Challenges of caring for the rapidly increasing HIV/AIDS senior population will have devastating social and economic effects if thoughtful analysis isn't given and weighed between prevention costs vs. care costs.

- Adequately-funded prevention programming must be instituted throughout all levels of federal health care agencies and appropriate affiliate agencies. Sources of revenue need to be designated specifically for HIV and AIDS awareness and prevention for those over 50, and not at the expense of cutting other HIV and AIDS programs or outreach efforts assigned for other core groups or demographics.

- Existing senior service-delivery systems, either federally funded or government affiliated, need to begin integrating prevention, awareness education, and outreach into current programming. These efforts shouldn't be incorporated into current processes as an un-funded or under-funded mandate to increase work load; but rather integrated in a fiscally responsible and efficient manner and with ample resources to support them.

- Prevention and awareness efforts need to include both education and outreach components. Targeted materials, communication channels, and knowledgeable available resources must be identified and specified to address this vulnerable population. Further, key sub groups of the senior demographic such as gay seniors, seniors living with HIV-AIDS, widows, etc. need to have appropriately crafted messaging and methods of communication for maximum effectiveness.

It's the Federal government's social, ethical, and economic duty to protect our citizens over 50, and provide them with the tools, resources and education they deserve to stay healthy. Every single one of you has the ability and compassion to deal with this disease in a realistic, forthright, and honorable manner. HIV and AIDS don't discriminate by race, gender or age, nor should the funds allocated to fund prevention and education to protect all American citizens, including those over 50.

Respectfully,

Thomas Bruner, Executive Director
Cascade AIDS Project

The CHAIRMAN. Tom, I am proud of you, and appreciate your efforts to be here today. I know well the Cascade AIDS work that you do, and it is a tremendous good that you do. I appreciate it, and also Shirley and Jeanine. You know, these hearings in the Senate Committee on Aging, they do a couple of things. First, you have given us some great ideas that we can put in the form of amendments to the Ryan White reauthorization. But there are a lot of seniors who watch the activity of this committee and who may be watching you on C-SPAN, and I think many of them will get ideas for how best to deal with their circumstances and how best to spread the news that you have to be careful. You need to seek medical help, get tested, and the Federal Government needs to do more in terms of research, Shirley, and for menopausal women who deal with this and what it all means to them.

So this hearing has been of value to me. If any of you have a concluding comment you want to make, Jeanine, do you have anything else you have heard or anything else you want to say?

Ms. REILLY. I want to say that it is important for all of us as Americans to take care of our seniors because with any luck, all of us will be there. If we don't look out for our elders at this point, it damages our cities and our States and our Nation. I thank you so much for focusing the Senate's attention on this really important issue.

The CHAIRMAN. Thank you.

Shirley, any final thoughts?

Ms. ROYSTER. I would also like to thank you. Thank you for inviting me.

The CHAIRMAN. You are welcome.

Ms. ROYSTER. Thank you for listening. I truly did not expect to be here this long. I did not expect to live 20 years after being diagnosed with HIV. I really didn't. Every day that I live is special to me. It is really, really a gift from God. I believe that.

But I also think that our mission, once we find out that we have HIV, is to tell somebody. Tell somebody. You know, you would be surprised at the people who come out of the woodwork that love you or that are willing to love you. This disease does not have to be something that will isolate people, although it can be. But there is love and families, and families can be resilient. I hope that my message today can let them know that this can happen.

Thank you.

The CHAIRMAN. Thank you, Shirley.

Tom.

Mr. BRUNER. Senator, today in this hearing is just one example, the most recent example, of the incredible leadership that you personally have provided to the Senate and to the country on the issues of HIV and AIDS. You have been an amazing advocate. You have been a tremendous asset. People have listened. They have stopped and rethought, they have reconsidered their views. They have been challenged to confront their biases and their stereotypes because of you and because of the role model that you have been, not just on aging issues but on an enormous array of HIV/AIDS issues. I hear it from my peers across the country in sister organizations to mine all the time.

So if I could be so bold, I would like to thank you publicly on behalf of all of us out there for your extraordinary leadership.

The CHAIRMAN. No thanks are required, Tom. I appreciate your kind words, and if you want to travel around, you can introduce me any time you want.

Mr. BRUNER. All right. Thank you.

The CHAIRMAN. All kidding aside, I appreciate the chance to work with you on this and many other issues. I appreciate each of you being here and our audience for listening, and the broader audience that may view this. I hope each will take this information and help to stem the spread of AIDS in persons 50 and older because it is a very serious condition. But there is information, there is research, there is work to be done so we all get to be seniors, and hopefully without AIDS. But if you have it, there is help.

With that, we are adjourned.

[Whereupon, at 4:21 p.m., the committee was adjourned.]

APPENDIX

PREPARED STATEMENT OF SENATOR HILLARY RODHAM CLINTON

I'd like to thank Senators Smith and Kohl for convening this hearing today to talk about HIV and its impact on baby boomers.

I know that Senator Smith has long been a champion of HIV/AIDS issues in the Senate, and we've worked together to introduce the *Early Treatment for HIV Act,* which gives states the option to provide Medicaid eligibility to low-income individuals living with HIV before they become disabled by AIDS.

I'm pleased that we're examining this issue in light of this year's reauthorization of the Ryan White CARE Act, which provides funding for essential care, treatment and support services for people living with HIV/AIDS.

In my state, we have a real need for the services funded through the CARE Act. New York has the highest number of AIDS cases in the country—more than 66,000 individuals are living with this disease.

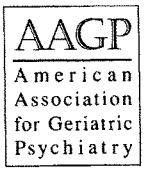
While advances in therapy have resulted in people with AIDS living longer, healthier lives, it has also increased the demand for the care and support services provided through the CARE Act. And, as we will learn today, the seniors living with AIDS have a special need for CARE Act program.

In addition to providing adequate funding for treatment and support services for people living with AIDS, we also need to focus on preventing transmission of HIV.

In New York, over 8,000 people were newly diagnosed with HIV last year, more than any other state. And I believe that it is critical to improve our prevention messages among our over-50 population, and encourage them to discuss testing with their medical providers.

In my state, we provide counseling about HIV and AIDS as a routine part of prenatal care, and I belive that we need to expand such counseling into more patient-provider encounters, including those that senior citizens have with their primary care physicians.

Again, I'd like to thank Senator Smith and Senator Kohl for holding this hearing and reminding us that AIDS is a disease that affects all Americans, including our seniors.



Joint Testimony for the Record

of the

American Psychiatric Association

and the

American Association for Geriatric Psychiatry

Presented to

the Special Committee on Aging

HIV Over Fifty: Exploring the New Threat

United States Senate

May 12, 2005

American Psychiatric Association
Division of Government Relations
1000 Wilson Blvd, Suite 1825
Arlington, VA 22209
Telephone: 703-907-7800
Fax: 703-907-1083

American Association for Geriatric Psychiatry
Department of Government Relations
7910 Woodmont Avenue, Suite 1050
Bethesda, MA 20814-3004
Telephone: 301-654-7850
Fax: 301-654-4137

The American Psychiatric Association (APA) is the nation's oldest medical specialty society, founded in 1844 with more than 36,000 members nationwide specializing in the diagnosis, treatment and prevention of mental illnesses and substance abuse disorders. The American Association for Geriatric Psychiatry (AAGP) is a professional membership organization dedicated to promoting the mental health and well being of older Americans and improving the care of those with late-life mental disorders. AAGP's membership consists of approximately 2,000 geriatric psychiatrists as well as other health professionals who focus on the mental health problems and needs of older adults. The APA and AAGP thank Senator Smith (R-OR), chair of the U.S. Senate Special Committee on Aging, and ranking member Senator Kohl (D-WI), for holding this hearing and for their interest in the subject of older Americans and Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS). The APA and the AAGP are pleased to submit the following written statement to the Committee regarding psychiatric and neuropsychiatric implications of older Americans and HIV/AIDS.

I. HIV/AIDS and Older Americans

The United States continues to face a growing health care crisis. Now in the third decade of the HIV/AIDS pandemic, there is no end in sight. In the U.S., an estimated 850,000-950,000 people are currently living with HIV. The devastation caused by AIDS has surpassed even the most dismal predictions of the early 1980s.

Acquired Immune Deficiency Syndrome (AIDS) is caused by the Human Immunodeficiency Virus (HIV). The virus attacks certain white blood cells of the immune system needed to fight infections called the CD4 "T helper" lymphocyte. As part of the body's response to the virus, the immune system produces antibodies, the measurement of which is used to identify HIV infection. The development of the end-stage of the infectious process is known as "AIDS".

Older individuals are increasingly affected by both full blown "AIDS" and the earlier, non-AIDS stages of HIV infection. New cases of HIV infection are appearing at the same rate in the USA as in previous years, but, as a result of improved treatments of HIV and AIDS, the prevalence of HIV infection is rising since infected individuals are living longer into older age than they had been with former, less effective treatments.

In recent years cases of HIV/AIDS in older Americans have far exceeded cases of HIV/AIDS among the general U.S. population. According to the U.S. Centers for Disease Control and Prevention (CDC), from 2000 to 2003 new diagnoses of HIV/AIDS in older Americans ages 45-64 almost doubled or more than doubled the rate of all other age groups. For individuals ages 45-54, the number of new diagnoses increased from 4,924 to 5,821, an 18 percent increase, and for ages 55-64, the number of new cases increased from 1,412 to 1,681, representing a 19 percent increase. No age group (each of a ten-year span) under age 45 exceeded an increase of more than ten percent,[1] demonstrating the gravity of infection trends among older Americans particularly.

Epidemic trends also highlight the continued and increasing spread of HIV among special populations, including older persons.[ii] Rates of infection among older Americans may be associated with sexual contact, contaminated blood transmission, and intravenous drug use. The majority of older individuals now infected with HIV acquired it from blood transfusions. Transmission through blood transfusion, however, has decreased dramatically since the introduction of routine blood bank screening procedures in 1985. HIV infection among the older persons > 50 (as defined by CDC) is now most commonly transmitted through sexual activity (homosexual, bisexual, and heterosexual transmission) as a result of high-risk behavior. Most sexually active older individuals are no longer concerned about contraception, do not perceive themselves at risk, use medicines for erectile dysfunction, and do not use condoms. While environmental factors may contribute to sex, the vital aspect of infection is risk level of behavior. Currently older persons either ignore or remain unaware of HIV/AIDS prevention strategies resulting in high-risk behaviors.

In addition, residential trends of older Americans may warrant examination. As older Americans reside more frequently in areas of common, close relation, such as residential living facilities and other close settings, opportunity for sexual contact and HIV transmission may increase. Although research is limited with respect to these new social and health trends, data yet demonstrate the marked rate of increase of high-risk behaviors and the dangerous and deadly transmission of HIV among older Americans.

Complicating further this growing problem of HIV among older Americans are factors relating to diagnosis and disease progression. HIV in most older individuals is often undiagnosed until symptoms or physical signs related to immunodeficiency are noted, and therefore untreated due to perception among health care professionals that older individuals are not at risk or not at high risk. In addition, normal age-related changes in immune function and poor nutrition may confound the differential diagnosis and/or contribute to disease progression.

II. HIV and Psychiatry

Insofar as HIV/AIDS attacks the body, it attacks the brain. As such, the involvement of psychiatrists and treatment of AIDS and HIV infection is essential. Clinical experience and research provide substantial evidence that HIV directly infects the brain soon after initial infection, which can result in psychiatric disorders (mental illness disorders) and neuropsychiatric disorders (mental illness disorders of the body's central nervous system), including HIV-associated dementia (HAD) complex,[iii iv v vi] minor cognitive-motor disorder (MCMD),[vii] delirium,[viii ix] depression,[x xi xii xiii], anxiety[xiv], psychosis[xv], pain and sleep disorders[xvi xvii]. Of individuals with AIDS prior to the introduction of current treatments, a substantial seventy-five percent experience changes to their central nervous system.[xviii] This prevalence of central nervous system effects and their relationships with the brain implore psychiatric contribution. HIV has been described as "a neuropsychiatric disease with systemic manifestations"[xix] whose assault on the brain requires the participation of psychiatrists throughout the course of illness.

Several important aspects of HIV/AIDS care and treatment place psychiatrists in the forefront of this epidemic, including, but not limited to the following factors: (1) psychiatric disorders can increase an individual's risk of acquiring sexually transmitted diseases;[xx] (2) pre-existing mental disorders (including substance abuse) can predate and/or complicate HIV-related illness;[xxi] (3) neuropsychiatric complications and psychiatric illness can affect adherence to antiretroviral therapy regimens;[xxii] (4) new antiretroviral treatments and combination therapies can affect the central nervous system and/or contribute to the development of psychiatric symptoms,[xxiii] (5) psychiatric syndromes can be especially challenging to recognize and accurately diagnose in the medically ill; and (6) as HIV/AIDS becomes increasingly a chronic disorder with the improvement of treatments and longer survival times, the need for comprehensive psychiatric care and services is expected to rise.

III. HIV, Older Individuals, and Psychiatry

The neuropsychiatric and psychiatric issues of HIV disease among older persons are complex. As an individual's body and brain age, immunity to disease decreases. HIV infection can produce neuropsychiatric illnesses at various intervals during infection. As discussed, neuropsychiatric illness can lead to motor and cognitive impairments, as defined under the mantle of HIV associated cognitive-motor complex. It is broadly divided into two clinical categories, HIV-associated minor cognitive-motor disorder (mild deficits in activities of daily living) and the more severe illness, HIV-associated dementia (HAD) (moderate to severe deficits in activities of daily living). Symptoms of these illnesses can so closely resemble other forms of neurological or psychiatric impairments already associated with the elderly, such as Alzheimer's disease, depression, and anxiety. Consequently, accurate diagnosis of HIV is difficult. Effects of HAD can include individual symptoms or a variety of symptoms, including psychomotor slowing (movement by action of the mind), decreased speed of information processing, attention deficit, impaired verbal memory as well as impaired speech, mood changes, and behavioral changes (fatigue). Compared to other dementias, the clinical course of HAD may be more rapid. Findings generally point to a need for physicians and caretakers to increasingly consider HIV infection as a possible cause for dementia-like symptoms observed, even in older persons who may not initially consider themselves to be at risk.

Additional illnesses can result from HIV/AIDS, including disturbances in the peripheral nervous system (distal symmetric polyneuropathy) and spinal cord (myelopathy). Both of these illnesses impose particular pain, which has in turn demonstrated hindrance to cognitive capability.[xxiv] Because the speed of cognitive ability directly correlates with overall psychological distress,[xxv] pain is of special concern. Additional diseases in older HIV/AIDS patients include delirium which, occurs frequently in late stages of AIDS, and mood-related brain illnesses, including psychotic depression, and mania.

A. Prognosis and Treatment

Despite these diagnostic complexities, HIV-related neuropsychiatric and psychiatric complications are among the most treatable complications of HIV disease. Effectively

treating these conditions can clearly enhance patients' quality of life. Treatments for HIV/AIDS among older individuals can include medication and psychotherapy. Of medicines, anti-anxiety, anti-depressant, mood stabilizing, and anti-psychotic treatments are appropriate for HIV/AIDS illnesses in older patients.

Antiretroviral medicines that treat HIV/AIDS also are fundamental. Incidence of HIV-associated dementia and central nervous system opportunistic infections (e.g., toxoplasmosis and cryptococcal meningitis) have been determined to be reduced by 50 percent since 1996, when highly active antiretroviral therapy (HAART) was pioneered for treatment.[xxvi] Utilization of antiretroviral medications can forestall disease progression and prolong life.

Although antiretroviral medications have demonstrated clear efficacy, there can be complications associated with them. In some patients, existing psychiatric conditions can prevent effectiveness of antiretroviral treatment.[xxvii] Older individuals with cognitive motor impairment, for example, generally demonstrate less adherence to antiretroviral medication.[xxviii] Another complication of antiretroviral treatment is that antiretroviral medications can cause development of psychiatric and neuropsychiatric conditions that cause moderate to severe loss in cognition and motor functions.[xxix]

Moreover, HIV/AIDS patients can experience complications when taking multiple medications for other ailments, including ailments spurred by aging. Correspondent to the use of multiple medications, many patients demonstrate evidence of complex illnesses. Managing these patients is often complicated as a result of compounded side effect profiles of these medications and as a result of interactions between and among multiple drugs. Some side effects of medications include, cognitive impairment, hallucinations, insomnia, depression , paranoia, headache, anxiety, psychosis, irritability, tearfulness, and apathy. As each medication works differently in each individual, and corresponding to multiple prescriptions, deliberate monitoring medications is important. Patients with HIV/AIDS are a vulnerable population with distinct medical needs and high sensitivity to many medications.

Making HIV/AIDS psychiatric illnesses more complex are comorbidities and social factors that undermine and stigmatize HIV/AIDS patients. Comorbidities can include depression, anxiety disorders, substance abuse, encephalitis, meningitis, cancers, and cognitive disorders. In older persons with HIV infection, diabetes mellitus, hypertension, and osteoarthritis are of particular concern. In addition, stigma placed on older individuals with HIV/AIDS can be greater than that of other populations, because of the social and moral beliefs of the older population.[xxx] As stigma increases, older individuals may be less inclined to seek assistance and medical treatment, and can, on the contrary, recourse themselves to isolation from people, caregivers, and needed treatment.

B. Barriers to Quality Care

1. Diagnosis and Treatment

Diagnosing HIV/AIDS in older individuals presents challenges, as many symptoms of HIV/AIDS also are a part of typical aging process. These overlapping symptoms include fatigue, depression, pain, diabetes mellitus, hypertension, osteoarthritis, Alzheimer's disease, and more. Primary care doctors and other specialists may easily overlook or delay accurate diagnosis of HIV infection.

Because HIV/AIDS can affect older individuals' brains substantially, psychiatric evaluation is important in diagnosing HIV/AIDS. As discussed, symptoms of HAD, the most common primary infection of the central nervous system, include impairment in cognitive, motor, and behavioral function. These impairments are demonstrated in poor memory, attention deficit, decreased information processing speed, incoordination, Parkinsonian symptoms, falling, anxiety, and superfluous emotion.

The challenge in diagnosing HAD and MCMD, as such and not as typical aging or other diseases like Alzheimer's Disease, is that symptoms are similar. Psychiatry and neuropsychiatry employ practices that help differentiate between HIV/AIDS and other geriatric illness. For example, psychiatric differential diagnoses can include, prominently, decline in verbal function, memory, concentration, and ambulation.[xxxi]

Complicating diagnosis of HIV/AIDS in older individuals can also be the lack of discussion of the topic of HIV/AIDS by primary care physicians and other caregivers. Also, discussion in primary care settings of sexual activity can occur less frequently than primary care discussion of other traditional health matters. Without correct and timely diagnosis of HIV/AIDS, there is a critical lag time in treatment, which provokes rapid immunologic progression, illnesses related to immunodeficiency, interacting comorbidities, and decreased survival time. Thus, timely and accurate diagnosis is critical for older individuals.

2. Drug Adherence

Adherence to taking medications regularly is vital as HIV/AIDS relentlessly replicates without antiretroviral medication intervention. Even 1-3 days of deviating from treatment can increase viral replication.

Adherence poses challenges to vulnerable older populations infected with HIV/AIDS, including older individuals with low incomes, multiple comorbidities, and social strain. These vulnerable individuals can have difficulty maneuvering through public systems of resources to access physical health care, mental health care, and needed medication treatments. These groups of individuals particularly are at risk for not receiving treatment and early intervention that can prolong their lives and improve their quality of life. Subsequently, caregiving and services that meet the economic, social, health, and emotional needs of this population is vital.

IV. Recommendations

First, the American Psychiatric Association and the American Association for Geriatric Psychiatry recognize the vital importance of provider and patient education about HIV/AIDS transmission specifically targeting older persons. Second, the APA and the AAGP suggest enactment of legislation that would increase access to treatment of HIV/AIDS, increase access to mental health care providers to provide for prevention, and address needed federal research. The APA makes the following recommendation to the Committee to address HIV/AIDS in older Americans:

A. An examination of the need for, and existence of, federal grants to educate and make aware caregivers and older Americans about HIV/AIDS in older Americans and about mental illness.

   1. Caregiver education to effect accurate and timely diagnosis of HIV/AIDS and to educate patients about the consequences of moderate- to high-risk sexual behavior in older age.

      a. Primary care providers and geriatricians. It is important these primary care providers and geriatricians be educated about HIV infection in older Americans, with respect to identifying psychiatric and neuropsychiatric symptoms that can mirror symptoms of aging. Early diagnosis is critical to treating HIV and prolonging life.

      b. Psychiatrists. It is essential that psychiatrists receive comprehensive education in the direct care and support for the HIV infected patient. Psychiatrists must be prepared to manage the complex medical issues that may lead to central nervous system dysfunction, assess and monitor patients for the neuropsychiatric consequences of HIV, aggressively treat substance abuse and other psychiatric disorders, manage the co-administration of psychotropic drugs and antiretroviral agents, facilitate the appropriate care of HIV infected patients with severe mental illness, promote antiretroviral treatment adherence, and respond to complex ethical issues.

   2. Patient education. Educating older Americans about the perils of moderate- to high-risk sexual behavior is critical in preventing transmission of HIV. Educating patients in settings specific to the older population should be targeted.

B. Legislation

   1. Enactment of H.R. 1125, the Medicare Copayment Equity Act, introduced by Representatives Ted Strickland (D-OH) and Tim Murphy (R-PA), which would reduce Medicare patients' coinsurance from the current 50 percent to 20 percent, the amount for all other care. This legislation would

reduce Medicare beneficiaries' financial burden, which may contribute to fewer mental health visits. If beneficiaries increase mental health visits as necessary, education to patients from providers and HIV/AIDS detection may increase.

2. Enactment of S. 311, Early Treatment for HIV Act of 2005, which would give states the option of providing Medicaid coverage for certain low-income, HIV-infected individuals. The APA applauds the leadership of Chairman Smith in introducing this legislation, which would help older Medicaid beneficiaries maneuver through the financial, social, and physical (cognitive and emotional) challenges of coping with HIV/AIDS.
3. Increases in Medicaid funding, through which substantial HIV/AIDS treatment funds are provided.

C. Federal Research and Treatments

1. Studies to determine the effects of HIV/AIDS on the brain and central nervous system in older persons: whether current antiretroviral treatments penetrate the blood-brain barrier sufficiently to reduce viral replication to the levels seen in the systemic circulation, where the brain represents a clinically important reservoir of latent and/or resistant virus, whether monitoring changes in brain tissue metabolites (using non-invasive techniques such as magnetic resonance spectroscopy) may contribute to the control of the disease in the central nervous system, and to what extent vaccines in development need to cover viral strains specific to the central nervous system.
2. Additional studies of the affects of aging on the brain and the immune system and the interaction between the two.
3. An examination of the amount of geriatric and psychogeriatric sampling in general federal research studies to ascertain mental health research needs and research disparities. A particular focus should be made to differentiate the sub-population of newly infected older individuals from that of older HIV infected individuals who have survived into older age because of the efficacy of HAART therapies.
4. Federal reporting, including CDC Surveillance reports, that quantify older Americans as a population at risk for HIV/AIDS.
5. An examination of the stigma associated with older age and HIV infection, particularly in minority populations and those with cognitive-motor disorder. Interventions to reduce HIV/AIDS stigma are a priority as well.
6. An examination of decreased access to care for psychiatric and neuropsychiatric disorders associated with older age and HIV infection, particularly in minority populations. Interventions to improve access to care for these disorders are a priority as well.

[i] U.S. Centers for Disease Control and Prevention. Estimated numbers of cases of HIV/AIDS. HIV/AIDS Surveillance Report, 2003.

[ii] Chiao EY, Ries KM, Sande MA: AIDS and the elderly. *Clinical Infect Dis* 1999 Apr;28(4): 740-5.

[iii] Masliah E, Achim CL, Ge N, et al. Cellular neuropathology in HIV encephalitis. In RW Price and SW Perry (Eds), *HIV, AIDS and the Brain*. Raven Press, NY, 1994; 119-131.

[iv] American Academy of Neurology: Nomenclature and research definition for neurologic manifestations of human immunodeficiency virus-type -1 infection. *Neurology* 1991; 41:778-785.

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