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Ryan White CARE Act [3]

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Michael - new draft

U.S. Department of Health and Human Services (HHS)
Recommendations for the Reauthorization of the Ryan White CARE Act *del*

Although much has been accomplished since passage of the CARE Act in 1990, serious challenges remain as the epidemic spreads among VULNERABLE populations and outpatient treatment costs continue TO increase. To meet these challenges, HHS is recommending several legislative changes DESIGNED TO IMPROVE AND EXPAND ACCESS TO CARE, INCREASE ACCOUNTABILITY AND ENHANCE SERVICE CAPACITY IN UNDERSERVED URBAN AND RURAL COMMUNITIES..

Increase Access to Care for Vulnerable Populations

- **HHS should work** with title I planning councils, States, and experts in the field to develop and implement activities including: estimateS OF the number of HIV-infected individuals in the region covered by the grant (including persons not currently receiving HIV-related health care); TO conduct needs-assessment activities among POPULATIONS not in care in order to establish service needs; and apply such estimates and needs-assessment information in planning for services.
- **GRANTEES under titles I and II should develop** strategies for using Medicaid and State Children's Health Insurance Programs funds to cover HIV-related health care costs of eligible individuals when PLANNING FOR SERVICES AND allocating funds.
- **GRANTEES ARE TO establish referral relationships between Ryan White providers and OTHER HEALTH CARE PROVIDERS THAT SERVE AS** key points of access to the health care system, for example, emergency rooms, family planning clinics, substance abuse TREATMENT facilities, detentional centers, and others.
- Allow use of titles I and II funds for (no capital letters - early intervention services) FOR PURPOSES OF IDENTIFYING PERSONS NEEDING HIV CARE AND BRINGING THEM INTO CARE WITHIN RYAN WHITE PROGRAMS AND REFERRAL NETWORKS SERVING AS KEY POINTS OF ENTRY.
- Expand eligibility of the Dental Reimbursement Program to include community health centers in order to expand services to smaller metropolitan and rural areas.
- IMPLEMENT A TITLE II ADAP SUPPLEMENTAL AWARD TO TARGET ADDITIONAL FUNDS TO STATES WITH DEMONSTRATED NEED FOR HIV-RELATED TREATMENTS. (*See cover note to OMB)

Assess and Improve Quality of Services

- Work with title I Planning Councils, States, and experts in the field to develop and implement a Quality Management program for all grantees in order to DEVELOP PERFORMANCE

MEASURES, ESTABLISH AN ASSESSMENT PROCESS, AND USE INFORMATION TO IMPROVE THE QUALITY OF CARE OF MEDICAL AND SUPPORT SERVICES.

- Provide additional resources to grantees for Quality Management Programs.
- Support services funded under the Act should be RELATED TO IMPROVED ACCESS TO HEALTH SERVICES AND HEALTH OUTCOMES

Capacity Development

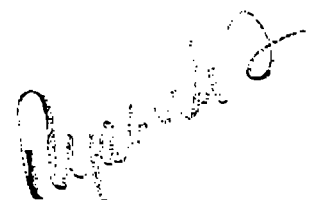
- Support EMA and State activities under titles I and II related to assessing needs for and implementing capacity development activities for low-income, historically underserved communities, IN ORDER TO PROMOTE ACCESS TO PRIMARY CARE SERVICES.
- Expand title III planning grants activities to include capacity development grants of \$150,000 over 3 years to enhance the delivery and benefits of HIV primary care services to low-income, historically underserved communities.
- Capacity (small D) development activities are for purposes of assisting communities to expand their capacity, preparedness, and expertise to deliver primary care services to individuals with HIV disease in historically underserved low income communities.

Funding and Demonstration Projects

- Fund a study of the delivery and financing of HIV services among low-income, under and uninsured persons conducted by the National Academy of Science/Institute of Medicine Study.
- The purpose of study is to examine key factors associated with the financing and delivery of HIV services in relation to the publicly and privately funded health services, general demographics (race/ethnicity, poverty, age, urban/rural, etc) and co-morbidities (substance abuse, mental health, homelessness) of HIV infected community members, regional variations in the funding and costs of delivery services, and available epidemiologic tools and data sets necessary for local and national planning and allocation decisions.

Other Recommendations

- Continue the title IV relationship with research programs but remove requirements related to enrollments in clinical trials.
- Increase title III administrative cap and establish title IV administrative caps.



AIDS | **for Children, Youth & Families**
ALLIANCE

FAX

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TO: Sarah / Sandy's office

FAX:

FROM: DAVID HARVEY, EXECUTIVE DIRECTOR
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DATE:

PAGES: 3

SUBJECT:

COMMENTS:

Title IV

Title IV of the Ryan White CARE Act

Title IV of the Ryan White CARE Act provides competitive grants to public and private nonprofit entities to develop and sustain comprehensive, coordinated systems of HIV care and services for low-income children, youth, women and families. Title IV provides a variety of critical services, including primary medical care, social services such as case management, and access to research. A unique aspect of Title IV projects is that they provide "family-centered care," which means that care and services can be built around the needs of whole families affected by HIV.

Title IV currently funds 58 grantees in 27 states, the District of Columbia and Puerto Rico, and these grantees provide or arrange for direct HIV services at several hundred clinical sites. These projects are enrolling - - and retaining - - extremely vulnerable populations in care. Title IV provides services to over 45,000 children, youth, women and families, and this number has continued to grow quickly. The Title IV program served 13% more individuals in 1997 than in 1996, with significant increases in all age groups.

Serving People of Color. Title IV continues to lead the Ryan White CARE Act in reaching people of color. In 1997, 58% of Title IV clients were African-American, and 23% were Latino. The number of African-American clients reported by Title IV projects increased by nearly 80% from 1995 to 1997, and continues to grow. The number of Latino and Asian-American clients has also steadily increased. Beginning in FY 1999, Title IV received additional targeted funding for services for African-Americans, and this funding is helping the program to increase access to care for this population.

Reducing Perinatal Transmission. A major success of the Ryan White Title IV program has been to help dramatically reduce the rate of perinatal HIV transmission in the United States. Title IV projects reduce perinatal transmission by providing outreach, counseling, and testing to women of childbearing age and health care to pregnant women and their children. The recent Institute of Medicine report to Secretary Shalala on efforts to reduce perinatal transmission identified the key role that Ryan White Title IV projects have played in this effort.

Reaching HIV Positive Youth. Title IV is leading the national effort to engage and retain HIV-positive young people in comprehensive health care. From 1995 to 1997, the number of young people ages 13-24 served by Title IV increased by 225%. Title IV projects have been particularly successful at reaching young women of color, one of the fastest-growing HIV risk groups in the nation.

In collaboration with the National Institutes of Health, the Title IV program has established the REACH Project, a research program that is studying the medical, psychosocial, and behavioral aspects of HIV in adolescents. With approximately 350

teens enrolled at 15 sites across the country, the REACH Project is the source of much of what is known about HIV disease in adolescents.

Providing Quality, Cost-Effective Health Care. Title IV has also proven to be remarkably efficient and cost-effective. Title IV is a very small program, representing only about 3% of FY 1999 funding for the Ryan White CARE Act as a whole. Yet the flexibility of Title IV funding enables HRSA to move resources quickly into the communities that are experiencing rising rates of HIV infections among children, youth, and women.

Title IV projects are also enabling low-income children, youth and women to take advantage of the promising new treatments for HIV. At the Women and Children HIV Program at Cook County Hospital, for example, a multidisciplinary team provides patient access to new HIV treatments and assists patients with adherence to the strict medication regimens. This effort has significantly improved the health of many clients. In 1997, the program saw a remarkable 60% decrease in the number of hospitalizations.



FAX TRANSMITTAL

ImpT

DATE: _____

To: SurlyFAX #: 456-2439FROM: Jim

____ PAGES INCLUDING COVER SHEET

NOTE:

Found it!
Do you love ME AGAIN!!

Mr. Chairman, members of the committee, my name is Sandy Thurman. I am Executive Director of AID Atlanta and a member of the Atlanta Title I Planning Council. It is indeed a rare pleasure to come to Washington with the expressed purpose of trumpeting some good news. In the AIDS epidemic we have entirely too much bad news: bad news about friends and colleagues who are ill and dying; bad news, all too often, about the inability of all levels of government to join us in a serious effort to halt this deadly disease. But I can honestly say that in the twelve years of this devastating epidemic, nothing has been as well received, nor more sorely needed, than the process and the resources of the Ryan White CARE Act, particularly Title I.

When Congress passed the Ryan White CARE Act in 1990, a message of hope went out to the thousands of people with AIDS, their friends, loved ones, families. That message was simple, direct and two-fold. First, the Congress, after more than a decade of neglect, recognized the problem -- the AIDS epidemic in America was truly a national disaster -- and second, the Congress committed the nation to providing the resources necessary to respond to the disaster in a comprehensive manner. The acronym "CARE" for Comprehensive AIDS Resources Emergency was well chosen.

Title I established a process for the creation of an HIV Planning Council within cities that have been severely impacted by HIV and AIDS. These councils reflect all disciplines responding to the AIDS epidemic as well as those infected and affected by HIV and AIDS. In this landmark piece of legislation our communities have been encouraged to work together in forging a comprehensive community response to AIDS.

The result has been astounding!

We have developed a shining example of public-private partnership -- local and state government,

for-profit and not-for-profit organizations, public health institutions and community-based organizations, people with AIDS from all walks of life -- all working in concert to meet the needs of people living with HIV/AIDS, their families and loved ones.

There are currently more than 641 organizations on the front line of the AIDS epidemic participating in Ryan White Planning Councils and hundreds more are receiving grants under Ryan White. The Health Resources and Services Administration (HRSA) has estimated that even with full funding the Ryan White CARE Act would only provide services to 30% of those in need. As you know this act is currently funded at less than one-third of the total this committee authorized. This is unacceptable.

The city of Atlanta has become the AIDS care "mecca" for the state of Georgia. 76% of the state's caseload resides in the Atlanta metropolitan area, and thousands of people with HIV and AIDS flock to the only public primary care clinic -- Grady Memorial Hospital's Infectious Disease Clinic -- and to my agency AID Atlanta. Before Ryan White, acutely ill patients with AIDS had to wait 6-7 weeks for an initial appointment. As a result, clients were dying or becoming seriously ill prior to receiving an evaluation.

The funds received from Title I provided the Atlanta Planning Council and AID Atlanta in particular with the opportunity to reduce waiting times by decentralizing care services into six satellite clinics. Our goals have been achieved: today, clients receive immediate emergency care, early intervention services within 2-3 days, and a complete evaluation within four weeks. Grady is reporting a reduction of 8% in patient admissions.

The good news of Ryan White, Mr. Chairman is reflected in the faces of patients and clients who

are receiving vitally needed services. I see it in the faces of service providers who now have some resources to offer. I even see it in the faces of bureaucrats and organization executives who frankly are surprised that amid this disaster, we have created a model of efficiency and cooperation .

The bad news today is that AIDS continues to devastate. Recent trends indicate that by 1995 non-drug using heterosexual infections will double. AIDS increasingly afflicts women, children and communities of color. 40% of the caseload in Atlanta is in communities of color. AIDS already is the leading cause of death for young men and women in many parts of the country. It is the third leading killer of children. More than 100 Americans will die today and everyday from AIDS until we act with aggressive intervention.

Two years ago, 16 American cities qualified for Title I funds. This year 18 cities have been declared "disaster areas" for AIDS. Next year there will be 24. We need to be emphatically clear: There is no end in sight. Our model for services, built on good will and good work, will collapse around us without a greater commitment of federal resources.

Quite frankly, Mr. Chairman, with the model in place and adequate funding, what we have here is a win/win situation. Using a basic premise of case management, we have developed a system of care which is both cost-effective and compassionate and which offers us an incredible return on our investment. By effectively utilizing all of the resources in our communities, including hundreds of thousands of dollars of in-kind and volunteer support, we are able to improve dramatically both the length and quality of life for our clients.

In the only study of its kind, Richard Sowell, a PhD from the Medical College of Georgia, examined the actual impact of community-based case management. This study, conducted at AID Atlanta, and presented last year at the 5th National Update Conference on HIV/AIDS in San

Francisco, confirmed that people with AIDS who were in a case-managed system realized 46 percent less in reported health care costs and lived 66 percent longer, and better, than people with AIDS who only had access to traditional, hospital-based care.

Case-managed patients were hospitalized less; had shorter lengths of stay when they were hospitalized; and were able to be productive longer and live longer on their own. This finding is of critical importance -- to the person with AIDS, to their families and loved ones who must care for them, and to each of us in this room, concerned with a federal response to AIDS which is conscious of cost and committed to care.

Let me tell you about some of the successes my colleagues in other Title I cities have had. Because of the Ryan White CARE Act, Boston now has a program of expanded gynecological care for HIV-infected women; 1,730 clients in Houston now have dental care; Jersey City has doubled the time pediatric AIDS treatment services are available; 10 newly hired case managers have counseled over 1,000 clients in San Juan; utilization of health centers targeting minorities and ethnic groups in Philadelphia has increased 104%; San Francisco's HIV-infected indigent population enjoys expanded physician time in four district health centers; in Newark, HIV-positive homeless people have access to housing, transportation and support services for the first time. These are only a few snapshots of success.

Community-based organizations, with in-kind and volunteer contributions, provide emotional support, counseling, transportation, skilled nursing, respite, meals on wheels, housing, legal services, pastoral care, family education and training. These services are coordinated with primary medical care to provide more with less with no duplication.

But most of all -- what we are fostering is community. We are caring for each other the old fashioned way -- people volunteering to help other people because they want to make life better

for someone else -- they want to make a difference. Under the guidance of our HIV Planning Council, we are working with the whole-hearted support of our leaders in local government, business, and churches. Together, with you, we are making a difference. In the AIDS world -- Ryan White is what is right with government.

We are building a model of health care delivery for the future -- not just institutions delivering services to people -- but people caring for people -- based on the age-old premise that we are called to community and public service.

As our hometown preacher from Atlanta, the Reverend Dr. Martin Luther King, Jr., once said, "Everybody can be great. Because anybody can serve. You don't have to make your subject and your verb agree to serve. You don't have to know about Plato and Aristotle to serve. You don't have to know Einstein's theory of relativity to serve. You don't have to know the second theory of thermodynamics in physics to serve. You only need a heart full of grace. A soul generated by love."

Mr. Chairman, this committee has demonstrated a heart full of grace in formulating and passing the Ryan White CARE Act. Your generosity and commitment to serving others sustains us in our commitment to do the same.

We thank you.

Q and A

General Points

- Community based control is so important
 - Allows communities to craft their own response
- Epidemic is different
- Partnerships
- Able to stitch together a tapestry of care that keeps people from falling through the cracks
- IOM is a great punt issue (everything formula wise)
 - (We respect everyone's opinion and research on this)
- We have enjoyed incredible bi-partisan support, at a time when we have seen the most rocky partisan landscape in a long time
- From Kennedy and Hatch to Jeffords and _____, it speaks to the best that this body has to offer
- We were hoping ten years ago that we would not be here. I never would have imagined that the epidemic wouldn't be over by now. We had hoped we would be out of business.
- We have made progress, but this progress has presented new challenges and problems.

AIDS exceptionalism -- cancer, diabetes?

- Whether we like it or not, the public health system could not afford this ten years ago, it cannot afford it now
 - If the health care was different, we might be able to do this; but right now, we don't have a system that, on either the private or public level, that can absorb the devastating impact of this epidemic;
- If all people were able to get services, this burden alone would bankrupt our national health care system;
- It is harder today that it was ten years ago, it is becoming more difficult to manage not easier;
- The design of this bill is to keep people out of hospital, the burden on just in-patient care would bankrupt (personal story: Sandy's doctor, no patients in the hospital)
- The reason that we have this is because this program is working, we're saving a bigger system by having this program. The public health system could not and now cannot absorb an epidemic like this one
- It's not about special programs for special people, its about keeping our public health system afloat and not sinking it beneath this epidemic.

Why hasn't Blank city qualified for Title I funding?

- I don't know specifically about your city, but five years ago when we looked at this Bill, we changed the formulas to effectively stop cities from coming on board. That was before protease inhibitors.

- This is a valid question. But we need more analysis.
- Does this still make sense in the context of today's epidemic? That is something for the IOM to look at.

Why is all of this money going into the cities?

- Nearly 80% of PLWAs, and probably even more living with HIV, fall in and around cities – the metropolitan areas;
- Atlanta does not just mean the downtown area;
- Washington DC serves all the way out to WV;
- This Act serves urban, rural, sub-urban areas.
- This is not about us vs. them, it creates partnerships
 - Personal: Sandy ran Titles I and II. That is why this works so well – we have the ability to dovetail the programs.
 - We've partnered the Title I and II in Georgia – One brought the PLWAs there, II allowed us to develop the infrastructure.
- The whole idea is to help the disaster areas;
 - Successful program if you can stop the city from becoming a Title I program;
 - There is not reward in this system – our best bet is to prevent cities from becoming Title I programs;
 - You don't want Des Moines to become a Title I City.
- Every county in the state of Georgia has reported AIDS cases, unlike when we first did this ten years ago. The epidemic continues to grow in the city – 70% or so are still located there.
- Most states that have Title I programs do not have Title II and III programs. That is why this Act works -- It allows the local community to play to their strengths, together.
- It is not always the case in every state that politicians are willing to work together (Atlanta example)

Indian Health Service?

- There is a special set aside in this Bill;
- There are special needs in those special populations, and working with the communities is a priority;
- We continue to work on this;
- We need better coordination, but this is not unique to HIV and AIDS. We are still struggling in this country as a whole with these issues.

What about the Medicaid program?

- Until PLWA are permanently disabled, they are not eligible to get those benefits;
- Any other health care program that can pay for services does, but this program supports them at this level of care for this disease when everything else falls through (and they always do);
- State by state, CARE Act becomes more necessary when other programs are not well funded or when they fall through.

Should we be buying ADAP drugs under federal purchasing programs?

- We don't purchase the drugs through the two systems that exist;
 - The drug companies don't want us to buy through those.
- We don't get any discounts – the states negotiate their own prices independently;
- What works best is that it is controlled as close as possible with the patients;
 - In this case, the state governments are the closest thing possible, and they are able to negotiate their own prices.

(HCFA negotiates Medicaid drugs)

Issues with squandering money?

- We have had problems, we fixed them.
- People are running these programs and people are not perfect.
- Accountability measures are built into this Bill. Our best bet is to work on them, and to fix them, not cover them up.

Community based organizations?

- You have to have good institutions to deliver good services; we do not want to build huge bureaucracies, but we do want the best possible people, the best possible services.
- No one, but the drug companies are making money off of this epidemic.
- There are business people in every city that are monitoring the organizations and services to make sure that we are being cost effective.
- That is the beauty of providing local service organizations, monitored by the community. All of these by law must release annual financial reports every year.
- There are caps on these budgets.
- It costs time and money to run these programs well, and this requires strong organizations.
- The more complex this epidemic becomes, the more qualified we need these people to be – and that costs money.
- Community leaders and AIDS activists are directing these programs and are going to have to be held accountable to their communities -- they are not going to squander their community's money.
- We are operating under fairly standard procedures.

What are the biggest problems in the CARE Act?

- Ten years ago as ED of AID Atlanta , we were crafting a system of care to help people die. Now, as the Czar, we are trying to help reauthorize a Bill that helps people live.
 - This changes the focus of the program
- The Act is nimble enough and quick enough to meet these new challenges;
- This doesn't require a change in the bill, it requires *US* to change – that is the beauty of this in the first place. The Bill is flexible enough.
- Changing every day...still caring for people with AIDS;
- We never anticipated all that we would be keeping people alive for more than 2 years;
- Vast majority of people that we serve are of minority communities;
 - Congress has approved funding for programs targeting specific minority communities;
 - At every turn, we are trying to craft something that works in concert and to not duplicate efforts – we are moving ahead, not covering old ground;
 - Nothing is ever perfect, but all things considered, and with the changing face of AIDS, the Administration and the Congress are successfully addressing this epidemic;
 - Challenges abound, but in the middle of a crisis, this is an incredible effort.

Soft services? How do you know that this money isn't being wasted?

- 79% of Ryan White is being spent on direct health care services;
- The need for support services, given the new face of AIDS, is very important to support people staying in care;
- One of the nice things about local control, is that communities define their priorities, what makes most sense to them.
- The money is always used to maintain the patient's quality of life.
- Sometimes massage therapy is the only way to manage pain, if the community has the resources, then the CARE Act will be there to support it.
- Consumers are crafting these support services, it is coming from the people who need the services;
- Massage therapy may be less expensive than a morphine drip. We must trust the consumer, the person living with AIDS.
- This whole issue of local control is so critical.
- This is not about you and me, this is about consumers and providers at the local level.
- Senator, neither you or I are doctors -- but from a provider standpoint, this is how we make these decisions.....
 - No one is taking a joy ride, here. There is no fun in this.
- We are trying to find the best way to take care of people – and there is ample proof that we are doing just that.

Mandatory Testing?

- In this bill, we are talking about caring for people already impacted.
- Mandatory testing is not sensible, and it's not cost effective. We need to be doing what is compassionate and cost effective, that is why we have a CARE Act.
- That is a state and local public health system decision
- If everyone assumes responsibility for themselves, we do not end up burdening the public health system
 - Everyone is at risk, we cannot make people more vulnerable by focusing on testing those at high risk;
 - Contact tracing – effective with other STDs? Partner notification might not work, might not be effective; and,
 - We want to encourage people to get tested, and to know their status. We cannot frighten them away with disincentives like mandatory partner notification. That is counter to our public health objectives.

Ryan White Testimony Points

I. Personal experience (Credibility)

II. Success of the bill (Working, cost effective...)

III. Challenges

I. Personal Experience

- I have seen the CARE Act from almost every perspective. I have acted as an advocate during the process of its drafting and inception, as a provider during my tenure as Executive Director of AID Atlanta, as an expert testifying before this committee in 1993, and now, as an Administration Official and a policy advocate.
- I said in 1993...
 - It is precisely those qualities that made the CARE Act work ten years ago that make it imperative we re-authorize it today.

II. Success of the bill

- CARE Act is working and continues to work
 - Title I and III greatest hits from Jeff/Tom
 - Title II greatest hits from NASTAD
 - Title IV greatest hits from David Harvey, et al.
- The Act has created partnerships among various sectors of the public health system, local governments, the community, providers, profit/non-profit and people living with AIDS to create a unique support network outside of the traditional health care system.
 - This is a model of services – we have developed a system of care that is compassionate (take more from old testimony).
 - Everybody wins. The CARE Act continues to be good for patients, good for communities and an effective way to save money
 - Every time we can keep a patient out of the hospital it saves us money.
[AAPH (1400 dollars/day we save) statistic]

- The CARE Act taken as a whole is a very effective model – the combination of the acts, and the partnerships it builds is a very efficient way to manage an epidemic that is in every other aspect ‘unmanageable’.
 - Title I – opportunity for local control
 - Title II – coordinating all aspects of the areas public health system
 - Title III – categorical grants to under-served communities
 - Specialty services for women, children, and families
- This bill in its parts and in its whole serves people in the most effective, most efficient way possible – It allows us to weave together a way of caring for PLWA that is unique to each city;

“In my own home city of Atlanta, we are blessed to have a very large health care institution, but this is not necessarily the case in every community. Every city is different, and the ability for local public health systems to respond to this epidemic is unique to every city.

They all have their own strengths and weaknesses. The Ryan White CARE Act allows us to strengthen our good points and to bolster our means to support the weak ones.”

- The dollars are being spent in the most efficient way possible;
 - 79% of every dollar goes to a direct primary health care service¹ which includes: Dental, mental, etc.
 - In some cases communities may have to prioritize and the special services may be necessary/possible (give example)

III. Challenges

- The crisis continues – lay out the case.
- The good news is that the CARE Act is working – it is allowing people to live longer and better lives. But this also means that we need more services to sustain the services now necessary to support the greater numbers of people *living* with AIDS.
- From research and from treatment, we are doing very well. But from a service standpoint, our challenges are harder and more difficult. The advent of protease inhibitors has presented us with a whole new array of challenges on a variety of service fronts;

¹ CAEAR Coalition/HRSA

- Medical
 - Nutrition
 - Adherence
 - Transportation (huge problem)
 - _____????
- Some of these challenges we have had to deal with before in public health, some are new to us and to the system.
 - The service needs that a person faces when they are homeless, drug addicts, new focus around service delivery.
 - Therapies must be strictly adhered to, from the medical standpoint, this means more time, more work, more energy;
 - The primary health care visit used to be 15 minutes twice a year, now it is 45 minutes² for 4 times a year – this quadruples time, this is just seeing the physician not including lab work, etc.
 - Face of the epidemic has changed dramatically since we last re-authorized this bill.
 - This point in itself has presented a whole new array of challenges in prevention and treatment.

² CAEAR Coalition



FAX TRANSMITTAL

DATE: 2/29/00TO: Sandy ThurmanFAX #: 456-2438FROM: Jennifer Vasiloff8 PAGES INCLUDING COVER SHEET

NOTE: FYI Tom asked that I share these with you. We prepared these Q&A for our witness at Thursday's hearing

Q AND A FOR RYAN WHITE HEARING

Positive:

1. How much money does this program save?

- Hundreds of millions of dollars have been saved over the last ten years.
- For each day of inpatient care we avoid by using RWCA resources we save \$1400 per day in either public reimbursement or local tax dollars used to support public hospital systems.
- As people with HIV and AIDS continue to improve by using new drug therapies there is a trend toward patients going back to work. When people are healthy enough to go back to work, and off public assistance and disability roles everyone wins. Ryan White is designed to help these people maintain care and health so they can stay productive for as long as possible.

2. Why is this program successful in meeting such diverse needs?

The combination of the four major titles of the bill allow for a multi-pronged approach to meeting the needs of people with AIDS no matter where they live or which unique situations they face in addressing the disease. Title I allows for local control so that those closest to the front lines of the epidemic can address the problems directly. Clearly in AIDS one size does not fit all. Title II provides a comprehensive state wide approach to making sure all communities have resources to meet the expanding need of people with AIDS. This is particularly important with regard to assistance in purchasing drug therapies. Title III is designed to help our front line health care centers with direct federal funding so that they can offer HIV testing and treatment in those communities that now find themselves part of the second wave of the AIDS crisis namely rural America and urban poor communities. Title IV provides for the unique blend of services necessary to meet the needs of women, children and families who are facing HIV and it related disease complications. This combination of federal, state and local effort along with a strong emphasis on partnerships at the local level is singularly unique in public health strategies and has brought us the success we seen in Ryan White meeting the diverse needs of nearly 1 million Americans.

3. What is the most serious challenge facing AIDS Service Organization's today and how should a reauthorization bill address those challenges?

The most serious challenge facing providers today is an ever expanding case load of patients that require services for prolonged periods of time. When this bill was written 10 years ago we were helping people with services while they died. Today we find ourselves in the happier position of helping people avail themselves of things that will help them live. This is good news at a human level but as providers of service this has increased our burden and cost by many fold. Not only do we take care of more people for longer periods of time but the medical care necessary to give patients a new lease on life is very expensive. You see it isn't just the drugs which are very costly but also the associated medical and support services that ensure the drugs can work effectively. In short, the good news is people are living longer the bad news is that resources have not kept up

with the demands of that trend. Reauthorization will enable this program to continue in its present form and allow those responsible for budget decisions to invest wisely in the programs and services this bill is designed to deliver. We are particularly encouraged that the Congress is considering expanding the bill to allow for limited but needed investment in capacity building. Helping AIDS organizations build the capacity to care for more and more patients for longer periods of time and with frequently complicated medical conditions is a wise, compassionate and cost-effective decision.

4. Accountability is very important – tell us how well these funds are spent and what evidence can you give to substantiate your point?

The funds distributed under the Ryan White CARE Act go through a series of formulas and grant making mechanics that provide for stringent levels of accountability and the ability to assure the Congress each year that funds are spent with efficiency and effectiveness. For the Title I program annual applications for formula and supplemental funds require the submission of data and compliance records. Once funds are received in a local community they are passed through a legislatively mandated planning council. Those councils are made up of public and private sector volunteers, including people with AIDS who have an enormous stake in assuring that not a dollar is wasted. I have been at those meetings and participated in the difficult work of awarding too few dollars for too many serious problems. Accountability is critically important to me. The Title II program also requires the state to use the funds in narrowly defined ways and insists the states comply with standards and legislative requirements. In fact Title II funds are now primarily spent on assisting people with HIV and AIDS in gaining access to promising new drug combinations. In the last three years states have had less money to meet the demand for these new drugs within the states. With life and health decisions such as these – accountability is measured in the wonderful trends of decreasing death rates and the return to work of people who had otherwise been completely disabled.

Have there been places where funds have not been spent well, Yes! But in those places the problems were discovered, people have been punished and the system has demanded reform. Indeed, the fact that we've had a few, very few, problems indicates our accountability systems work.

5. We hear about the AIDS epidemic changing how has this program adapted to those changes?

The most dramatic changes in the epidemic have been in the area of medical treatment. Once a program designed to assist people who were dying rapidly Ryan White is now a program that assists people in attaining medical and support services that promote life and health. No where is that more dramatic than in the recent data indicating that the expenditures on primary health care services within Ryan White now claim nearly 70 cents of every dollar. Similarly a recent study by the CAEAR Coalition noted that the average length of a medical visit to a Title III program increased by 65%. The average COST of medical visits rose an astounding 89.3% between 1995-1997. Today more people are seeking care and the care they are receiving is more expensive in both therapeutics and clinical services. There has been a dramatic shift in Ryan White funds in

the last ten years -- specifically away from palliative care and toward aggressive clinical care and management. This legislation and its unique design has allowed this shift to happen quickly and effectively within all Titles of the bill.

Also, the epidemic is changing color and sex. Today, 64% of Title I clients are people of color. In 1996, the largest number of new clients entering Ryan White programs were African Americans. For Title III, one third of the patients served are women and two thirds are African American. While these numbers are disproportional to the actual demographics of the disease they very closely track the emerging trends in the epidemic and directly reflect the disproportionate need for services within communities of color and those that are geographically isolated or under served.

Lastly, we must recognize that every American community has been touched by AIDS over the last twenty years. The epidemic presents different problems in urban America than it does in rural America but each problem requires our collective response. Today AIDS remains a disease located primarily in and around large urban areas. Title I now serves 74% of all AIDS cases in the nation. But we must be clear, a Title I area may be urban, suburban and even rural. For example right here in Washington DC the EMA serves counties as far away as West Virginia and nearly as far south as Richmond VA. This does not diminish the need or the challenge to meet the needs of rural America. Today, half of all Title III funds are going to rural areas to assist in providing critically needed HIV health care.

We hope Congress will pass a bill that creates a new supplemental program within Title II to address the needs of areas that fall out of the definition of Title I EMA. No one with in the AIDS community believes the simple answer of dividing the pie proportionally is right. We could not manage this epidemic in rural America only got 25% of these funds. Similarly, the people presenting with HIV infection and AIDS in urban hospitals frequently present with many seriously related other health and social conditions, including homelessness, mental health issues or active substance abuse. This complex medical picture is a very real scenario for AIDS providers today.

Negative:

1. Why should there be a program like this just for people with AIDS?

In a perfect world where health care was accessible for anyone who needed it for any reason there would be no need for a program like Ryan White. We must remember 10 years ago when people with HIV faced massive discrimination, loss of job -- and health insurance-- and a medical establishment that had little to offer severely ill and dying citizens. The need for Ryan White then was to keep the public health system in the nation from a state of virtual collapse. It has WORKED. I wish I could say things have changed but the need for Ryan White is still the same. We still do not have health care reform that would allow necessary care for an epidemic like this one to be meet.

Let me be clear, If every person with HIV attempted to use our current systems of care, without the Ryan White CARE Act in place, the system would explode. There is a real need for

speciality care in AIDS. The medical advances are rapid and complicated. The associated support services needed to get people on treatment and keep them on it are critical to preventing new strains of this deadly virus. Simply put Ryan White saves all of us money by keeping people out of hospitals and away from the most expensive kinds of care – namely the emergency rooms. For each person Ryan White helps stay out of the hospital our system of care saves \$1400 per day. That's critically important not only to the person with AIDS but the child with appendicitis or the elderly person with a broken hip. Closed or clogged emergency rooms have happened and more would happen without Ryan White. A bankrupt public health system would be a national disaster that would and could effect every citizen. We see this bill as a necessary fire wall to that disaster and hope someday we'll have a system in place to make this bill unnecessary – we simply aren't there today.

2. My state does not have a Title I city and I hear from our providers and patients that they feel short changed by this program – How do you respond?

First, I'm glad your state doesn't have Title I city – I'm sure your happy that the epidemic in your community has not reached the disastrous threshold that it has meet in 51 other cities across this nation. In so many ways that is good news. Second, let me say that in an atmosphere of crisis and we are still in an AIDS crisis -- everyone feels short changed. There is not enough to go around -- there is more need than resources -- there is more to do in every clinic, program, city, county and state. No one is getting enough so any conversation about someone getting too much is simply not reality.

Specifically the reasons one city qualifies and others don't is beyond me but I understand that qualifying as a Title I city requires the area to meet a certain number of cases of AIDS within a period of time. Five years ago, when Congress re-authorized the program they specifically changed these thresholds to slow the tide of newly eligible cities each year. From 1991 when 16 cities were eligible to today when 51 cities qualify the growth has been staggering. The change in the qualification standards is now based on the number of AIDS cases an area has had over 10 years. Five years ago this made sense to some people but today when new drugs can keep people alive for 10 years or more I think this standard may need some revision. I understand the Congress will ask the Institute of Medicine for a study of this issue and others that affect the qualifications for Title I as well as the factors used to distribute funds within all Titles of the CARE Act. This is needed. It should be done slowly, with thought and data -- and with care. We must not rapidly or carelessly disrupt this important but fragile system of care. I look forward to the IOM report and its thoughtful conclusions.

3. My concern in AIDS is the innocent babies and the women who have been infected. How are you addressing their needs?

As you know anyone with HIV is eligible for services under all titles of the Ryan White CARE Act – this includes women and children – and we do know they are increasingly becoming infected particularly within communities of color. Title I and II require the distribution of funds to match the demographics of the epidemic in the state or local area. In addition, there is Title IV as a separate title that is specifically designed to assist programs that specialize in services to

women, children, youth and families with providing AIDS care and services. This program in communities I live and visit is working very well.

4. I have heard that this program is paying for services that are unnecessary — things like massage therapy or dog-walking services. Can you assure the committee that this is not the case?

First, 69% of all Ryan White services in Title I are for primary medical health care services. This means direct funding for the doctors visit, the medication, the lab work, home health service, and even hospice service when all else has failed. In some communities local planning the needs of people living with HIV may indeed prioritize other types of services to support people in maintaining health. We must respect local decisions, particularly those made in concert with consumers of services. But, indeed I understand and support the need for some alternative forms of assistance to people with AIDS. If massage therapy helps relieve pain and keeps someone from an expensive hospital stay — I think we should support that. Massage is less expensive than morphine. Our job is to take care of people and save money — this is a good example of how we do both.

5. With such a large amount of funding dedicated to purchasing these new drugs, which you have noted are very expensive, why is there no requirement to buy the drugs in bulk using existing federal mechanisms in order to get cheaper prices?

While I understand there may be other federal health programs that buy pharmaceutical products in bulk, that is not the current system within Ryan White. The reason may be we didn't have these drugs 10 years ago or even 5 years ago. Another reason may have to do with our strong reliance on local control and decision making. This singular aspect of the CARE Act has brought us much success and we believe the evidence suggests it is working. The ADAP program resides within Title II which allows the states great latitude in defining the kinds of services that best meet the needs of the local populations. This flexibility is extended to drug purchasing arrangements as well. Perhaps more study on this question is required in the future but for now — we need to reauthorize this bill and ensure these drugs are getting to those who need them.

6. AIDS Activists —your people have demonstrated against this program saying that it only pays for the high salaries of staff within organizations that do not meet the needs of people with AIDS. Can you respond to this criticism?

My first rule of understanding criticism is to consider the source. This vocal and small group also informs the public — via its web site— that HIV is a “harmless virus” and that AIDS is not caused by HIV. Credibility is an important standard in addressing legitimate criticism. That said — Good stewardship of federal funds is essential in our ability to tell taxpayers and Congress that we are using your resources well. This stewardship requires that certain formalities be in place — namely organizations with competent personnel. In the communities across this country wonderful clinics and AIDS service organizations are doing more with less. Their boards or directors, made up of some of the best people in the communities, are working to be sure public and private resources are being put to the best use.

Drugs do not walk to patients, helping people get one meal a day that allows the nutrition necessary to take an AIDS drug cocktail requires work, helping someone get to and from 10 medical appointments a week requires attention. We need the doctors – in deed we need the best doctors, nurses, social workers, case managers, substance abuse counselors, nutritionists, home health care aides to be helping us manage this epidemic. They need to work within institutions – public or private that are well managed by Executive Directors and Boards. None of us are naive enough to believe any of these services would happen without an incredibly coordinated effort. Program support and administrative overhead with Ryan White is generally capped at 10% or less within the titles. This is really low and we're proud of it. In a recent study by the CAEAR Coalition 1999 anticipated program support and administrative costs for all Title I cities will be 10%. I'll bet that our critics organizational budgets can meet that test.

Can we do better? Yes. We are always looking for ways to get a bigger bang for YOUR buck but today I believe we are doing the best job possible and we'll keep doing that until this epidemic is gone.

7. As a condition of receiving federal funds, some have suggested this bill should require the mandatory testing of all pregnant women and those receiving assistance in medical clinics receiving Ryan White funds and that people testing positive be reported by name to public health officials. What is your position on these requirements?

These are complicated and hotly contested public health strategies and we need to proceed cautiously. In most cases our public health experts at the national, state and local level encourage us to make these decisions locally. Our first response is not to create a national "one-size-fits-all" standard for either mandatory names reporting or testing policy. In the past Congress has traditionally deferred to state public health discretion on these matter and for the past twenty years in AIDS that approach has brought success.

On the issue mandatory names reporting this issue needs to be left to the states for the following reasons:

1. States currently have various forms of HIV surveillance and they are not uniform. CDC has only recently given guidelines for such systems and there must be time allowed for states to make the necessary changes that have been suggested.
2. This would be the first federally mandated surveillance system for any communicable disease. This precedent is dangerous and could seriously erode the trust and confidence we need from affected communities
3. HIV case surveillance by name or identifier is only one of several approaches epidemiologist use to track diseases. Over reliance on one form over another – including the resources it would require to implement such a mandate– would be damaging to the overall effectiveness of the system.
4. CDC recommends name based identifiers but has pledged to work with states and local

public health groups to implement programs that use unique identifiers as an alternative.

If Congress chooses to take action in this area perhaps significant resources should be directed to the CDC to develop a nationwide, effective system of HIV surveillance as an extension of state AIDS surveillance systems. Such a project could be developed and completed by 2003. This step may be our most effective and prudent.

FAX TRANSMISSION

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Fax #: 202-456-2437 Tel #: 202 456 2437 Pages: 29, plus
cover sheet

From: David Brownell
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Subject: Requested mtg's for RW CARE Act
reauth hearings

Comments: _____

- ① Points for 7-21-98 Coburn briefing (Part: Notif/Spousal) - 13 pages
 - ② Exec Summary - OIG report on Spousal Notif - 4 pages
 - ③ Testimony (HDCaule) on Partner Notif (re: Mandatory) - 10 pages
 - ④ Perinatal/newborn testing - 2 pages
- _____
- _____

Does the Secretary think that HIV testing of newborns should be a routine practice?

Giving every child a healthy start in life is the goal we strive to achieve. This starts with good prenatal care and continues through birth and early childhood immunizations. The PHS guidelines recommend that all pregnant women receive HIV counseling and a voluntary HIV test or accept an HIV test for their newborn, so that appropriate care can be provided to both mother and baby. We see pediatricians, obstetricians and nurse midwives working closely together to achieve this good quality of care.

Why doesn't the Federal government require HIV testing of newborns?

The Department strongly encourages pregnant women to learn their HIV status, or to accept an HIV test for their baby. Many studies have shown that most women accept an HIV test once they are told about possible benefits to their baby, and this percentage rises to over 90 percent when a prenatal care provider strongly encourages this test during the course of prenatal care. The IOM study noted that a mandatory approach to testing newborns has limited utility in preventing HIV transmission from mother to child. Mandatory testing of newborns has not been required to achieve the enormous reductions in perinatal HIV transmission to date, and our goal is to bring down to zero the number of new perinatal AIDS cases through the provision of good quality prenatal and perinatal care. In addition, NIH is continuing research to find even more effective ways to prevent perinatal transmission and to increase our understanding of the timing and mechanism involved in mother-to-child transmission.

Does the Department/Secretary think pregnant women should be tested?

Yes. The Department recommends universal HIV counseling and voluntary testing for all pregnant women. These guidelines are being revised to strengthen even more the recommendation that all pregnant women be strongly encouraged to accept the HIV test for themselves and their newborns, if mothers have not been tested.

Why does perinatal transmission continue to occur?

Some children in the U.S. continue to become infected with HIV through maternal transmission. Some of the possible reasons for continuing perinatal HIV transmission include: (1) less than 2 percent of all pregnant women receive no prenatal care. However in a four State study, 14 percent of pregnant women with HIV infection receive no prenatal care. Moreover, 35 percent of HIV-infected pregnant women who use drugs receive no prenatal care, compared with only 8 percent of HIV-infected pregnant women who do not use drugs; (2) some providers still do not offer HIV testing to pregnant women. Reasons cited by these providers include a lack of time and resources, the perception that the woman is not at risk, and legal requirements for pretest counseling; and (3) while test acceptance rates are high and improving, not all women who are offered HIV testing accept it. Some of the major reasons for refusal of testing include the belief that one is not at risk for HIV, and the lack of a provider's strong recommendation for testing. Additionally, some women continue to express mistrust of provider.

information and concerns about being forced to accept testing and/or ZDV chemoprophylaxis.

Q: Why not make testing of pregnant women and newborns and disclosure of test results mandatory?

A: Our 11 year experience with HIV counseling and testing supports our belief that voluntary testing is much more likely to result in positive prevention outcomes than is a mandatory approach. Current regimens to prevent mother-to-child HIV transmission require a pregnant woman to take drugs throughout the 2nd and 3rd trimester of her pregnancy, receive the drug intravenously during labor and delivery, and give it to her baby for 6 weeks after birth. Although HIV testing can be mandated, treatment cannot. Adhering to the regimen for preventing mother-to-child transmission depends, in large part, on a trusting relationship between the woman and her health care providers. Mandatory testing is likely to drive pregnant women away from seeking prenatal care because of the very real fears of discrimination, domestic violence, and severe psychological problems.

**Briefing of Representative Coburn on HIV Prevention Partner/Spousal
Notification Requirements,
July 21, 1998**

- **Public health perspective on partner notification**
- **Review of CDC/HRSA process for certification**
- **Summary of actions taken/planned to be taken by States**
- **Follow-up since certification**
- **Overview of data available to CDC on State partner notification activities**
- **Review of the situations in California, New Jersey, and New York State**
- **Questions and discussion**

Coburn. cur

Public Health Perspective on HIV Prevention Partner/Spousal Notification

- **Spouses and other sex/needle-sharing partners need to be reached, counseled and provided HIV testing and other services.**
- Partner/spousal notification is an essential component of a comprehensive program to prevent HIV infection. CDC has required states to establish standards and implement procedures for partner notification since 1988.
- Generally HIV-infected persons and their partners readily accept partner notification services and, with appropriate counseling, will not only provide confidential, very sensitive information, but will actively assist in finding and encouraging partners and spouses to receive testing and counseling.
- Programs depend on the trust and cooperation of HIV-infected persons to identify and locate sex and needle-sharing partners, including spouses.
- Because HIV is a lifelong infection, potential for exposure to sex or needle-sharing partners exists over the long term and programs need to maintain trusting relationships as they provide counseling and other services to help reduce or eliminate HIV risks.
- Partner/spousal notification will be increasingly important as the effectiveness of prevention efforts and antiretroviral therapies and treatment improve.
- Fear or misunderstanding regarding health department policies and practices could lead to HIV-infected persons not coming forward or not revealing confidential information needed to reach partners and spouses.

Requiring A Good Faith Effort to Notify Spouses of Known HIV-Infected Individuals:

Process for Certification of States

- CDC and HRSA program and legal staff developed proposed procedures and criteria for certifying state compliance.
- Opportunities were provided for input by state/local health department and community representatives into proposed policies/procedures
- Examples of activities were developed that would constitute a minimal "good faith" effort to notify spouses.
- A packet of instructions was mailed to each state, territory, Puerto Rico, and the District of Columbia.
- Each state was required to certify to CDC in writing its intent to comply with the spousal notification requirements. States were also requested to provide a summary of relevant administrative actions taken or other planned activities or legislation.
- Certification submissions were reviewed by CDC staff and also provided to HRSA for their review.
- All states certified compliance prior to the February 1, 1997, due date.

A Good Faith Effort to Notify Spouses

- Examples of a minimal good faith effort were provided to all states and were used as the basis for review of submissions.
- Examples included:
 - Asking all known HIV-infected persons if they have, or have had, a spouse(s) within the 10-year period prior to diagnosis with HIV infection and informing them that they should notify their spouse(s) of the potential exposure to HIV.
 - Making reasonable efforts to determine if each HIV-infected individual intends to notify his or her spouse or agrees to have a qualified health care provider notify them.
 - If the HIV-infected individual is unable or unwilling to notify his or her spouse, making available culturally competent services by the provider or the health department to do so.
 - Developing state policies that address situations involving HIV-infected individuals who do not plan to notify their spouses and who refuse health department assistance. CDC suggested that States refer to the recommendations made by ASTHO regarding the "privilege to disclose" in developing their policies.
 - Implementing reasonable procedures to ensure that spouses receive referrals for HIV testing, other prevention services, and treatment..
 - Establishing agreements between health departments and public and private health care providers to ensure spouses are notified.

Response by States to Spousal Notification Requirements

- All states certified compliance and were taking action to implement.
- No state opposed the requirements or was in any way resistant to implementation.
- States did request more guidance from CDC on program operations and protocols for spousal notification and partner notification in general.

Summary of actions taken or planned to take based on initial responses of states:

- 32 states reported to CDC that their current procedures provided for spousal notification. All agreed to take reasonable actions to require a good faith effort is made to notify spouses.
- 44 sent communications to private physicians.
- 51 were planning special training initiatives.
- 17 states substantially revised protocols.
- [Insert data from NCSL on legislation]

Follow-up Since State Certification of Compliance with

Spousal Notification Requirements

- Beginning in 1997, CDC made compliance with spousal notification requirements a specific condition for HIV prevention cooperative funding of states.
- CDC began a process for developing comprehensive guidelines for HIV prevention partner notification. Draft guidelines will be mailed to all health departments for comment later this month.
- Several states have begun their own process for developing state-specific guidance on HIV prevention partner notification (including Alaska, California, and New York State).
- CDC staff published scientific articles on HIV prevention partner notification in the peer-reviewed journals, emphasizing its importance especially as it relates to primary prevention and linkage of HIV-infected persons to antiretroviral treatment.
- Spousal notification requirements have been reviewed and emphasized by CDC at numerous meetings, conferences and workshops involving state/local HIV prevention programs and national organizations.

HIV Prevention Partner Notification/Spousal Notification:

New York State

- The New York State health department does require a good faith effort to notify spouses as required by CDC and Federal law.
- New York State has reviewed its partner/spousal notification policies and confirms that its programs operate in accordance with national guidelines.
- The State has updated its protocols and training materials and is disseminating materials to promote the availability of partner notification services. Materials explicitly reference spousal notification requirements.
- 9,174 sex or needle-sharing partners, including spouses, were notified and received HIV testing and counseling during the first two quarters of 1997. 396 (4.31%) were found to be HIV infected.
- Statements quoted in the New York Times on January 25, 1998, by New York City health officials incorrectly represented policies of the State.

HIV Prevention Partner Notification/Spousal Notification California

- California renamed its program: "Spousal and Partner Notification" to emphasis spousal notification as a primary objective.
- The State revised its program and operational guidance to reflect the priority of spousal notification.
- It incorporated the spousal notification requirements into all State contracts with local health departments and other organizations to ensure statewide compliance.
- California developed training materials to emphasize the importance of spousal notification. Hundreds of counseling and testing staff will be trained in a statewide (\$520,000) effort.
- The State presented to the California Medical Association and the California Conference of Local Health Officers to address implementation of spousal notification requirements in the private sector. The CMA adopted a resolution strongly supporting partner notification by private physicians.
- California data

HIV Prevention Partner Notification/Spousal Notification New Jersey

- New Jersey asserted that administrative actions, policies, and practices have existed since 1988 which require a good faith effort to notify spouses. They have since reported to CDC that they are requiring a good faith effort as required by Federal law.
- State legislation was introduced in November 1996 to formally authorize HIV prevention partner notification, but did not pass.
- 3,788 sex or needle-sharing partners, including spouses, were notified and received HIV testing and counseling during the first two quarters of 1998; 173 (4.56%) were found to be HIV infected. Situations involving HIV-infected persons who refuse to notify, or consent to allow the health department, are extremely rare.

Partner Counseling and Referral Data

- All States and territories must provide counseling, testing, and partner notification and referral services as a condition of receiving CDC HIV prevention funding.
- There is no national database with comprehensive information on Partner Notification/Spousal Notification activities. However, States, Territories and local areas participate in a national data system including more than 2 million tests annually reported from nearly 10,000 publicly funded counseling and testing sites.
- While this system does not differentiate spouses from others who are sex or needle-sharing partners, it does list the reason for seeking HIV counseling and testing services including as partner referral or provider referral. It also tends to underestimate the number of persons who are referred by partners.
 - Of the 81,999 tests reported for 1996, 35,260 were referred by their partners, and 46,739 were referred by the health department; more than half were female.
 - 4.0% were HIV seropositive.
- In the first two quarters of 1997, 68,556 tests were reported. Of these, 29,896 were referred by partners, and 38,660 by the health department; like 1996, more than half were female.
 - 3.6% were HIV seropositive.
 - The 1997 partial year figures, if projected for a 12 month period, will show a significant increase in the number of partners who were referred.

Spousal Notification Conferences

Spousal notification requirements have been reviewed and emphasized by CDC at numerous meetings, conferences, workshops involving state/local HIV prevention programs and national organizations including:

September 1996- April 1997	Numerous teleconferences with State AIDS program directors
October 1996	Scientific consultation on Partner Notification for HIV and other STDs
December 1996- June 1997	Multiple State site visits by CDC
June 1997	External expert consultation to develop principles for CDC guidance for HIV Prevention Counseling and Referral Services
June 1997	National Organization Consultants
October 1997	HIV Satellite Prevention Teleconference reaching 12,000 health care providers nationwide.

March 1998

1998 HIV Prevention Summit
meeting of 1,100 community
planning co-chairs

July 1998

Follow-up assessment of State
programs begins

Achieving an Optimal Partner/Spousal Notification Program in the United States

- States have clearly complied with Federal law requiring that a good faith effort be made to notify spouses of known HIV-infected individuals of their exposure to HIV. — These efforts form the basic foundations of a program.
- States are supportive of increased efforts to reach, counsel, test, and refer spouses and other sex/needle-sharing partners at high risk for HIV. Almost all are trying to make this activity a high priority component of their comprehensive efforts to prevent HIV.
- Achieving an optimal program versus meeting the minimal requirements of current law will require increased counseling and testing services, substantial increases in trained counselors, more access to antiretroviral treatment and other needed services, establishment of new data collection systems, and the resources to cover the costs of such a large, but urgently needed program.

Department of Health and Human Services

**OFFICE OF
INSPECTOR GENERAL**

DRAFT

THE RYAN WHITE CARE ACT

**Implementation of the Spousal
Notification Requirement**

JUNE GIBBS BROWN - INSPECTOR GENERAL

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MAY 1999

OEI-05-98-00391

EXECUTIVE SUMMARY

PURPOSE

To identify whether States are implementing their approved plans to ensure a good faith effort is made to notify spouses of persons infected with HIV of their possible exposure.

BACKGROUND

Section 8 of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act requires that any State receiving Ryan White Title II funding take administrative or legislative action to require a *good faith effort* be made to notify current and former spouses of known HIV-infected patients of possible exposure. A State that does not comply with this requirement will lose its Title II funding. Title II provides funds to States for health care and support services for those with HIV and AIDS. The total Title II appropriation for FY 1999 was over \$709 million.

Each State provided the Centers for Disease Control and Prevention (CDC) with information on existing or planned legislative and/or administrative actions in order to comply with Section 8 requirements. The CDC approved the certifications of compliance submitted by all 50 States, the District of Columbia and U.S. territories. We assumed that CDC's approval of certifications indicates State activities constitute a good faith effort as required.

The requirement for States to make a "good faith effort" does not mandate that all spouses of HIV positive individuals be notified, but does require States to establish procedures which facilitate faithful attempts to notify all impacted spouses.

States have administered HIV and STD partner notification programs which included spouses for many years. The activities to which States certified were both ongoing efforts and additions to their notification programs which were designed to specifically address spousal notification requirements.

We reviewed all 51 State certifications. We collected documentation and conducted site visits with State public health staff and HIV test site counselors in six States with high prevalence of HIV cases. Additionally, we interviewed and collected documentation from State public health staff in five randomly selected States.

This evaluation was conducted at the request of Congressman Thomas Coburn.

FINDINGS

The 11 sampled States have taken action on their approved plans

All sampled States have followed up on certified activities, including revising counseling guidelines and contract language, updating training materials, retraining counselors and informing providers about changes due to Section 8 of the Ryan White CARE Act. Some States have initiated additional notification activities not contained in their original certifications.

States are responding to common barriers

Efforts to notify spouses and partners of persons with HIV are hampered by legislative and administrative barriers, by the structure of State and local governments and by physician, counselor and patient concerns. States have responded to barriers by offering freedom from liability for providers who notify, and by organizing elicitation and notification programs to fit into existing governmental and health care structures. Some States offer training for physicians and counselors, and make efforts to explain the process and benefits of notification to persons newly diagnosed with HIV.

Several States are undertaking promising notification efforts

While all sampled States have done what they certified to, several States have taken actions which appear particularly useful or successful. Several States have made efforts regarding provider and counselor training, data utilization and notification efforts which balance informing partners and maintaining confidentiality for index cases.

Data collection is limited and uneven

None of the 11 sampled States collects data specifically on the number of spouses who have been notified of their HIV exposure risk. Five sampled States collect data on partner notification. The six others currently do not collect notification data as part of their programmatic efforts. Three of these States are currently developing or piloting data systems. In at least one State which does not collect data at the statewide level, some counties collect local data on notification.

RECOMMENDATIONS

While States have taken action on their certifications, their efforts do not completely insure that vulnerable people are always made aware of their possible exposure to HIV. Based on our findings, additional efforts need to be undertaken to insure maximum notification while ensuring confidentiality.

Continue to facilitate understanding of notification efforts through publicity, education and training

The CDC currently engages in public education efforts on a number of HIV-related issues. To increase knowledge for all parties, we recommend that CDC augment its current efforts by facilitating targeted education campaigns and provider trainings.

Establish a national effort to publicize notification goals, efforts and benefits.

Publicizing information about notification nationally can increase awareness and broaden acceptance of the purpose and benefits of informing spouses and partners about their HIV risk. We recommend that CDC establish targeted public affairs efforts for providers, HIV advocacy groups and the public. Spouse and partner notification should be addressed at senior levels in the department, and information about State efforts should be conveyed to the general public in a manner that increases the issue's acceptability.

Facilitate local cooperation and collaboration. We recommend that CDC facilitate local level collaboration between State and local public health departments and private providers. Over 80 percent of HIV tests are conducted in the private sector. Training, technical assistance and other written and oral guidance can help public health departments and private providers understand the process of spouse and partner notification, their roles in the process and the benefits of partner notification.

Share good practices, replicable efforts

We recommend that CDC facilitate the sharing of information about successful State notification practices, including training, data collection and other efforts which enhance spouse and partner notification outcomes. The CDC should sponsor multi-State meetings on notification issues and efforts, and encourage the spread of promising practices.

Encourage the establishment of data collection systems

We recommend that CDC encourage the development and use of data collection systems to monitor State spouse and partner elicitation and notification efforts. Information collected provides a snapshot of what efforts are working and which may need more attention. The agency should facilitate the development of pilot and full-scale data collection programs, identifying successful State data collection efforts and facilitating information sharing between States on notification data collection issues. Data on elicitation and notification can be aggregate information which does not require States to collect and store identifying information on partners or index cases. Due to the substantial costs involved in data collection, the above recommendation is contingent on the availability of funding.

TESTIMONY OF
HELENE D. GAYLE, M.D., M.P.H.
DIRECTOR
NATIONAL CENTER FOR HIV, STD,
AND TB PREVENTION
CENTERS FOR DISEASE CONTROL AND PREVENTION
DEPARTMENT OF HEALTH AND HUMAN SERVICES

before the

SUBCOMMITTEE ON HEALTH AND ENVIRONMENT
COMMITTEE ON COMMERCE
U.S. HOUSE OF REPRESENTATIVES

September 29, 1998

I am Dr. Helene Gayle, Director of the National Center for HIV, STD, and TB Prevention at the Centers for Disease Control and Prevention. Thank you for the opportunity to testify today about issues related to HIV prevention partner counseling and referral services in the context of H.R. 4431, the HIV Partner Protection Act. I'm especially happy to be here because it's an opportunity for me to share with you CDC's updated guidance on HIV partner counseling and referral services -- which has just been released for public comment.

However, before we focus on partner counseling and referral services, let me briefly describe the major goal of HIV prevention in this country and the sound public health approaches that we think are needed to achieve this goal. Our goal is to prevent HIV infection by reducing behaviors likely to transmit the virus and assisting individuals at risk or already infected in gaining access to prevention services, medical care, and other needed services. This ambitious goal can be achieved only by using a comprehensive strategy. Elements of this strategy must include monitoring the epidemic; informing the public regarding risk and modes of transmission; conducting health education and risk-reduction activities, including school-based education efforts for youth; promoting and implementing HIV prevention counseling and testing; providing referrals for medical treatment as well as prevention and social services; and promoting and implementing STD screening and treatment. An essential component of HIV counseling and testing is reaching out to and counseling sex and needle-sharing partners of persons identified as HIV positive. These partners are often unaware that they have been exposed to HIV and some may already be infected. All must have access to counseling, testing, and other prevention or treatment services. Each of these elements contributes to preventing the spread of HIV. Together, they become a powerful prevention strategy. No single activity, by itself, will achieve the overall goal of preventing new HIV infections.

I will briefly describe CDC's current recommendations for partner counseling and referral services, or PCRS, and our current requirements for programs providing these services. The goals of PCRS are, first, to provide services to sex and needle-sharing partners of HIV-infected individuals so they can avoid infection or, if already infected, can prevent transmission of HIV to others; second, to help HIV-infected partners gain earlier access to counseling, medical evaluation, and other prevention, treatment, and support services. CDC has required States to establish standards and implement procedures for PCRS since 1988, when it was referred to as "partner notification."

PCRS is a process that begins when people receive HIV prevention counseling and testing. If a person tests positive, the PCRS provider and client together formulate a plan for reaching any sex or needle-sharing partners. The plan should be one that will result in each partner's being informed of possible exposure to HIV and provided with accurate information and counseling about HIV transmission and prevention. Next, the HIV-infected client voluntarily discloses identifying information about partners, and the client and/or the provider informs each partner of possible exposure to HIV. The next step is really the core of PCRS practice: assisting the partner in accessing additional counseling, testing, and other support services. Throughout this process, the confidentiality of the infected person's identity and that of their partners must be preserved.

Let me elaborate on a critical point here that has always been a cornerstone of partner services for HIV and all other STDs. The PCRS process, by its nature, is a voluntary one on the part of the client. A client who tests positive for HIV or any other STDs cannot be mandated to reveal names of partners. In the wake of receiving an HIV-positive test result, clients may fear

discrimination, abuse, or domestic violence; they may fear the loss of a job and health insurance or the loss of important personal relationships. The success of the PCRS process absolutely hinges on the trust and cooperation of the person living with HIV, their partners, and their communities. We know that people will cooperate if they believe that their confidentiality will be protected; otherwise they may avoid the system altogether. The way to maximize the public health benefit is to have a valuable service -- one with skilled counselors fully supported by adequate resources -- that people perceive as beneficial and easy-to-use.

Partner counseling and referral services related to HIV infection have evolved from similar services, known as "contact tracing," that were begun in this country in the 1930s as a method of preventing the spread of syphilis. This prevention effort was called contact tracing because public health workers would, and still do, conduct analyses to determine which sex partners were most likely to be infected and then make confidential efforts to locate them and provide treatment. Contact tracing services later expanded to include partners of persons infected with gonorrhea and other sexually transmitted diseases, including HIV, and came to be known as "partner notification" in the 1980s. Today, the term "HIV partner counseling and referral services" more accurately reflects the range of services available to HIV-infected persons, their partners, and affected communities through this essential public health activity.

But of necessity, PCRS for HIV differs from partner services for other STDs. The primary difference is that, despite recent advances in treatment, we do not yet have a cure for AIDS, so HIV, unlike syphilis and gonorrhea, remains a life-long issue for those affected. For HIV-infected persons, PCRS needs to be continuously available. The process begins as soon as an HIV-infected person learns their serostatus, and it continues throughout that person's

counseling and treatment. Also, because society frequently stigmatizes and sometimes discriminates against HIV-infected persons and their families and friends, counseling and support must be provided for clients who choose to notify their own partners. For exposed partners who test positive for HIV, PCRS provides assistance in reducing risks posed to others and accessing medical evaluation, treatment, and other prevention and support services to prolong life. As new prevention tools emerge, such as vaccines, better behavioral interventions, and even more effective antiretroviral therapies, PCRS will almost certainly become an even more important prevention tool.

States, territories, and local areas contribute to a national data system maintained by CDC that includes information on more than two million HIV tests reported annually from nearly 10,000 publicly funded counseling and testing sites. While this system does not differentiate spouses from others who are sex or needle-sharing partners, it does record the reasons for seeking HIV counseling and testing services, including referrals by partners and health departments. In 1996, 81,999 tests were conducted for people who were referred for PCRS; of these, 35,260 (43 percent) were referred by their partners, and 46,739 (57 percent) were referred by the health department. More than half of all the people referred were female. Many of these persons did not realize they might have been exposed to HIV and thus did not consider themselves at risk for infection until they received the referral. Nationally in 1996, 4 percent of these referred partners tested HIV seropositive, and in some areas up to 15 to 20 percent were HIV positive. This represents a much higher rate than the national average of 1.5 percent who tested HIV positive at publicly funded test sites that year. These data underscore the importance of the PCRS process in reaching high-risk populations and providing individuals with the critical

linkage to appropriate prevention and treatment services. The data also illustrate the degree of success PCRS has already demonstrated.

Concerning the effectiveness of PCRS, we know that, in general, HIV-infected persons and their partners readily accept PCRS and, with appropriate counseling, will not only provide confidential and very sensitive information, but will actively assist in finding and encouraging partners and spouses to receive counseling and testing. Also, when located, sex partners are generally receptive to confidential notification by the client or the health department and will usually seek HIV testing. Another indication of the efficacy of PCRS is the fact that many people at high risk for infection are linked by this process to prevention services that have been proven to be effective.

Notwithstanding these benefits to public health, it is also important to note the practical limitations of PCRS. Frequently it is difficult or impossible to determine exactly when a person became infected with HIV and when specific sex or needle-sharing partners were exposed to the virus. During the potentially long period during which the virus could have been transmitted, the HIV-infected person may have had many partners. In addition, the HIV-infected person may not be able to identify all partners or know how to reach others who are known. Because of the long time periods involved, often it is difficult for the client or health department to locate all the partners, especially those exposed years earlier. Also, while many HIV-infected persons willingly participate in PCRS, fear or misunderstanding of health department policies and practices may keep some HIV-infected persons from coming forward or revealing information needed to reach partners and spouses. Another limitation is the lack of human and financial resources in the public health arena necessary to carry out this important prevention activity.

Let me now describe some of the numerous ways that CDC has been working to further strengthen and enhance PCRS activities. As a result of the reauthorization of the Ryan White legislation, each State is required to certify to CDC in writing the State's intent to comply with the spousal notification requirements contained in the legislation. Programmatic and legal staff of CDC and the Health Resources Services Administration have developed procedures and criteria for certifying each State's compliance with Ryan White CARE Act requirements that mandate that States make a good faith effort to notify spouses of known HIV-infected individuals. All States certified compliance by February 1997 and have taken action to implement spousal notification. No state opposed the requirements.

In addition to the specific activities related to spousal notification, CDC also provides technical assistance and guidance to help States achieve optimal performance in their PCRS programs. Spousal notification requirements have been reviewed and emphasized by CDC at numerous meetings, conferences, and workshops involving State and local HIV prevention programs and national organizations. CDC has published scientific articles on HIV prevention partner notification in peer-reviewed journals, emphasizing its importance, especially as it relates to primary prevention and linkage of HIV-infected persons to treatment. CDC has delivered training on PCRS through a satellite video conference and at national conferences, and training is currently being conducted at State and local health departments for staff who implement PCRS programs.

As I mentioned at the beginning, CDC, with input from a wide range of partners, also has developed comprehensive guidelines for HIV PCRS and recently mailed the draft to all health departments for comment. The HIV Partner Protection Act of 1998 and this new PCRS

Guidance share important goals of notifying partners, including spouses, who may have been exposed to HIV and linking them to appropriate prevention and medical services. CDC believes that the new PCRS Guidance elevates partner counseling and referral services to a higher standard of public health practice and a greater degree of potential effectiveness. We will receive comments on the Guidance and will then finalize and implement it. If fully funded with adequate resources, we believe that PCRS would be very effective in achieving the goal of the HIV prevention while enactment of legislation such as the Partner Protection Act of 1998 would not add further public health benefit.

Let me now briefly address some other issues related to the HIV Partner Protection Act. The Act departs from the CDC Guidelines and science-based public health practice by mandating reporting of all HIV-positive tests, by client name, without any provision to support the continuation of anonymous testing. The resulting effect will be to discourage and drastically reduce anonymous testing opportunities. Anonymous testing has been strongly encouraged by CDC Guidelines and is integral to public health practice because it has been proven to bring people for testing earlier in the course of infection and also bring in people who might never access such services or who might access them only when symptoms of disease develop. CDC currently recommends that people who test positive in anonymous settings be linked with medical care so they can receive life-prolonging clinical services. In States that require name reporting, the names of clients who tested positive anonymously are reported to State health departments at the point of interacting with medical care providers.

In addition, we are concerned that directive legislation may inadvertently constrain the application of sound public health activities that require greater flexibility. For example, studies

have shown that clients might fear having their partners notified because they have reason to anticipate a violent reaction from the partner. Providers must be sensitive to the threat of violence and other issues of concern to the client. PCRS providers should have the flexibility to make an assessment prior to notifying the partner and seek expert consultation before proceeding with notification. Legislative mandates could decrease the flexibility that public health staff require to apply sound judgment in complicated situations, as are frequently encountered when providing PCRS, especially those situations involving the potential for interpersonal violence. Passage of this or other legislation that might reduce this flexibility could prevent clients who fear such violence from seeking counseling and testing for HIV.

What then are our recommendations? We would like to have the opportunity to implement the new PCRS Guidance and then evaluate its outcomes and impact. CDC will provide technical assistance to State and local programs to build the service delivery capacity of PCRS programs and will continually assess PCRS practice across the country as programs are further developed and strengthened. Knowing the subcommittee's interest and concern, we would be happy to provide a progress report in six months from the date the Guidance is finalized, which we anticipate to be by year's end.

CDC is committed to strengthening HIV prevention efforts in reaching sex and needle-sharing partners, providing them with counseling about prevention, and, if they are infected, linking them to medical care and treatment. For this to be accomplished, CDC could support State and local health departments in expanding counseling and testing services, increasing the number of skilled counselors who establish that all-important trust with clients, providing more access to antiretroviral treatment and other needed services, and establishing new data collection

systems. A significant investment of resources is needed to cover the costs of this large but essential piece of a comprehensive HIV prevention strategy.

Thank you for the opportunity to present our views on this important public health topic. I will be glad to respond to any questions you or other members of the subcommittee may have.



1242 market street. s.f. ca 94102
tel 415. 487. 5777 fax 415. 487. 5771

Sandy Thurman
Director
Office of National AIDS Policy
808 17th St., NW #820
Washington, DC 20006
via fax: (202) 632-1096

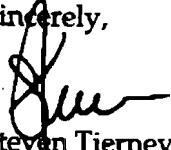
Dear Ms. Thurman:

I am writing to ask you to support increased funding for Title IV of the Ryan White CARE Act for FY 1999, as well as funding increases for other titles of the Ryan White CARE Act. Title IV projects that support confidential social services, primary medical care and access to research for children, youth and families reach 338 sites in 27 states, the District of Columbia and Puerto Rico. Title IV sites serve an estimated 50,000 HIV infected and affected children, youth, at-risk youth, women, men and families. Demand for services has tripled during the past three years.

This year the White House focused a great deal of attention on the growing needs of youth and pregnant women living with HIV/AIDS. Title IV, as stated in White House reports, is vital to addressing these needs. Over 75% of Title IV projects provide direct primary medical care to children, youth, at-risk youth and pregnant women with HIV and AIDS. Medicaid does not fully reimburse Title IV projects for costs of primary medical care. Over 65% of Title IV projects are the principle source of primary medical care for children, youth, at-risk youth and pregnant women with HIV and AIDS living in their geographic areas. Our program, through a collaborative effort of ten different youth-serving agencies within the Project Alliance for the Health of Adolescents framework, provides direct primary medical services and social services to over 200 HIV positive youth in San Francisco. As a Ryan White CARE Act Title IV project I can tell you that our program is vital to our community.

Women and youth are the fastest growing population infected and affected with HIV in the United States and need greater access to Title IV projects. Additional funding for Title IV will support increased primary medical care and participation in clinical research by children, youth and women with HIV, particularly African-Americans and Latinos. I strongly urge you to increase funding for Title IV and all titles of the Ryan White CARE Act.

Sincerely,


Steven Tierney
Executive Director,
Health Initiatives for Youth

cc: AIDS Policy Center

*Sandy -
Happy Holidays -
I'll see you in 98
for drinks with Toak!
Cheers
A*



1242 market street, s.f. ca 94102

tel 415. 487. 5777 fax 415. 487. 5771

Facsimile Coversheet

TO:

SANDY THURMAN

AGENCY:

OFFICE OF NATIONAL AIDS POLICY

FAX#:

202-632-1096

FROM:

Brett VanBenschoten
Project Assistant, Project AHEAD

PHONE:

415-487-5777 Ext. 22

FAX:

415-487-5771

TOTAL PAGES:

2

(INCLUDING COVER SHEET)

DATE:

12/19/97

COMMENTS:

NASTAD

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS

PRIORITY**FACSIMILE TRANSMISSION**

632-1096

to

Sandra Thurman

from

B. J. Harris

date

11/20/97

page/s to follow

4

- ☒ As requested
- ☐ Review and comment
- ☐ As discussed
- ☐ Please respond
- ☐ For your information

If transmission is not
complete, please call
202-434-8090

comments

PRIORITY

NASTAD

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS

MEMORANDUM

DT: November 20, 1997

TO: Sandra Thurman, Director, Office of National AIDS Policy

FR: Joseph Kelly, Deputy Director, NASTAD 
B.J. Harris, Director of Government Relations, NASTAD 

RE: FY 99 Funding Requests

As requested, attached are preliminary FY 99 HIV/AIDS budget recommendations from the state AIDS directors. These figures include funding recommendations with justifications for the Centers for Disease Control and Prevention's HIV prevention, surveillance, and STD programs as well as state Title II core funding needs for the Ryan White CARE Act.

We are still in the process of calculating state ADAP resource needs for FY 99. You can expect a preliminary figure for this in the next day or two. We are consulting with the state programs and treatment advocates to arrive at a consistent number.

We hope the attached information is helpful and we look forward to working with you.

If you have any questions, please contact B.J. at 434-8068.

Attachment

Preliminary FY 1999 HIV/AIDS Budget Recommendations from State AIDS Directors

Centers for Disease Control and Prevention

HIV Prevention

High priority needs identified by state AIDS directors to support HIV prevention programs through the cooperative agreements with state and local health departments in FY 1999 include the following items. **An additional \$90 million in FY 99 is required to address these issues:**

- **HIV prevention for substance users** - Additional support for substance abuse treatment and other harm reduction interventions is consistently identified as a very high priority among AIDS directors.
- **Targeted prevention for subpopulations** - AIDS cases have not declined for all populations. Increased funding is needed for HIV prevention targeting the "emerging" at risk groups including women of color at risk, youth in high risk situations, and gay men of color, in addition to continued funding of prevention for the well-recognized at risk groups.
- **Enhanced HIV counseling and testing** - The availability of effective treatment is prompting a renewed interest in counseling and testing programs funded with public support. Project areas are interested in utilizing new testing technologies - oral testing and rapid tests - in non-clinical settings and require funding for training and implementation of these new testing modalities. Funding for more targeted counseling testing including aggressive outreach and mobile units is also needed.
- **Implementation of new CDC program guidance** - CDC is issuing new program guidance for both partner notification and prevention case management programs. Resources are needed to enable states to implement the new guidance and expand and enhance these prevention interventions. In particular, states have expressed a great interest in expanding HIV prevention services targeting HIV infected people and their sexual/needle-sharing partners through both partner services and prevention case management.
- Broadcast and print media materials for use with general public that can be locally adapted as well as support for the translation of these materials into multiple languages.
- Enhanced funding for evaluation of HIV prevention models and interventions and dissemination of "what works" to jurisdictions.

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Sandra Thurman

NASTAD Preliminary Budget Recommendations

HIV Surveillance

High priority needs identified by state AIDS directors to support HIV and AIDS surveillance activities in FY 1999 include the following. **An additional \$30 million is needed to undertake these efforts:**

- Guidance and funding from the CDC for implementation of active HIV case reporting in all jurisdictions.
- Continued funding for population-based blinded serosurveys in hospitals, drug treatment clinics, STD and adolescent health settings.
- Increased funding for behavioral surveillance to learn more about changes in behavior related to HIV prevention.
- Increased funding for perinatal surveillance in the absence of the SCBW.

Therefore, the total requested funding for HIV prevention and surveillance programs for FY 99 is **\$120 million** greater than the FY 98 level.

STD Programs

An additional \$60 million is needed to fund STD programs adequately. Priority should be given to the following activities:

- Increased funding for syphilis elimination in areas across the country with high incidence, particularly in the south and rural areas.
- Increased funding for screening women including urine screening for GC and Chlamydia and single dose therapy.
- Support for STD surveillance.
- Support for behavioral interventions for people at risk for STDs.
- Expanded partner notification services for all STDs not just syphilis and gonorrhea.
- Improved outreach services with incorporation of less invasive testing modalities.
- Increased flexibility for states to determine priorities for STD funding based on the state's STD epidemiology.

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Sandra Thurman

NASTAD Preliminary Budget Recommendations

Health Resources and Services Administration

Ryan White CARE Act, Core Title II Program

High priority needs identified by state AIDS directors to support core Title II programs in FY 1999 which would require **an additional \$85 million in Title II core funding above FY 98 levels:**

- **Primary care, including viral load testing and monitoring** - Viral load testing continues to be an additive cost that is borne by the Title II programs - particularly in providing reimbursement for lower cost state laboratory processing of viral load tests.
- **Rural primary care services** - Many states are needing to bolster HIV care services which are in rural areas which may be outside of managed care environments. In addition, transportation to and from care services for individuals eligible for Title II services is a continuing problem area in more remote areas of larger rural states.
- **Expanding insurance continuation and insurance purchasing programs** - Approximately 30 states have high risk insurance pools for individuals who are deemed uninsurable, and approximately 20 of those states now use their high risk insurance pools as an alternative mechanism of guaranteed issue of insurance for Health Insurance Portability Act eligible individuals. This option is opening up in more states and states need to augment their use of federal funds for this purpose. In the state of Minnesota, which has a well-funded state insurance program, funds are limited to those who are disabled. Use of more flexible federal dollars is viewed as critically important to fill the gap for those people who are not HIV symptomatic.
- **Enhanced case management** - Competent, well-trained case managers are needed to help people living with HIV to navigate the increasingly complex social services and medical care systems. The complications and barriers to care which are the result of recent legislation such as welfare reform and immigration laws, the complexity and expense of drug treatment regimens, and the managed care version of Medicaid, all combine to make increased case management assistance needed for many clients of Title II service programs.
- **Job training and employment readiness** - This is cited as one of the major emerging needs in state and local Title II programs. Unfortunately, HRSA has not yet made a favorable determination on the flexible use of CARE Act funds for vocational rehabilitation. State programs report that they lack other funding streams with which to provide these services. For example, New York State reports that although the state receives \$400 million in federal funding from the Department of Labor for vocational programs to implement welfare to work, none of those dollars is available to establish HIV-specific welfare to work demos. These would be potentially cost-effective services to provide given the feasibility of getting people on more stable forms of insurance.



FAX TRANSMITTAL

DATE: 3/7/00

TO: Sandy Thurman

FAX #: 456-2438

FROM: Thomas Sheridan

3 PAGES INCLUDING COVER SHEET

NOTE:



TO: SANDY THURMAN
FROM: TOM SHERIDAN
RE: PRESIDENTIAL "BULLY PULPIT"
DATE: 6 MARCH 2000

As you and I have discussed on numerous occasions, there is an urgent need to engage the President and the "bully pulpit" of the White House on the need to re-authorize the Ryan White CARE Act in the earliest days of this Congress.

There is serious disappointment that the President did not avail himself of opportunities created around World AIDS Day or the State of the Union address to accomplish this goal. However, there are still ample opportunities for the President to join in a bi-partisan call for the prompt re-authorization of the nation's centerpiece AIDS policy.

As you know it is critical that the Senate pass a bill before the end of March. The ability to produce such a document and rally the support is greatly assisted by the annual AIDS Watch event scheduled for March 26-28. On those dates 600 advocates will be in town. We are asking our Senate champions (Jeffords and Kennedy) to attempt to have the bill on the Senate floor no later than March 28. There may be opportunity for the President to meet with leaders on the morning of the vote to create press attention and place the support of the White House behind this bill. Similarly, advocates will be in town the Saturday prior to AIDS Watch (March 25) and the President could use his weekly radio address to assist in moving the public debate and the Senate toward passage. My personal belief is that the community is at its strongest in the Senate and with AIDS Watch as an advocacy event. Optimistically, our hope is to extract commitments from Senate leaders in the next two weeks. If we are successful, Presidential leadership is very helpful and welcome, however not critical at this point. If the Senate gets stuck- the President's assistance in moving the Senate will become more critical.

The House of Representatives is our more serious challenge and appears to be where presidential assistance will be more necessary. After the Senate has completed action on a bi-partisan and nearly unanimous bill we can use the President most effectively by actually doing a Ryan White CARE Act event in a location that provides a backdrop to the services the bill provides. My guess is that by the first few weeks of May we'll know exactly how well or poorly the bill is doing in the House and what exactly the President can say to assist. To that end, the San Francisco

AIDS Foundations Annual dinner is scheduled for **Thursday, May 11, 2000** and is worth trying to secure a commitment from the White House for the President to attend.

I would strongly recommend that the President consider going to this event and promoting the message of re-authorizing the CARE Act. Should this date not work for the President then any event during the first 15 days of May would be helpful. We can examine possibilities based on the Presidents travel schedule or I can provide you with a list of events during this time frame that might provide venues for a presidential event. Timing is critical.

Your timely response to these ideas and suggestions would be greatly appreciated.