

Governor's Advisory Council on HIV/AIDS

Report of the Bellingham, Washington HIV Update Forum Findings and Recommendations

Background

The Governor's Advisory Council on HIV/AIDS conducted a public forum in Bellingham on September 12, 2006. The forum was conducted to assess current HIV/AIDS prevention and treatment services in the five counties (Whatcom, Island, San Juan, Skagit and Snohomish) of northwest Washington and to help determine whether those services are meeting the needs of area residents, particularly in the Native American communities. (A meeting agenda with a list of forum participants is attached as Appendix A.)

Summary of Key Findings

As of August 31, 2006, Region 3 had 781 presumed living cases of HIV/AIDS. As of August 31, 2006 there were 9311 persons living with HIV/AIDS in Washington State. This number has been increasing about 5% annually since effective treatments became available.

Newly diagnosed cases of HIV infection in the five counties of AIDSNET Region 3 (northwest Washington,) were averaging 45-55 a year in 2000-2004, but increased to over 60 new cases in 2005. This spike in new cases—while alarming—is not yet indicative of a trend of rising HIV infections. Epidemiologists caution that when the actual number of cases is small, as it is in Region 3, more time is required to determine whether the increase is an aberration, or an indication.

While the majority of the newly diagnosed cases are among men who have sex with men, women represent 21% of the new cases—a proportion higher than the state as a whole. Most of the cases among women are the result of exposure through heterosexual contact, again a higher proportion than statewide. The partners of these women are likely to report injection drug use; or identify themselves as bisexuals. A majority of the new cases (63%) are 30-49 years of age.

As is the case statewide, the majority of those living with HIV/AIDS in Region 3 are white. Blacks represent 9% of the cases, yet they make up only 1% of the region's population. The infection rate among blacks is seven times higher than among whites.

Region 3 has 12 tribes, the state's second highest proportion of Native Americans and Alaska Natives. Their infection rate is twice that of whites. A higher percentage of Native American and Alaska Native cases are among women, and the result of exposure through injection drug use.

Provider Services and Access to care for HIV+ 's

As is the case statewide, public dollars in the region available for HIV prevention, treatment and care services are shrinking and are not keeping up with the increasing numbers of persons living with HIV/AIDS.

But the care infrastructure in northwest Washington—while squeezed—is solid. There is excellent cooperation and coordination between county health departments; the Evergreen AIDS Foundation; the tribes; and Bellingham's Title III funded clinic—the Interfaith Community Center—which is considered an essential leg in the region's care infrastructure.

Region 3 is trying to better target its shrinking prevention dollars, by more aggressively seeking to test among people at the highest risk.

There is a belief among providers that public dollars could be better utilized if monies were awarded directly to the counties instead of filtering through the state; but this may be problematic given the status of current state and federal laws governing the funding mechanisms. (A further discussion of this point is found in the "Complete Findings" section of this report.)

Funding issues aside, the biggest barrier to prevention and care services is a "barrier of fear," grounded in the religious and cultural values of the mostly rural region. There are other issues.

As elsewhere in the state, many people with HIV, who are dependent on the public infrastructure for assistance, have multiple other health problems; such as drug use, mental health or developmental disabilities.

As in other rural areas, transportation is a barrier to care, with many unable to afford private transportation and limited and difficult public transit options.

Access to both mental health and dental providers is difficult.

There are too few Medicare and Medicaid providers—with low reimbursement rates cited as the reason. For clients of the Early Intervention Program (EIP,) and the uninsured, referrals to specialists are virtually impossible.

Some Region 3 patients prefer to seek treatment in Seattle (at Harborview) because of the stigma of seeking care in their own smaller communities and perceptions that care in Seattle may be better.

There was praise for the Snohomish County Health department's case management efforts, but concerns that an increasing caseload has now mandated that it no longer serve Region 3 clients who don't actually reside within the county. This creates a "funding silo" which shuts out some rural clients.

While there was near universal praise for the region's Title III clinic (Interfaith Community Center,) testimony was received that waits for providers at the center are too long; that there are not enough doctors or dentists; and that it is unable to respond to emergencies. The region's AIDS service organization (Evergreen) was lauded but, in one instance, was also criticized as disorganized; unresponsive; and failing in individual instances to provide adequate case management. "Should the region not have a standard of care?"

There was also testimony that the region's planning council and one of the region's care consortia are not representative of real consumers, and that GACHA itself did not devote enough of its forum time to communicate with consumers. (All public testimony is included as Appendix B.)

In a written response (Appendix C) to the public testimony, the Interfaith Community Health Center noted that its policies prohibit public comments on individual patient complaints, but Interfaith stated it regularly monitors the quality of its care through a Continuous Quality Improvement program (CQI.) The CQI tracks multiple service indicators including patient satisfaction, health and safety issues, access to care and ease of making appointments. If data indicates the center is falling below standards, improvements are implemented.

The Region 3 Planning Council does include consumer representatives as well as non-conflicted community representatives. Consortia within the region are involved in discussions aimed at increasing consumer representation.

HIV in the Native American Communities

Within the Native American communities, there is only "vague" awareness of HIV. HIV remains stigmatized; so much so that most tribe members prefer to seek services elsewhere, such as the Interfaith clinic or through Evergreen. Alcoholism is a contributing factor to HIV infection within the communities.

Those providing HIV services within the communities believe more HIV testing, particularly among women, is critically needed.

Given limited resources, it is difficult for an individual county, particularly a small county which may have four tribes within its jurisdiction, to effectively serve the Native American community. A regional effort would be a more beneficial approach.

The Lummi Nation does not spend any of its own health care funds on HIV prevention or care, citing the demands of other health issues such as diabetes and alcoholism. The HIV budgets of other tribes were not determined. Some of the tribes are working together on HIV and other health issues; but overall there is no coordinated effort.

Grants would be helpful to address these issues in the Native American community, but those available are too large for individual tribes to successfully win. Smaller-need grants could help fill the void.

In later discussions, it was learned that Project Red Talon, a Portland-based Native American organization does provide some regional coordination for the tribes but the extent of the project was not determined.

Other Issues

All five counties within the region offer needle exchange programs, but none are pharmacy based.

There is quiet resistance to HIV testing in jails, because that would mandate treatment and the funds are lacking to provide it.

Recommendations

- 1. The governor should facilitate coalition building among the state's Native American tribes.** A region-wide approach would allow the state's tribes to coordinate HIV prevention and care efforts and allow them to potentially compete more successfully for federal grants which could provide funds, in particular, for more testing.
- 2. GACHA should request a briefing from Project Red Talon to learn more of their activities and how it may be of assistance to the governor's potential efforts and to all tribes in the state.**
- 3. DOH should closely monitor the 2006 epidemiologic data in Region 3 to determine if the recent rise in HIV infections is a one-time spike, or representative of a trend.**
- 4. GACHA encourages consumer representation and participation on the Region 3 Planning Council and at the region's consortia.** Specifically, GACHA believes community planning benefits from the experiences and perspective of consumers.
- 5. Reimbursement rates by Medicare, Medicaid to primary care providers should be increased.** The increasing number of providers not accepting Medicaid or Medicare-only patients has a major impact on access to care particularly in non-urban areas.
- 6. Consideration of expanding EIP coverage to medical specialists that are frequently required in the care of HIV such as liver specialists and neurologists should be investigated.** Access to specialty care is an increasing problem for Medicare and EIP clients.
- 7. As future funding decisions are made, consideration should be given to the impact on rural areas in which current allocations are creating regional "funding silos" within the state, fragmenting care and prevention services.**

Complete Findings

The epidemiologic trends in the region and state are included as an attachment to this report (Appendix D.)

Both statewide and in Region 3, public dollars have not kept up with the increasing numbers of persons presumed living with HIV/AIDS.

Region 3's combined state (omnibus) and federal (CDC) HIV prevention grant funding peaked in 2002 at \$1,306,354. In 2006 the total amount was \$1,149,502, or 12.0 % less than in 2002.

Region 3 state HIV prevention grant funding was basically “flat” throughout all of the 1990’s. Between 1999 and 2006 the region saw 11.33% reduction in state grants. Between the combined grants peak year of 2002 and 2006 there was a 9.32% reduction. Region 3 federal (CDC) HIV prevention grant funding grew slowly at first, then more rapidly at various times since 1994 with the implementation of CDC’s national initiative for community prevention planning. It peaked in 2002 but declined 19.52% since then (as of 2006).

Statewide, as of August 31, 2006 there were 9311 persons presumed living with HIV/AIDS. This number has been increasing about 5% annually since effective treatments became available, while funding has been declining.

Statewide, the total of all public (state and federal, including Ryan White) dollars for HIV/AIDS prevention and care declined 3% in SFY06. (From \$50.8 million in SFY05, to \$49.1 million in SFY06.) Sixty-one percent of the public dollars in SFY06 were direct federal funds (down from 62 % in SFY05,) 32% were state funds (down from 33 %,) and 7 % were local funds (up from 5 %,) although these local funds included Ryan White Title I federal funds. (No Title I funds are spent in Region 3.) Title III funds are spent in Region 3, and Interfaith, the Title III clinic, absorbed a 2.5% reduction in its 2006-7 grant award. But in 2006 (to date,) the numbers of patient contacts at the clinic are below 2005 numbers.

In spite of these funding reductions, the care infrastructure in northwest Washington, while squeezed, is solid. There is excellent cooperation and coordination between county health departments; the Evergreen AIDS Foundation; the tribes; and Bellingham’s Title III funded clinic—the Interfaith Community Center—considered an essential leg in the region’s care infrastructure.

Region 3 is trying to target its shrinking prevention dollars better, by more aggressively seeking to test among people at the highest risk. It’s believed that when the numbers of infections are small, as in Region 3 that *proven* “retail” intervention works best as opposed to community based efforts.

There is a belief among providers that public dollars could be better utilized if monies were awarded directly to the counties instead of filtering through the state, which is a slow process, but may be an unavoidable one, as is discussed below.

The funding structure for the state and the region’s HIV/AIDS program is complex and dictated by existing state and federal law. State and federal funds are distributed by the state Department of Health through the Regional AIDS Service Network (AIDSNET) system as established in Chapter 70.24 of the Revised Code of Washington. These funds are then contracted to the lead health department in each region, and then sub-contracted to other local health jurisdictions and community-based organizations within the region.

The original Ryan White CARE Act required that a consortium of service providers be established to identify needs and plan for the use of federal funds for HIV/AIDS care services. A “lead agency” is identified in each consortium to administer and sub-contract funds. The Department of Health contracts directly with the lead agency. One or more consortia are established in each region. Region 3 has two consortia – one serving Snohomish County with

the Snohomish Health District serving as the lead agency, the other serving Island, San Juan, Skagit and Whatcom counties, with the Evergreen AIDS Foundation serving as lead.

Funding issues aside, the biggest barrier to prevention and care services is a “barrier of fear,” founded in the religious and cultural values of the mostly rural region. The stigma of HIV is a barrier to effective prevention efforts. In the region’s schools, discussion of sex is taboo.

Time and capacity of providers are barriers to accessing care. The separate informed HIV consent process has contributed to this time constraint, but the new DOH regulations should ease this. Interfaith doctors can not treat in hospitals.

As elsewhere in the state, many people with HIV who are dependent on the public infrastructure for assistance have multiple other issues, such as drug use, mental health or developmental disabilities.

As in other rural areas, transportation is a barrier to care with many unable to afford private transportation and limited and difficult public transport options.

Access to both mental health and dental providers is difficult.

Poverty itself is a barrier to care. Access to affordable housing is an issue. There are too few Medicaid and Medicare providers, with low reimbursement rates cited as the reason. For the uninsured, referrals to specialists are virtually impossible.

Some Region 3 patients prefer to seek treatment in Seattle (at Harborview) because of the stigma of seeking care in their own smaller communities, and perceptions that care in Seattle may be better.

While there was near universal praise for the region’s Title III clinic (Interfaith Community Center,) testimony was received that waits for providers at the center are too long; that there are not enough doctors or dentists; and that it is unable to respond to emergencies. The region’s AIDS service organization (Evergreen) was lauded but, in one instance, was also criticized as disorganized; unresponsive; and failing in individual instances to provide adequate case management. “Should the region not have a standard of care?”

There was also testimony that the region’s planning council and one of the region’s care consortia are not representative of real consumers, and that GACHA itself did not devote enough of its forum time to communicate with consumers. (All public testimony is included as Appendix B.)

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The Region 3 Planning Council does include consumer representatives as well as non-conflicted community representatives. The North Counties consortium is involved in discussions aimed at increasing consumer representation on its panel.

There was praise for the Snohomish County Health department's case management efforts; but concerns that an increasing caseload has now mandated that it no longer serve Region 3 clients who don't actually reside within the county. There was a call for a 'standard' of care within the region.

HIV in the Native American Communities

A May 2006 HIV Prevention Needs assessment conducted by the National Native American AIDS Prevention Center within the Lummi Nation found the community only "vaguely" aware of HIV issues. HIV remains stigmatized; so much so that most tribe members prefer to seek services elsewhere, such as the Interfaith clinic or through Evergreen. Alcoholism is a contributing factor to HIV infection within the communities.

One new health program, "Ti-chee," has been launched to assist Native HIV+ clients "achieve their spiritual, emotional, physical, and mental well being" through a series of seminars and in-office consultations and a 24-hour support line.

Those providing HIV services within the communities believe more HIV testing, particularly among women, is critically needed.

It is difficult for an individual county, particularly a small county which may have four tribes within its jurisdiction, to effectively serve the Native American community given limited resources. A more beneficial approach may be a regional effort.

One tribe, the Lummi Nation, does not spend any of its own health care funds on HIV prevention or care, citing the demands of other health issues such as diabetes and alcoholism. The HIV budgets, if any, of other tribes were not determined. Some of the tribes are working together on HIV and other health issues, but not all. There is no coordinated effort.

Grants would be helpful to address these issues in the Native American community, but those available are too large for individual tribes to successfully compete. Smaller-need grants could help fill the void.

Other Issues

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There is quiet resistance to HIV testing in jails, because that would mandate treatment and the funds are lacking to provide it.

September 12, 2006

To members of the Governor's Advisory Council on HIV/AIDS (2)

Thank you for the opportunity to comment during this forum on HIV. My name is Marc Smith. I received an HIV+ diagnosis 21 years ago and an AIDS diagnosis 9 years ago. I am retired and have resided in Bellingham 3 years. I have been active as a volunteer in the HIV/AIDS community for 25 years, and currently an active member of Positive Frontiers, a local all volunteer support network for people living with HIV/AIDS.

When I retired to Bellingham in the summer of 2003, I was eager to continue my volunteer activity in the HIV/AIDS community. Feeling a need to "pay my dues" I started attending various HIV/AIDS meetings in the community and traveled to Region 3 Planning meetings at my own expense. I also signed up at the local ASO and clinic for services, where my experience was so unsettling and frustrating that I choose to receive most of my medical care and case management from Madison Clinic in Seattle.

Based on my personal experience I would like to focus my remarks today on two questions you posed to the second panel: barriers to finding community health care providers and barriers to consumer advocacy.

I have sat in many meetings where the Title III clinic, Interfaith Community Health Clinic, is held up as a model of effective and efficient medical treatment. When I first signed up as a client of Evergreen AIDS Foundation I was told the only option was the Title III clinic. When I asked about resources in Seattle, I was told I could go there but there would be no travel assistance. So, I signed up and made appointments for the primary care physician, the dentist and HIV specialist in Bellingham. Between the three providers my appointments were changed and postponed 13 times before I saw them. It was during this time that I heard about Madison Clinic and decided to go to Seattle for most of my medical care at my own expense.

All I receive from Interfaith is dental care. The dentist is great, but it is a two month wait for an appointment, and emergency care is non existent. Bills have arrived over a year after I have received service, and because they are over a year old my insurance has refused to pay for services they normally cover.

As the above intake story is three years old I thought maybe things have improved. But a recent trip to the St. Joseph Hospital emergency room have shown me that things have not. I have no idea what primary care is

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like at Interfaith, but a recent foot infection and toe amputation have shown me that care in Bellingham is stretched very thin. Six week waits to see specialists were circumvented by going through the emergency room at the hospital. The infectious disease doctors (the 2 HIV doctors for Bellingham) see patients only by referral. They each are on call at the hospital 2 weeks a month and one travels to Skagit county one week a month. The care was excellent when I finally saw them. Instead of waiting 6 weeks for an orthopedic surgeon I was told to go to the hospital emergency room. Again, the care was excellent when I took pot-luck at the hospital.

This round about story illustrates there are not enough doctors in Bellingham for HIV, and specialists if needed. Travel to Seattle is still necessary and with no assistance provided through Evergreen AIDS and Ryan White Care Act, adequate medical care will continue to be a problem.

At the beginning of my time in Bellingham I was disappointed with the level of consumer participation I experienced, and during the past three years it seems to have gotten worse with most of the barriers institutionalized by the very agencies that say they are helping the HIV/AIDS community. A couple of years ago the board meetings of Evergreen AIDS Foundation were closed to consumers. I have heard that there are consumers on the Board but I have no idea who they are, or how I reach my so called representative(s).

After a year of attending Region 3 Planning Council meetings and applying for a position, I was told that they are happy with the current representatives from Whatcom County. I found it frustrating that on the application they asked if the applicant is a member of one of the target populations or if the applicant is "familiar with" the issues of one of the target populations. It seems the Council is satisfied with a provider familiar with issues instead of having a consumer represent him or her self. This attitude was made clear to me when one of the Council members told me during a meeting that consumers do not make good Council members because we are too close to the issues and do not make good decisions. At the time, I wondered if her Title III position and salary created a conflict of interest, and if she is able to make decisions which are in the consumer's best interest.

And last year the North Counties Care Consortium approved new by-laws; grandfathering in all provider positions and eliminating all consumer positions except the existing co-chair who was "provisionally" allowed to keep his position. As far as I know there was no discussion amongst consumers as to keeping or selecting a new "representative". The old by-laws allowed consumers to become full voting consortium

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members by their own initiative after attending 3 consortium meetings; the rewritten by-laws stated providers select individuals they want to represent consumers.

And as a final comment about consumer advocacy, I would suggest you look at your own agenda for today. With the exception of 25 minutes of public testimony at the end of the day, where do you engage consumers and discuss what would make their lives better, or educate consumers on how they can participate in policy discussions about their own care, or ask a consumer what prevention message they hear. I feel that if you really want meaningful participation by a broad range of consumers, you (the state), need to begin a comprehensive program of recruiting, educating and mentoring consumers, and not view us as merely a necessary evil for fund raising and job retention.

Thank you again for this opportunity to comment.

September 12, 2006

Dear Members of the Governor's Advisory Council on HIV/AIDS;

My name is Roger, I have AIDS. I have lived in Whatcom County for 9 years and have been a client of Evergreen AIDS Foundation for 6 years. My comments today are about case management and my experience with both Evergreen AIDS Foundation and Snohomish Health District.

In 2005, after constant unfulfilled promises, useless lip service and disrespect from Evergreen AIDS, I choose to be case managed by the Snohomish Health District. I faced numerous health issues and got through the nightmare of the new Part D Medicare Drug Plan selection process with assistance from the Snohomish Health District. I want to thank Gloria Fielder and her staff at the Snohomish Health District for their superior service and support.

Unfortunately, because of an overload of clients and policy changes, those of us living in Region 3; but not within Snohomish County, are no longer eligible for case management services through the Snohomish Health District. I am left with only two poor case management options: I can go back to Evergreen AIDS, or I can do my own case management. I have chosen to case manage myself until there are significant changes at Evergreen AIDS Foundation.

As a consumer, I found the case management experience between the Snohomish Health District and Evergreen AIDS Foundation very different. And I am hoping there will be some standard of care; some minimum requirements for case management developed for all of Region 3.

Thank you for the opportunity to share my experience at this forum, and I would like this testimony to be part of the public record.

Sincerely,

Roger W.
Bellingham, WA 98226