THE POSITIVE QUARTERLY

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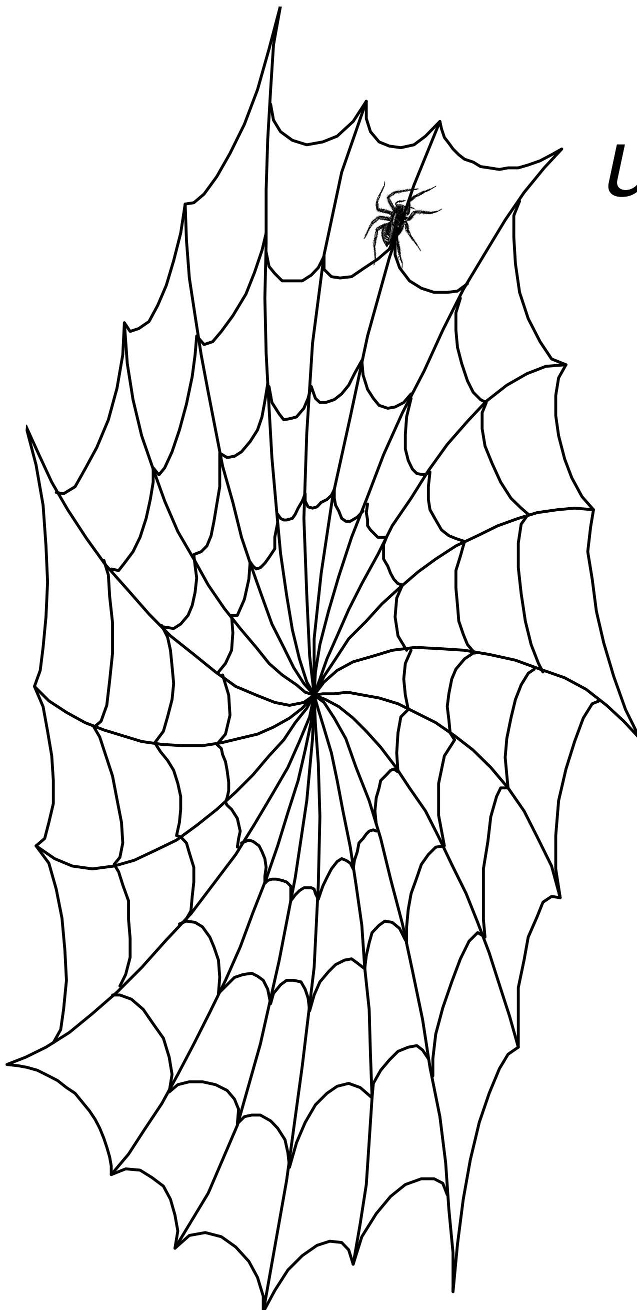

When spider webs unite they can tie up a lion.

-Ethiopian proverb

As we look back and take note of how much the Task Force has accomplished the past few years, you have to admit—it's pretty impressive. We have been represented on the national scene at such events as AIDS Watch and at national and international conferences. Some of our members submitted abstracts and presented at many of these conferences.

We invited nationally renown AIDS activists, strategists and philosophers to our state functions and worked to establish communication with federal and state elected officials—and are on first-name basis with many of their legislative assistants. Sponsorship of regional community forums allowed us to conduct needs assessments and exposed us to data analysis.

Some serious editorials and commentaries have been printed in The Positive Quarterly. Derrick Anderson's plea after his return from Durban, South Africa for us to rediscover "passionate urgency" and my appeal for us to unite with other disenfranchised communities beyond the HIV/AIDS umbrella were key moments strategically and philosophically. (Positive Quarterly, Oct-Dec 2000)

Three months earlier I had compared AIDS funding levels to those of federal subsidies to multinational corporations, and questioned our nation's priorities with the results. Nearly a year later, Derrick was lamenting that Social Justice AIDS had become the Industry of AIDS. I wrote that having to negotiate year after year for adequately funded HIV/AIDS legislation was "ludicrous and insulting."

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The Ugly Truth: "Entitlement Mindset" Threatens Integrity, Misses Message of Advocacy

COMMENTARY

By
Mark Peterson
Task Force Chair

After reading this article, PWAs and those affected by HIV will either herald my words as wisdom gained from experience or as the rantings of a new "Viral Judas." I guess the thing to remember is that my term as Task Force chair ends in May 2003. As I look over the articles I have written in this newsletter while chair, I'm proud to say that for better or worse, I have always tried to tell the truth. This issue is no different but, the truth I'm going to tell may sting a little more than usual. See, I'm planning on talking to you about PWAs and the nature of the 'entitlement mindset."

I don't mind setting myself up for the "slings and arrows" cast my way by those who disagree. If my skin were that thin, I never would have made it out of Region 1 Community Planning alive. The position of Task Force chair *requires* that I step out of my own comfort zone and attempt to objectively advocate for *all* PWAs in Michigan. It's a tall order and I know I have failed at several points, but I keep trying to stay honest. This desire to remain honest has run me smack in the middle of the omnipresent, unsaid, felt-only-under-the-surface ugly truth of PWAs believing (and behaving like) having HIV infection e*ntitles* them to certain "propers."

Before we get too far into this, I'm not talking about those pillars of empowerment that PWAs fought for 20 years ago that ensure our inclusion. The mandates in HRSA and CDC programs are the hinge pins of our advocacy and must be upheld and utilized. What I'm talking about here is the petty stuff we find ourselves demanding like it was the cure.

We've all either seen or been part of the "entitlement mindset." It has us PWAs spinning like divas at the smallest slight, whether perceived or actual and exploding the meeting/group/session etc. into bits with our biggest bomb...negative guilt. It's so prevalent and PWAs have become so acquainted with its use that it is often the first tool used. I had the occasion to be on the receiving end of it myself recently. It was painful and a little bemusing to see the other PWA's face when I reminded him that I was positive too and the "you'll never *really* understand" comment was mis-aimed.

This mindset has also infected many of our service providers and community planning partners. I've seen community planning partners and staff help to perpetuate this type of entitlement thinking by helping us focus on the trivial. One must realize, this is being done in order to draw our attention away from the serious issues which, if addressed by a truly educated and empowered group of PWAs, would change the power structure of community planning from a grantee-down to a PWA-down model. (Yes, that was PWA-down.)

We can only blame ourselves and our PWA leaders for staying in this Three Card Monty game of focusing only on the trivial issue of the moment instead of becoming truly effective directors of community planning. This method of conducting PWA input comes from a misunderstanding of our responsibilities.

The fact that PWAs hold respected positions in HIV care and prevention planning is due to the efforts of PWAs advocating for each other. I'm sorry, but if I hear the whole "I gotta get me mine" crud from one more PWA, I'm gonna scream. The Ryan White CARE Act and CDC HIV prevention funds were NOT designed to be milked for every possible cent to make my life better. The CARE Act was created...now get this... to be a payer of *last resort* for public health care. I'll say that once more for effect: payer of last resort for *public* health care. Some may accurately say that from its beginning it was designed to be the bottom of the barrel of health care. It was created to insure the bare minimum standards for treatment of individuals who were/are traditionally mistreated by the larger health care establishment. It exists to ensure that PWAs aren't screened out of proper care because of providers' homophobia, racism or simple ignorant fear of this disease. So with this in mind, where do we PWAs get off demanding we use RWCA transportation dollars to do anything but get us to and from care providers and back? Where do we find the character to ask that we get any kind of perk at the expense of others? I sometimes

hear statements like, “they (agency X) got a lot of money. They can do_________(fill in the blank) for me.” We act like the money an agency receives for programs is just lying around and can be utilized at the whim of its directors.

The funds for HIV care and prevention are coming under more scrutiny and restrictions now than ever before. This is not the time for PWA Divas to start making egotistical demands. Now is the time for all PWAs who understand our funding streams to ensure others are brought up to speed. It is also the time for those who have not had the opportunity to learn about the CARE Act or CDC requirements to take initiative and demand of their PWA leadership the best possible advocacy training possible.

Here are some simple suggestions:

- If you find yourself looking at meetings or other chances to give input as a way to manipulate the system to get only what *you* want...**do us all a favor, cash in your stipend and go home.**
- If you are being contrary simply to show other PWAs that you’re willing to stand your ground...**you’re not being helpful...join a committee and do some work instead.**
- If you are in a PWA leadership position and you use that position to foster bias on race, gender and/or orientation...**you’ve just accomplished more harm to the validity of PWAs than any of our detractors ever have. You need to leave now.**

On a more positive note, we need to be reminded of just exactly what our job is. Those of us who choose to be a positive force for directing, advising and contributing to the effective planning for HIV care and prevention resources must do so with integrity. We need to (myself included) continue to advocate for *ALL* PWAs. Letting go of our “stuff” is hard but necessary. If we advocate from a place of integrity, we will be that voice of reason which truly reflects the needs and desires of PWAs and contributes to the creation and maintenance of the best possible HIV/AIDS services.

Or, we could continue to misuse “negative guilt” through self-only-advocacy and tantrums and then demand respect. Remember, respect is not an entitlement. Respect is earned.

See, I said that I might sting a bit. Just imagine though, how much worse it could’ve been if I had brought up that whole “gee, to get HIV you have to get it from someone *with* HIV. What are we PWAs doing to address the fact that we may be in some part responsible for this issue?”

Responsibility...kind of a two edged sword, huh?

Does anyone wonder what happened with the surveys they filled out at last year’s PWA retreat?

Entering all that data has been a daunting project, but preliminary figures are in the process of being interpreted. Task Force chair-elect, Tim Monahan, presented some results at the September MHAC meeting. What follows is a combination of those results and a brief summation from raw data printouts.

Respondents were predominately male by more than half. Average age was 41.15 years. The largest age group in the state epi-profile is 30-39. Support groups were the highest ranked met need, followed by case management, transportation and housing. Highest unmet needs included housing, recreational/social and food/nutrition.

1994 was the average year to receive an HIV+ diagnosis. “I didn’t think I was at risk” was rated the highest response regarding infection. 71% have had protected sex with someone who knew their status. 34% reported having unprotected sex with someone who knew their status, but an almost equal number of respondents did not answer that question. 19% felt comfortable having protected sex without disclosing to their partners, but again there was a high level of no response. A solid 63% were sure they had not infected anyone else, with a high answer rate for that question. 47% reported practicing/maintaining safe sex as a challenge.

Over 50% found information on safer sex practices very useful. 62% found counseling/support to help make living with HIV decisions very useful, and 43% found counseling very useful in helping to practice safer sex. Opportunities to socialize with other HIV positives was the top response and ranked very useful at 73%. Over 50% have friends who know their HIV+ status and 74% reported families who know their HIV+ status. 83% report sex partners knowing their positive status. A majority prefer their next partner be HIV positive.

Examination of data shows a high non-response rate primarily with the prevention survey. Fine-tuning questions should promote higher answer rates on this sensitive topic. Find Monahan's MHAC power point presentation on the Task Force website at *http://www.mipwa.org*. More detailed results will be available in the coming months.

(Continued from page 1)

Concurrently, Mark was charging us to speak with One Voice (you can even *hear* it in capital letters) and to stop being "Power Divas" (caps AND parentheses).

News-wise, we've applauded the creation of needle exchange programs and youth concerts, AIDS Rides and HIV/AIDS radio shows. We spotlighted women's issues and men living down low. We were stunned at 9-11 but pulled ourselves out of the symbolic rubble far enough to realize the fight remains, the dreams for a just world starkly redefined and yet eerily unchanged. We profiled an AIDS organization on the brink of its re-definition, only to find it disbanded and reworked in an entirely different way before the next issue hit the streets. Mark had a one-on-one with a major federal appointee, only to find the fellow deposed as we went to print. (We were able to squeeze in a disclaimer.) We helped fellow HIV positives organize a task force in another state.

Which brings me back to The Positive Quarterly and the role it had in these emotional, frustrating, visionary and impassioned moments. By my estimates, and based on an average of 300 sentences per issue, I have either written or approved over 3,600 sentences during the three years of my tenure as editor-in chief. Only two of those sentences were ever pointed out to be poorly crafted. But I thank God for the most recent one, if my lack of forethought ultimately produced a connection that identifies unmet needs and allows me to extend a hand to help make those changes happen. Of all my years served, I pray allow me but this one success.

-Gary Karch

As regional planning groups are dissolved to make way for a newly streamlined statewide process, the Task Force stands poised to take on additional responsibilities to assure that HIV positive participation is part of the process. Needs assessment, which at the last MHAC meeting was acknowledged to be useful as an ongoing process and not just for every three years, can be undertaken by the Task Force. But persons need not be members of the Task Force or MHAC to become involved. Those who flinch at the idea of becoming involved in the larger organizations are welcome to become involved in Task Force or MHAC committees or workgroups, and know their contribution will be appreciated.

The Task Force just voted to make women's issues a permanent committee, upgrading its importance. Others such as needs assessment, legislative education and marketing can always use extra hands and hearts. MHAC has an African American workgroup whose chair, Willie Smith, said at September's meeting they wanted to "not focus so much on risk gaps...but [on] how culture affects messages and how they perceive messages." Impressive! Helping to develop their issue paper offers more chance for participation. The MHAC rural, youth and Hepatitis workgroups all need representation from their respective communities in order to attain their goals.

It is an unbalanced effort if only a few people, all of whom are also living with HIV and AIDS, continue to do more than their share. Trying to represent vast, diverse constituencies while at the same time trying to comprehend the confusing and often arcane language of federal guidelines, in order to preserve the integrity of the programs they define, is pretty daunting.

Hopefully there is a wave of new empowered individuals on the sidelines waiting to become a part of this process, because there are persons and entities who would much rather see us—the HIV positive community—relegated to some sideline, to be brought out like grandma's old silver set, tarnish wiped off for the next public display, only to be relegated to the china cabinet once the festivities are over. Assuring our presence at the table, and the integrity of that presence, will take more than a few sets of eyes.

-G.K.

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Michigan's PLWH/A Task Force
P.O. Box 26294
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Email: info@mipwa.org
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Editor/Marketing Chair: Gary Karch
Task Force Chair: Mark Peterson
Chair-Elect: Tim Monahan
Membership & Management Chair: Selvy Hall
Special Events Committee: Dan Stone
Outreach & Needs Assessment Chair: David Rupprecht
Legislative Education Chair: Rick Otterbein
Women's Issues: Linda Searcy

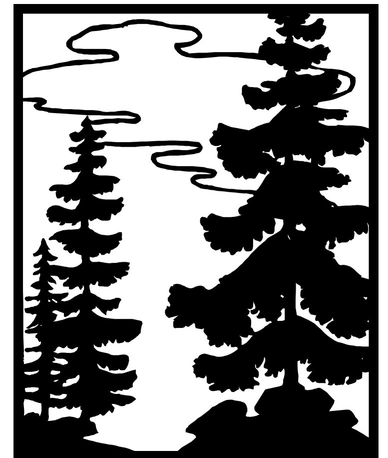
Plan for retreat 2003 gets early start

"Mind, Body and Soul" is the theme for next year's Task Force-sponsored PWA retreat, to be held at the Treetops Resort in Gaylord. The retreat is planned for March 28-30, 2003. Michigan's premier event for the HIV-infected community is often the first chance for newly-diagnosed individuals to meet and socialize with other HIV positives on such a large scale.

Treetops is by all accounts a beautiful location, and promises to provide the perfect setting for making new friends and attending workshops in health, psychological well being and political issues, as well as allowing for a stress-free weekend. Retreat attendees are asked to fill out several in-depth surveys on access to care, prevention, quality of life and medical adherence. [See survey results from this year's retreat elsewhere in this issue.]

Last year's retreat was planned to coordinate with the display of the AIDS Memorial Quilt at Grand Valley State College, which caused a problem in finding a hotel large enough in the area to accommodate retreat participants. Because of the limited hotel accommodations, and the high number of scholarship applicants, many ended up on a waiting list. In an effort to include as many people as possible at next year's retreat, priority will be given to people who applied for scholarships last year, but were placed on this waiting list. Persons who meet that criteria will receive a separate mailing informing them of their priority status and will be encouraged to apply for scholarships. Balanced representation between metropolitan Detroit, other cities and towns throughout the state, and rural areas are also part of the scholarship review process. Applications for next year's retreat will be available in November, with a January 1 deadline for applications to be received by the Task Force.

Guest speakers at last year's retreat included Gil Kudrin, founder of the Night Sweats and T-Cells design group, which provides jobs to HIV-infected individuals, Cleve Jones, founder of the AIDS Memorial Quilt, and Terje Anderson, executive director of the National Association of People with AIDS.



The Coca-Cola corporation is the target of a Global Day of Protest against their refusal to provide comprehensive healthcare—including life-sustaining antiretroviral treatments—to all of their African workforce and dependents. October 17, 2002 is the designated day of protest against what is being called "medical apartheid."

Coke reaped volumes of favorable publicity in June, 2001, when it announced a "partnership" with UNAIDS and other entities to combat AIDS in Africa, which was to include payment for HIV/AIDS treatment and care for its HIV infected workers. While they did extend coverage to their 1,500 "direct" employees, Coke neglected to provide for the larger workforce of more than 100,000 employees who work for subsidiaries and major suppliers, bottlers, canners and distributors who possess Coke's exclusive licensing agreements. These companies could be mandated to provide adequate coverage as part of these contracts.

The Health GAP Global Access Project reported that out-sourcing has become key to business strategies of multinational corporations who seek to avoid labor and environmental obligations. Coke's feeding off the positive spin attributed to its miniscule response is characteristic of that ruse.

Coke's operating profit margin in Africa is twice that of North America (41% vs. 20%). Africa is one of Coke's largest emerging markets. Last year, its net revenues in Africa exceeded $620 million, and its worldwide net revenues reached $20 billion. Coke's profit margin is expected to rise 12% in the next 4 years in Africa, exceeding Coke profit margins in all other regions of the world.

Coca-Cola itself and its affiliates provide relatively good wages within the African formal economy. But as Health GAP says, "The fundamental question, however, is not about legalistic issues like corporate control, strategic outsourcing, and licensing agreements. The issue is whether the corporate sector has responsibility to respond to an HIV pandemic that it has historically neglected at best and intensified at worst."

The company and its affiliates may have contributed to single-sex worksites and trucking routes that have directly intensified the pandemic, along with a lack of safe-sex education and condoms. A little HIV with your Coke, anyone?

First Major Effort by Task Force Targets HIV-Positive Incarcerated Community

Problems Revealed, Solutions Presented in Department of Corrections Position Paper

Michigan's Persons Living with HIV/AIDS Task Force has completed its first policy position paper, a major task that was conceived over several years of advocacy and research. This paper examines the multiple issues involved with providing prevention and care services to inmates incarcerated within the Michigan Department of Corrections (MDOC), identifies which systems work and offers suggested changes or modifications to existing structures.

One difficulty identified is the often conflicting requirements of the MDOC versus the Michigan Department of Community Health (MDCH.) On the one hand, the MDOC is charged with providing a "correctional environment for the legal offender to serve their sentence." At the same time, MDCH "provides resources for discharge and transition planning to the HIV infected inmate." Therefore, it can be surmised that these "competing values" can compromise provision of care to the incarcerated.

The MDOC receives Ryan White Title II funds to provide HIV case management discharge planning to inmates due for release, with transition assistance to care services on the outside. Bi-monthly meetings with incarcerated individuals are also convened. These meetings are "highly confidential" and utilize audio/visual tele-meeting equipment that allows for multiple site participation. The Task Force's presence in these situations provided valuable insight and information which was incorporated into the report.

Experiences cited from key informants include breach of confidentiality when HIV medications are delivered in color-coded, clear plastic, or "bio-hazard" bags. Some inmates, upon getting tested for HIV prior to release, are given their test results on color-coded paper, "carried with the inmate in obvious view of other inmates therefore outing their HIV status to the prison community."

Some HIV positive inmates suffer lapses in the "continuity of receiving their medications as scheduled," and "risk not having their specific medication stocked" at the pharmacy if they are transferred to another facility. The need for snack bags to comply with medication guidelines are occasionally ignored by kitchen staff. Many inmates do not see infectious disease doctors for periods of 6 months or more. Some females do not receive regular gynecological exams.

Some of the changes to existing protocol suggested by the Task Force include making condoms available for inmates and allowing for an empowered role by inmates in the design and implementation of care/prevention services and by former inmates to act as peer educators. Providing HIV/AIDS educational material at all facilities in English and Spanish, and perfecting the continuum of care so that no inmate/patient is denied or delayed medical/pharmaceutical services is recommended.

Of concern is the training and re-training in such areas as case management, with an emphasis on the special needs of HIV infected inmates, and legal training for MDOC medical staff emphasizing Section 1983 of the Civil Rights Act of 1964 that calls for compliance to not "deprive any person of any right, privilege, or immunity secured by the Constitution and laws of the United States."

Other recommendations include creating a training model for corrections staff that emphasizes the importance of confidentiality, creating an in-prison resource person to address HIV health, care and prevention issues, and having the MDOC create a workgroup to address the needs of incarcerated persons. Engaging HIV positive inmates in participatory groups such as the Task Force or in Michigan's HIV/AIDS Council is also indicated.

The paper recommends reviewing "best practices that exist within other correctional settings, nationally and globally" to examine such innovations as syringe exchange programs in Germany and condom distribution in Mississippi.

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Task Force research also identified larger issues inherent within society that contribute to institutional incarceration. These include the need for public policy that "exposes the correlation between HIV infected inmates and the communities to which they return."

"Communities of color are not only disproportionately impacted by the HIV pandemic, they are also disproportionately impacted by long-standing societal racist practices that led to the large number of individuals of color becoming incarcerated," the paper says.

Former Task Force chair Derrick Anderson and Selvy Hall-Kinnard were instrumental in identifying the need to advocate for this population unable to help themselves.

Also assisting on the Department of Corrections workgroup was David Rupprecht, who had initially been appointed by HAPIS as liaison to the men's consortia in correctional facilities and continued his involvement through the Task Force as Needs Assessment chair and DOC Workgroup co-chair. Anderson was the document's principal writer.

The position paper will be distributed first to the Department of Corrections administration, individual correctional facilities and wardens, Michigan Department of Community Health administration and staff, and state legislators.

Broader distribution to the general public and media is also planned. The paper will be available on the Task Force website in the near future.

Women in Prison Issue Prompts National Attention

Keeping family ties despite an increased incarceration of women was just one of the issues discussed at A Journey in Justice: The 10th National Roundtable for Women in Prison held at Columbia University in New York City in June.

Representing Michigan's PLWH/A Task Force was Selvy Hall-Kinnard. Data was shared from various states concerning the problems encountered by women in prison and out.

Current sociological trends were described, such as the corporatism of prison systems and the phenomena of building whole cities around prisons, thereby using prisons as a catalyst for economic growth. This practice relegates inmates to "product" status, further dehumanizes the community and encourages legislation that increases the length of sentences, which helps to guarantee job security for correctional facility employees.

Threats to withhold prescription medicine are commonly used as behavioral control. In some states, women wait two years or more without receiving a pap smear. Podiatrists are used for all medical care in one sample institution.

Incarcerated women have higher rates of HIV infection than their male counterparts. In state prisons the incidence of HIV ranges from 12 to 26 percent among women compared to 8 to 21 percent among men (1997 figures).

In addition to his contribution as principal writer for the Task Force position paper on HIV/AIDS in Michigan's correctional facilities, Derrick Anderson conducted research over the past several years in conjunction with obtaining his Master's Degree in Social Work from the University of Michigan. He has analyzed different aspects of Michigan's "War on Drugs" and "Get Tough on Crime" campaigns and examined their corollary impact upon communities of color and the perpetuation of institutionalized racism. Here are some of his findings:

- Sentences for not disclosing HIV status to sex partners has created a significant increase of individuals living with HIV while incarcerated. Behaviors associated with HIV infection, IV drug use, and high-risk sexual behaviors are also endemic to this population.
- HIV stigma, homophobia, sexism, and racism are issues that impact upon the individual living with HIV disease in prison. HIV disease and incarceration are two epidemics which have disproportionately impacted upon African American men and women.
- Nearly half of all female prisoners have suffered from some form of sexual/physical abuse prior to incarceration. More than two-thirds of women in prison have children under the age of 18, and 75% are the sole custodial parent. The female population continues to grow at a much faster rate than the male population.
- These women are easily targeted for sexual assault by corrections officers who threaten them with trumped-up charges of violating prison regulations which would deny them visitation rights with their children.
- The plight that women in prison today experience parallels abuses that women of color faced during the period of slavery in our country. Routine violence and sexual abuse, with not one case ever reported nor prosecuted during that time, and systematic removal of children from their mother's care and "sold like cattle to the highest bidder" is repeated in the revocation of parental rights of women in prison today and the media's silence on sexual abuse inside correctional facilities.
- The "Drug Wars" returns inmates to the outside with their voting rights permanently revoked, thereby creating an ever-growing class without a voice.

HIV Positives Can Help Ailing Detroit

Poor Detroit. Despite such valiant attempts at reinventing herself with a renaissance of development and new political leadership, the city faced a setback with the recent headlines in the Detroit News (Sept. 15, 2002) disclosing a "rampant" syphilis outbreak in the metropolitan area. Warnings from the federal Centers for Disease Control and Prevention alerted the Detroit Health Department as far back as three years ago, with limited results. Now Detroit leads the nation in new diagnoses of the curable sexually transmitted disease.

Opinion

News stories report that staff responsible for finding syphilis cases were not supervised adequately, and proper data collection and analysis did not occur. Intervention workers were in need of training and received "minimal" oversight. Cases were closed without learning partner identities and other demographics that could have lead to better control of the disease.

The health department apparently took too long in filling a key position. Money already received for community groups sat unused because the department "failed to develop eligibility criteria and guidelines."

Vans utilized for HIV testing arrived at designated sites hours late, and existing structures such as HIV outreach workers were not made aware of the emergence. As we all know, where other STDs exist, HIV isn't far behind. Detroit was also "repeatedly cited" for failure to "connect with community-based organizations already waging fights with HIV, AIDS and other sexually transmitted diseases."

Some staff changes have already been made, and the CDC says the department is now "moving in the right direction" (AP 9-18-02). We applaud those efforts.

Detroit can continue to regain control by emphasizing frank communication and collaborative efforts that engage the committed rank-and-file, where most truly effective and innovative approaches must occur. Surely such persons exist who care deeply enough about their city that they would commit to the vast job that lies ahead.

For at the same time this situation has presented itself, there are individuals right here and now, living with HIV, scraping by to make house, rent, and utility payments, driving cars held together with duct tape, trying to sustain their energies with food donations, who possess the skills and expertise, as well as desire, to return to work.

Although it is not a given that any of these persons are qualified to help within the particular STD positions under examination, it supports the larger opinion that such job opportunities exist in other government departments both on the state and federal level, in Michigan and in other states, within community health or not. Attrition in federal and state government workforces due to anticipated retirements in upcoming years only adds to the potential source of possible job opportunities for the HIV infected population. And compliance with disability discrimination guidelines should be more readily assumed on the government level than in the private sector.

I recently spoke with job counselors for Michigan Rehabilitation Services (MRS) in Benton Harbor on HIV/AIDS and back-to-work issues. My presentation followed one concerning disability, cultural diversity, discrimination, and factors that contribute to high unemployment.

These professionals can help to incorporate willing HIV/AIDS patients back into a working environment. The Michigan Department of Community Health has an opportunity to help set and expand upon innovative national standards by mentoring those HIV positive persons with whom they have been working side-by-side for years into work and college study credit, in collaboration with MRS.

Understandably, present compensation levels were arranged when back-to-work guidelines were more restrictive, and were made to not endanger anyone's benefits. But enhanced federal incentives now exist that raise levels of earned income and encourage the disabled to ease into the job market without immediately endangering disability benefits. These new models should be tested, critiqued, and improved. Not everyone will be up to the challenge, but some may.

Persons living with HIV/AIDS and volunteering at various levels of state, regional, private and government organizations have been to date the most under-compensated professional contributors to the cause of their own disease. It is time that PWAs be acknowledged for their skills, dedication, intelligence and passion.

We must be ever vigilant to not allow ourselves used as cheap validation or succumb to ingrained, institutionalized patronization. Grant us that dignity and just see what we can do.

-G. Karch.