Interview with Bill Burman, MD Medical Provider
July 8, 2010

Please think about how individuals with HIV disease access primary medical care in the 6-County Greater Denver Area.

1. In your opinion, what's working with the system of HIV care?

What's working is that we've got a good spectrum of care. In addition to primary care, we have ancillary services including dental, pharmacy, and case management.

2. In your experience, what are the challenges of using the system of HIV care?

Some of the biggest challenges we face are geographic and administrative limitations. These are not necessarily the Ryan White Care Act's problems, but they can raise difficulties. For example, for a long time there were very limited resources available for out-of-county and out-of-county undocumented HIV positive persons, though this has been greatly improved with the addition of clinics at MCPN and Clinica Tepeyac.

Another ongoing problem is the coordination of the various parts of care. For instance, primary care and case management take place in different geographic locations and communication can be difficult. I like Mark Thrun's idea to have on-site case management, similar to what we have in Scottsbluff, where the Nebraska AIDS Project case manager is on-site during clinic, making coordination much easier.

There are some barriers to this approach, including turf wars, and providing resources such as office space as well as sharing privileged health information to non-Denver Health employees. An example of these problems is the Infectious Diseases pharmacy at Denver Health trying to use Colorado AIDS Project (CAP) assistance for co-pays: there are inevitable delays in transferring money from one entity to the other. So having CAP as the 'single payor' has both advantages and disadvantages.

3. As a representative of medical providers, where are the major gaps in services for those with HIV disease?

There aren't any major gaps, we just need to continue to provide and expand comprehensive care. Examples of previous gaps that have since been fixed are the out-of-county/undocumented clients and those in Denver City and County community corrections. However, what about metro Denver jails outside of Denver County? It would be nice to have a similar system as that in Denver, with a jail-based social worker providing transitional case management.

4. In your opinion, what will the system of HIV care look like in the next 3-5 years?

I expect the care provided by the Ryan White Care Act to shrink. With the new Affordable Care Act, CICP rolls should go down. If I were Congress, I would expect it to shrink, since if we're expanding Medicaid eligibility, there should be less clients in need of a payor of last resort. The question is whether those disorganized patients who have difficulty navigating the healthcare system will be able to continue getting Medicaid. Given the eligibility requirements set to take place in 2014, it's unclear what percentage of our patients will qualify for insurance. We still don't have all the details about how this care will be delivered. Hopefully, Ryan White will maintain the ability to bridge the gap.

Note: Bill went on to describe the incredible system of organization currently in place that was made possible by the Ryan White Care Act. He explained that translating research into clinical practice can often be difficult and occur in a piecemeal fashion, but that in the case of HIV research, new advances result in near immediate changes in clinical practice among Ryan White-funded clinics. This is perfectly demonstrated by the precipitous decline in death rates that occurred nearly immediately after triple drug therapy was introduced. This kind of success would not have been possible without the Ryan White Care Act, and Dr. Burman expressed his hope that this system be maintained through the anticipated changes in healthcare delivery.

Email response from Jean Finn Policy
July 7, 2010

1. In your opinion what is working with the system of HIV-care?

There seem to be a broad array of clinical and supportive services available to persons with HIV infection. Since substance use and mental illness are drivers of the HIV epidemic in Colorado, I will always advocate for more mental health and substance abuse treatment (inpatient and outpatient-including methadone maintenance) services.

2. In your experience, what are the challenges of using the system of HIV-care?

HIV-care, like health care in general, has its own language, practices, and routines. The fragmentation of the system and the need to go to multiple practitioners is a struggle for clients. These aspects of the system make it difficult for clients to navigate, especially when they do not feel well, are in crisis or overwhelmed by their day-to-day circumstances.

I think we need to seriously and honestly examine and address the barriers that inhibit client's access to health care and their ability to stick with their treatment regimes. I mean this in a way to say frequently at meetings people are unable or unwilling to take a hard look at their own services and to address the barriers to services, we look at what makes it easier for us as a provider rather than what will make the services easier to tolerate for the clients.

3. As a representative of (consumers, policy makers, medical providers or support service providers), where are the major gaps in services for those with HIV-Disease?

I would like to see evidence based prevention interventions designed for clinical practices integrated into clinical services. An example is Partnership for Health which can be found on CDC's website on evidence based interventions, http://www.cdc.gov/hiv/topics/research/prs/evidence-based-interventions.htm .

4. In your opinion, what will the system of HIV-care will look like in the next 3-5 years?

Oh this one is so hard to answer. Truly, I have no idea based on what may happen with health care reform. I would hope that HIV care will be integrated into the health care system as a whole and normalized like other complex clinical conditions with some level of case management and support services. There may be some gains and losses in this scenario.

Email response from Steve Johnson MD Medical Provider
July 27, 2010

1. In your opinion what is working with the system of HIV-care?

2. In your experience, what are the challenges of using the system of HIV-care? Overall, the system of HIV care in Denver is very good and likely better than many other metro areas with less resources per HIV+ patient. I see three major challenges. First and foremost, funding of HIV care remains a challenge. Although the grant funds are substantial, they fund less than half of the cost of HIV care for uninsured patients at DHMC and at University Hospital. The situation is better at CHIP because of their smaller population and numerous funding sources. The lack of growth in HIV funding for primary care has led to a progressive decline in funding for services relative to the patient population. This creates difficulties in arranging specialty care and also with access to certain medications with the reduced ADAP formulary. A second challenge is the lack of integration and information sharing amongst the various RW funded organizations. For example, some patients bounce from DHMC to University and back. Accessing information from each other's systems is a challenge and not routine. Treatment plans from Dental Clinics, CBOs, Mental Health, and Substance abuse organizations seldom make it back to the primary care providers. A third challenge is the requirements for data entry and reporting. Although I understand the importance of this from the feds perspective, it leads to many thousands of dollars that could be used to provide care to be used for data management.

3. As a representative of medical providers, where are the major gaps in services for those with HIV-Disease? I don't think that there are major gaps in service that impact outcome although the lack of full access to specialty care remains a challenge. Expansion of the ADAP formulary would also be helpful. More focus on back to work programs and getting patients off of disability would be helpful.

4. In your opinion, what will the system of HIV-care will look like in the next 3-5 years? I think that the system of HIV care will likely be positively impacted by the health care reform rollout. Patients on CICP will move to high-risk insurance pools or medicaid which will lead to improved coverage of medications and improved access to specialty care and procedures. Ryan White funds will still be important in funding certain activities (e.g. an HIV Cancer Clinic or an HIV Mental Health program) that simply won't be possible under medicaid. The system will need to be fully focused on comprehensive HIV primary care. General health issues, aging, and co-morbidity management will be much more important than specific HIV acitivities such as ART and PCP prophylaxis. My hope is that the existing HIV programs will become the "Medical Home" for primary care for HIV+ patients.

Email response from Peter Ralin Policy
July 30, 2010

1. In your opinion what is working with the system of HIV-care?

Excellent collaboration/referral among providers; between the different RW Programs, between the Grantee & Planning Council; excellent (compared to most jurisdiction around the nation) indigent patient care programs for both residents of Denver at DH & the other CO counties at either UCH or the Part C providers; having both a CPCRA Program (DH) & an ACTG (UCH) to augment access for patients to medications/care & excellent HIV clinical care providers.

2. In your experience, what are the challenges of using the system of HIV-care?

Linkages to care, navigating the system of care. Ensuring an adequately funded continuum of care to enhance access to & retention in care.

3. As a representative of (consumers, policy makers, medical providers or support service providers), where are the major gaps in services for those with HIV-Disease?

Increased resources for substance abuse, mental health services, transportation, housing & other services to enhance access to & retention in care & medication adherence. Identifying the large number of infected individuals who are not in care & getting & retaining them in care.

4. In your opinion, what will the system of HIV-care will look like in the next 3-5 years?
5.

Very difficult to say due to the gradual implementation between now & 2014 of Health Care Reform. I believe that as Health Care Reform is implemented, many services provided under all RW Programs will likely be supplanted by patients having access to insurance coverage. I do believe that there will still remain the need for those services provided currently by RW that will not be covered by health insurance. As the remaining states (i.e. CA, NY, IL, GA, CT) have mature CDC names-based reporting systems in place, despite the hold harmless provisions of Part A, formula funding allocations will shift away from the Denver TGA to EMA's in those states. The total federal allocations to RW will not meet the increasing demand of increased patients due to the continuing economic downturn. The funding provided by the State General Assembly & Tobacco Settlement Funds for ADAP, a necessary component of primary medical care, is very much in jeopardy with budgetary constraints on the state. Additionally, as more individuals who are currently not in care are identified & access care greater demand that may not be sustainable could develop. Only if Health Care Reform provides current RW funded individuals with adequate health insurance can the demand for care be met. (We are clearly at a tipping point.)

Key Informant Interview—Lorenzo Ramirez, July 1, 2010. — In person Interview

Please think about how individuals with HIV-Disease access primary medical care in the 6-County Greater Denver Area[1]

1. In your opinion what is working with the system of HIV-care?

Informant has experience in the COBRA, Kaiser and (most recently) Denver Health systems. Within the Denver Health ID Clinic, there is good follow up, expertise, emphasis on medication and the location is practical. The ID Clinic has HIV-specialized providers, even some who are HIV positive themselves—makes clients feel that they have a vested interest and can relate well.

2. In your experience, what are the challenges of using the system of HIV-care?

Navigation of the system is a serious challenge, especially for the newly diagnosed and non-English speakers. More client advocacy is essential for: explaining what services are available, filling out paperwork, signing up for various assistance programs, scheduling and reminding clients about appointments, and adherence to meds. The case loads of client advocates are currently too big with limited resources.

3. As a representative of (consumers, policy makers, medical providers or support service providers), where are the major gaps in services for those with HIV-Disease?

Connecting newly diagnosed with advocates/case managers. Follow up support, including reminders about appointments. Technology seems to be an untapped resource. More mental health services are needed, specifically psychologists. There is a gap in the use of dental services, patients need more education about the importance of oral hygiene and it's affect on overall health. In general, more education is needed.

4. In your opinion, what will the system of HIV-care will look like in the next 3-5 years?

HIV as a chronic disease is falling off the radar and the old prevention messages will no longer be effective. Prevention messages and awareness campaigns should focus on new themes and should be connected with other health initiatives (general health, wellness and manageable diseases). We should work to keep care and meds covered even though funding may be reduced. Mental health should be a greater focus. There should be more of an emphasis on including families in addition to patients—families should be involved in education and programs.

Suggestion: Affected/infected communities and individuals should be involved in planning for future care, and their input should be addressed.

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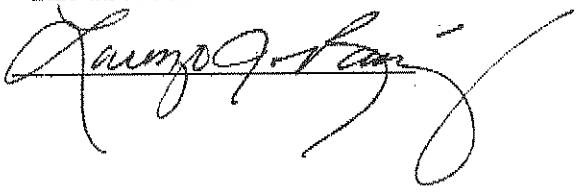
[1] As with any qualitative research, responses will prompt clarifying questions. Because those clarifying questions cannot be anticipated, they can only be listed following official approval.

Key Word Definitions: For consistency, the following terms of definition will be offered to all interviewees:

- Care – access to primary medical care and medications to treat HIV-Disease
- Consumer – Individual infected with HIV Disease, using Ryan White services
- Core clinical services – Dental, medical, or pharmaceutical care

***The above information is accurate.**



Key Informant Interview –Robert George July 15, 2010 – Phone Interview

Please think about how individuals with HIV-Disease access primary medical care in the 6-County Greater Denver Area[1]

1. In your opinion what is working with the system of HIV-care?

The systems for the un/under-insured, such as CICP and ADAP, are working well and it is an easy process to get clients into. Primary medical care clinics understand the care needs of HIV positive individuals as well as the general barriers that impact care. Colorado AIDS Project's case management system has great a relationship and strong communication with the clinics. Monthly conferences are held with Colorado AIDS Project and the 3 main public clinics (2 DH and 1 University). In general, support for patients entering care, continuing care and exiting care is good. Patient navigation of the system seems to work well with use of medical and non medical case management.

2. In your experience, what are the challenges of using the system of HIV-care?

Clients have trouble getting meds through clinic pharmacies because of the copay. Financial assistance is available but the process and time that it takes make getting meds affordably, in a timely manner, difficult. If patients seek non-HIV-care outside of Denver Health, that process is difficult especially for those who are uninsured or underinsured. Helping patients prioritize HIV-care long term can be difficult. Clients need support in preparing the paperwork and documentation required for CICP and ADAP; they don't always have all the information they need for such appointments.

3. As a representative of (consumers, policy makers, medical providers or support service providers), where are the major gaps in services for those with HIV-Disease?

There is a gap in services for people exiting incarceration. This population may be overwhelmed with finding housing, jobs, parole expectations, etc.; therefore, healthcare is sometimes a low priority—linkage to care, services and support geared towards this population are needed.

Also, in general, individualized therapy and counseling is lacking—there are not enough resources to provide individualized therapy to those who need it.

4. In your opinion, what will the system of HIV-care will look like in the next 3-5 years?

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In a few years, things may not be that different because systems are slow to change. Not sure how the new healthcare policy will affect Ryan White funding and services. If there is a decrease in funding, the worry is that there will be a decrease in the level of service. The hope for the future is that, at a minimum, currently established services will be maintained. Would like to see an increase in support services and better quality services; specifically, a more manageable and effective case management system and better support for mental health and substance abuse issues. For the future, we should focus also on Non-HIV health care issues that will be affecting HIV-positive individuals and how those can be addressed in order to have a more holistic affect on the health of those infected with HIV.

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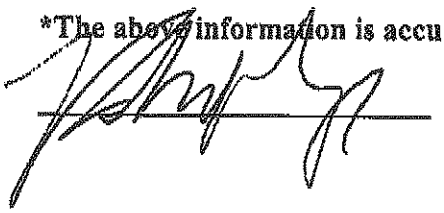

Key Informant Interview—Kari, July 1, 2010. – Phone Interview

Please think about how individuals with HIV-Disease access primary medical care in the 6-County Greater Denver Area[1]

1. In your opinion what is working with the system of HIV-care?

The ADAP and Insurance Continuation programs are working well in spite of the fact that administrators often seem to be flooded. I also think that the fact that there is an avenue of care for the uninsured/underinsured at DH is good. I think that depending on which institution you access case management/psychosocial support CAN be wonderful (although on the flip side it can leave a lot to be desired).

2. In your experience, what are the challenges of using the system of HIV-care?

While our system/services have not been cut to the bare bones I do feel that are many areas where we could improve and a few where we have a void. I have found that for many people it is difficult to navigate the system; specifically, filling out the correct paperwork, obtaining the correct supporting documentation, and only having to complete the same (or very similar) paperwork once (not three times for the three places you get service (for example CAP, CHIP, Howard dental). I think patients are often asked to repeat information or processes which fosters a disenchantment with the system as a whole (while I think/know/understand paperwork is important streamlining the process could alleviate this issue.

I also see that there are huge language barriers in the system, not just non-english speakers but also when explaining services/populations/categories using terminology and concepts that patient do not always identify with or understand. In my opinion it is essential to have forms, explanations and dialogue in a manner that patients can comprehend.

In Colorado the system is MSM-care focused. Services are not directed towards women or youth and the unique issues they may have, i.e. bringing children to appointments, women's health, volatile lives, substance abuse needs, mental health issues etc. Even prevention/outreach/educations seems to be directed at the msm/gay community and that is typically where the message stops. 25% of the infection rate in this state is women and youth tend to be the fastest growing category for new infection nationwide.....it's time to share the pie.

Location/transportation is often an issue; for people living in less centralized areas of the TGA finding care can be difficult.

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3. As a representative of (**consumers**, policy makers, medical providers or **support service providers**), where are the major gaps in services for those with HIV-Disease?

Services are lacking for undocumented populations, refugee populations, women and youth overall. It's difficult to get comprehensive care that is not gay-centric. It can be difficult to access support services from the various organizations that offer them (i.e. CAP, Empowerment, etc.) and while I know the Planning Council does not have control over specific organizations it would be beneficial if all organizations administered benefits the same way across the board. For example, a client might get $7.00 toward a phone bill from one ASO and $20.00 if they accessed assistance from another ASO. This issue falls more to the actual Denver Office of HIV Resources so I am not sure what the Planning Council can do to remedy the situation. It seems that because of whatever history is out there it is often difficult to get long term survivors and providers to participate in feedback and discussion in more meaningful ways. Everything I listed above in question #2 seems to be, in my mind, a challenge as well as a gap in the system.

4. In your opinion, what will the system of HIV-care will look like in the next 3-5 years?

Scarcity of resources may result in cutting back on services in a system that already presents many challenges and gaps. Identifying HIV as a chronic disease is double edge sword and I am not sure we can handle the strains of consistent new infections rates coupled with the every present aging hiv population, financially or systematically. It is important that we enhance prevention, with general prevention education rather than geared towards specific populations. I think that building better partnerships and streamlining processes (more complete packages) will go a long way to cutting costs and creating better complete care for PLWHA.

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Kari Hall

Signature

Key Informant Interview

Carol Lease, Women's AIDS Project, the Empowerment Program — July 22 - Emailed Interview

Please think about how individuals with HIV-Disease access primary medical care in the 6-County Greater Denver Area[1]

1. **In your opinion what is working with the system of HIV-care?**

a) ADAP – Colorado has been able to get people who need assistance medications;

b) The I.D. Clinic at DPH has a good staff that works well with women living with HIV/AIDS;

c) Case management services (medical and non-medical) provide the glue that keeps both the newly diagnosed and individuals who have multiple barriers to medical treatment and adherence (homelessness, drug use, mental illness, racial and ethnic health disparities, incarceration, poverty, involvement in the criminal justice system) connected to medical care;

d) The provision of supportive services funded by Ryan White – transportation, emergency assistance, food help keep PLWHA who are living in poverty connected to vial case management and medical services;

2. **In your experience, what are the challenges of using the system of HIV-care?**

The Denver TGA has succeeded in developing an efficient, accessible continuum of care for PLWHAs. However, the success of the coordination of Care and Prevention services has yet to be realized in part due to the fact that the process is barely two years old and also due to the challenges involved in addressing a variety of issues concerning rural, urban, state, local government and community organizations.

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Carol Lease
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3. As a representative of (consumers, policy makers, medical providers or support service providers), where are the major gaps in services for those with HIV-Disease?

a) Employment and training services for PLWHAs who are able to work but may have intermittent periods of unemployment due to health issues throughout their lives.

b) Secondary prevention services for PLWHAs.

c) Syringe exchanges for PLWHAs who are injecting drugs.

3. In your opinion, what will the system of HIV-care will look like in the next 3-5 years?

a) The effect of Health Care Reform on Ryan White funded services in Colorado;

b) Colorado's on-going budget crisis;

c) The common belief is to treat HIV infection like any other chronic disease but the reality is that there is still tremendous stigma associated with PLWHAs that does affect access to testing and care, especially for marginalized populations.

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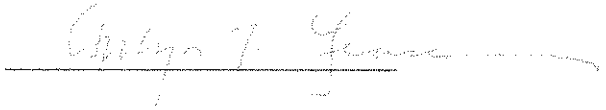

Key Informant Interview Kate Leos, Women's AIDS Project, the Empowerment Program July 21 – Emailed Interview Medical Case Manager (card lease requested)

Please think about how individuals with HIV-Disease access primary medical care in the 6-County Greater Denver Area[1]

1. **In your opinion what is working with the system of HIV-care?**

There a lot of things that are working well. The staff at the ID clinics, particularly the team at Denver Health, work hard to engage and keep high-risk patients in care. Medical and non-medical case management are both integral parts of the system, and continue to be vital in the support of participants on many different levels. The ADAP system has stayed strong, even through financial challenges, and everything that is funded by Ryan White (transportation, emergency financial assistance, etc.) help keep our participants connected to services.

2. **In your experience, what are the challenges of using the system of HIV-care?**

I think overall, the continuum of care works well. The challenges I've seen participants struggle with include fear of accessing services and a lack of knowledge about what is available to them. Stigma is still a major issue, especially in marginalized populations, so education is imperative, both in prevention and in care.

3. **As a representative of (consumers, policy makers, medical providers or support service providers), where are the major gaps in services for those with HIV-Disease?**

I think more opportunities for participants to *do* something with their days, whether it's training as peer advocates, volunteer opportunities, or support to go back to work. Once participants get stable (housing, medical care, off substances, etc.), many of them are then at a loss with how to spend their time.

4. **In your opinion, what will the system of HIV-care will look like in the next 3-5 years?**

I look forward to finding out how the new health care reform will affect Ryan White funding and services – I think that will be a key component of how our system will change. I also anticipate many changes in case management – certification programs for case managers, a triaged system, etc.

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