

## **DHRPC – Key Informant Interviews for Evaluation and Assessment Committee**

Brooke Bender, MPH

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Didi Fahey, PhD

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Key Informant interviews were established to inform the DHRPC of details not covered with the quantitative analyses of existing data (Annual Data Plan). Individuals selected for these interviews currently have the reputations of holding information specific to their representative group.

### **Procedure:**

Individuals selected as Key Informants were asked to participate in a 20-30 minute in-person or telephone interview, or respond to questions via e-mail. Prior to releasing information to the DHRPC, all interviewees will be asked to review their responses and approve of their release in writing. Only at that time, will all responses be made part of the public record.

Selection of the Key Informants began with a nominating process at the Evaluation and Assessment Committee meeting on April 22, 2010. At that meeting, it was decided that two individuals each from Policy, Consumers, Medical Providers, and Support Service Providers must be selected by the committee.

Selected individuals were emailed an invitation to participate. They were informed of both the nature of the interview and of the questions to be asked. Additionally, they were informed that their participation was completely voluntary and they may withdraw from participation at any time during the process. As it will become part of the public record, no withdrawal will be permitted after written approval of their transcribed interview has been obtained from the interviewee.

### *Email Invitation:*

You have been identified by members of the Denver HIV Resources Planning Council as a key stakeholder who would be beneficial to interview as part of our 2010 needs assessment. This is a unique opportunity to share your perspective relating to the current and future needs of HIV positive individuals and services in the area. The interview will take approximately 30 minutes and we will work with your schedule to try to meet in person, on the phone or over email. After the interview, the information will be compiled for you to review and approve before it becomes part of our report.

If you would not like to participate, feel free to respond to this email. Otherwise please expect a call in the near future from one of our members, who will explain more and schedule an interview time with you.

Thank you.

*Phone Calls:*

Two of the DHRPC Evaluation and Assessment Committee members volunteered to conduct the key stakeholder interviews: Brooke Bender, MPH and Joshua Blum, MD. Brooke was responsible for interviewing the Consumers and Support Service Providers, while Josh interviewed the Policy and Medical Providers.

*Questions:*

The following questions –in the order listed below –were asked during the interviews. Please remember that interviews took place over the telephone, in person, or through e-mail. No interview lasted longer than 30 minutes, and all responders were asked to review and approve their responses in writing.

Please think about how individuals with HIV-Disease access primary medical care in the 6-County Greater Denver Area<sup>1</sup>

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

*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
- Denver – 6 Counties comprising the Greater Denver Metropolitan Region (Adams, Arapahoe, Broomfield, Denver, Douglas, Jefferson)
- Future – 3-5 years
- HIV-Disease – HIV/AIDS
- Non-medical support service providers (non medical case management)

*Analysis:*

After all of the approved responses were collected, they were compiled and analyzed for common themes. Responses were also compared by participant group, i.e. Medical Providers, Policy, Consumers and Support Service Providers.

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<sup>1</sup> 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.

## **Results:**

### *Participants:*

All eight of the approached Key Informants agreed to participate and one extended the invitation onto a coworker from her agency. Therefore, we collected a total of nine responses; five via email, two via telephone, and two in person.

### *Medical Providers:*

- Bill Burman, MD, Denver Health (in person);
- Steven Johnson MD, University of Colorado School of Medicine (email)

### *Policy Representatives:*

- Jean Finn (email)
- Peter Ralin (email)

### *Support Service Providers:*

- Robert George, Colorado AIDS Project (phone)
- Carol Lease, Empowerment Program (email)
- Kate Leos, Empowerment Program (email)

### *Consumers:*

- Kari Hartel (phone)
- Lorenzo Ramirez (in person)

Common themes across participant groups:

- 1. In your opinion what is working with the system of HIV-care?**
  - ADAP
  - Communication, collaboration, referrals
  - Access for under/un-insured
  - Good spectrum of care/services
  - ID clinics
  - Medical and non-medical case management
  
- 2. In your experience, what are the challenges of using the system of HIV-care?**
  - Navigation of the system, clients' paperwork
  - Funding
  - Coordination of care, seeing multiple providers in different locations
  
- 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?**
  - Mental health/counseling services
  - Focused attention on subgroups: newly diagnosed, recently incarcerated, women, youth, undocumented people
  - Retention of care
  - Employment services
  
- 4. In your opinion, what will the system of HIV-care will look like in the next 3-5 years?**
  - Unsure of how health care reform will affect RW services
  - Medicaid taking on more of our clients
  - Worry about services being cut

Responses broken down by participant groups:

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

*Medical Providers*

- Good spectrum of 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.

*Policy*

- Broad array of clinical and supportive services
- Collaboration/referral among providers
- Indigent patient care
- CPCRA Program (DH) & an ACTG (UCH)

*Support Service Providers*

- Services for under/un-insured: ADAP, CICIP
- Relationships and communication between CAP's case managers and clinics
- Medical and non-medical case management.
- ADAP
- The ID clinic at DPH

*Consumers*

- ADAP program
- Access for un/under-insured
- Provider follow-up and expertise at DH
- ID clinics
- Medical and non-medical case management

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

*Medical Providers*

- Geographic and administrative limitations
- Primary care and case management take place in different geographic locations
- Resources for out-of-county and undocumented HIV positive persons
- Funding
- Lack of integration and information sharing amongst RW funded organizations
- Requirements for data entry and reporting

*Policy*

- The fragmentation of the system and the need to go to multiple practitioners
- Navigation of the system
- Barriers to health care and the ability to stick with treatment regimes
- Linkages to care
- Ensuring an adequately funded continuum of care

### *Support Service Providers*

- Medicine copay
- Paperwork
- Obtaining financial assistance in a timely manner
- Coordination of care and prevention services
- Stigma
- Education

### *Consumers*

- Navigation of the system, paperwork
- Few services directed towards women and youth
- Navigation of the system for newly diagnosed and non-english speakers, paperwork
- Case load of client advocates are too big

### **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?**

#### *Medical Providers*

- Comprehensive care
- Metro Denver jails outside of Denver County
- Lack of full access to specialty care
- Expansion of the ADAP formulary
- Back to work programs and getting patients off of disability

#### *Policy*

- Evidence based prevention interventions designed for clinical practices
- Resources for substance abuse, mental health services, transportation, housing & other services to enhance access to & retention in care & medication adherence
- Identifying individuals who are not in care & getting & retaining them in care

#### *Support Service Provider*

- Services for those exiting incarceration
- Individualized therapy and counseling
- Employment and training services
- Secondary prevention services
- Syringe exchanges

#### *Consumers*

- Services for undocumented people, youth and women; difficult to get comprehensive care that isn't gay-centric.
- Connecting newly diagnosed with case management
- Follow up support
- Mental health and dental services

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

*Medical Providers*

- Ryan White Care Act will shrink. With the new Affordable Care Act, CICP rolls should go down. Expansion of Medicaid eligibility 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.
- Patients on CICP will move to high-risk insurance pools or Medicaid, leading to improved coverage of medications and improved access to specialty care and procedures. Ryan White funds will still be important in funding certain activities that simply won't be possible under Medicaid. The system will need to be fully focused on comprehensive HIV primary care.

*Policy*

- HIV care will be integrated into the health care system as a whole and normalized, with case management and support services.
- ADAP is in jeopardy with budgetary constraints on the state. Only if Health Care Reform provides current RW funded individuals with adequate health insurance can the demand for care be met.

*Support Service Providers*

- Possible decrease in funding and services
- The effect of health care reform on RW services, CO's budget crisis, can't be treated as other chronic diseases because of stigma
- Changes in case management—certification programs for case managers and a triaged system

*Consumers*

- Scarcity of resources may mean cutting back services, should have general prevention strategies rather than geared towards specific populations
- HIV is falling off the radar, come up with new prevention messages, include families, meds and mental health should be a focus

**Summary:**

Of the nine responses we received, there were a number of common themes. Overall, participants were positive about the general system of HIV-care. Denver Health, the ID clinics and case management were all highlighted as services that are working well. The challenges identified with using the system mostly related to patient navigation of the system, logistics and coordination of care. It seems that both providers and consumers would like to see more support for navigating the system and development of the system to where patients can apply for and access services more efficiently. Participants pointed out gaps in specific services, such as mental health and employment services, but also identified areas that need more focus such as attention of individual populations and working to ensure retention of care. The participants were both hopeful and concerned about how the health care reform will affect Ryan White funding and services. Most believe there will be gaps in the health care system that will require Ryan White supplementation. Overall, there were not significant differences in responses between the participant groups.