



THE DURHAM HEALTH INNOVATIONS PROJECT

DURHAM

Health

INNOVATIONS

HIV/STD/HEPATITIS

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Executive Summary

The greatest and most persistent communicable disease challenges faced by Durham County residents are from sexually transmitted diseases (STDs), including HIV/AIDS and its co-morbidity with infections that share common risk factors such as viral hepatitis. The high rates of preventable AIDS deaths in Durham indicate that a significant number of people in Durham are either not being diagnosed early enough in the progression of their HIV disease, or that they are not entering care, or are being lost to care at some point after diagnosis.

The Durham Health Innovation's HIV/STD/Hepatitis Team followed decades of partnership and collaboration between community groups, faith-based organizations, health providers, and service organizations. Team members participated in an eight-month planning process including input from a Community Outreach Working Group, a Clinical Working Group, focus groups, key informant interviews, a pastor's meeting, and a community town hall meeting.

The Team's model of care applies the care coordination model for persons with infectious diseases including HIV/STDs/hepatitis, and has recognized the need to combine both medically-oriented and social (community-based) models under a network approach. While the term "integrated" can refer to a care coordination model with both medical and social components, we also use the term as an approach to care and prevention of HIV/STDs/hepatitis due to shared risk factors. A network approach between agencies providing services for persons at risk or diagnosed with these infections is critical to our integrated care coordination model in order to facilitate the exchange of information about client needs and available services, and to reduce the number of individuals not available to access care or are lost-to-care by establishing an interagency "safety net" of resources for the community.

Our model of care is contingent upon inter-agency networking of comprehensive prevention and care services: 1) coordinated and accessible patient care for persons with HIV/STD/hepatitis in the community including after hours, with a focus on secondary prevention of infections (i.e. STDs in HIV-infected persons, HIV infection in patients with hepatitis C), 2) care bridge coordination (CBC) for persons newly diagnosed with HIV or HIV-infected persons who are lost-to-care in order to link them with medical and psychosocial assistance; 3) a shared database between providers with basic client information to facilitate quality care and CBC; 4) integrated clinic and community-based testing for HIV/STD/hepatitis with screening for other infectious and chronic diseases; 5) combined approach to education for the public, faith-based organizations, healthcare providers and patients "bundled" with other chronic or communicable diseases; and 6) coordinated public information activities for HIV/STD/hepatitis to increase awareness and acceptance of these diseases and primary prevention activities. The model of care in essence includes care coordination of services (medically-oriented model) and community coordination (social model), with the assumption that the care of individuals at risk for or with HIV/STDs/hepatitis cannot be successfully attained without optimizing the information and prevention strategies available in the community and the individual's sociosexual network that may be hindered by lack of awareness, information, or stigma with regards to these infections.

Our model of care will have both financial and operational impacts on providers of clinical services for HIV/STDs/hepatitis (e.g., DUHS, DCHD, Lincoln EIC) as well as economic impact on the community. Maintaining persons in care will result in both costs and benefits, though the overall net impact will yield significant cost savings. Components of the model are generalizable to other urban communities experiencing high morbidities of HIV/STDs/hepatitis as the problems noted in Durham County are not unique.

Our model of care will improve key health metrics including incidence rates of HIV/STDs/hepatitis, percent of youth and adults testing for HIV/STDs/hepatitis, percent of HIV-infected persons who enter and remain in medical care, utilization of health care services including outpatient, emergency department visits and inpatient hospitalizations. Although the volume of testing in the community may not substantially increase from its current volume, coordination of primary prevention services should increase efficiency of activities to reach populations not well accessed by existing programs (i.e. intravenous drug users, commercial sex workers). Care bridge coordination will assist by providing a safety net for HIV-infected persons in the community who are not in care due to psychosocial issues that cannot be addressed by healthcare providers alone.

HEALTH NEEDS & METRICS

- ◆ State the health issue concisely
- ◆ Define health needs county-wide and within subpopulations: race, gender, income, insurance status (private, Medicaid, SCHIP, Medicare, none), geography, Duke-covered lives
- ◆ What environmental components contribute to the health needs
- ◆ Comparison to state and national numbers
- ◆ What are the key health metrics that can be used to measure the current state of health and to judge whether we have an improvement in health in Durham County?

Health Issues. The greatest and most persistent communicable disease challenges faced by Durham County residents are from sexually transmitted diseases (STDs), including HIV/AIDS and its comorbidity with infections that share common risk factors such as viral hepatitis.

Durham currently ranks third highest among the state's 100 counties in rates per capita of HIV and AIDS. The death rate per 100,000 due to AIDS is 9.6 in Durham compared to 5.2 across North Carolina. *The AIDS death rate for Blacks in Durham County is 30/100,000.* These high rates of preventable AIDS deaths in Durham indicate that a significant number of people in Durham are either not being diagnosed early enough in the progression of their HIV disease, or that they are not entering care, or are being lost to care at some point after diagnosis. HIV/AIDS and other STDs disproportionately affect African Americans persons in North Carolina. In 2007, the rate of HIV infection among African Americans was 78.2 per 100,000, more than seven times that of Whites (10.7 per 100,000). The highest concentration of new infections is among African American men, at a rate of 108.5 per 100,000, which is almost six times greater than that of Whites. The largest disparity occurred among African American females with a rate of 52.4 per 100,000 for new diagnoses – this rate is more than 16 times higher than that of White females (3.2). In 2006, HIV/AIDS was the 9th leading cause of death for African Americans in North Carolina and the 7th leading cause of death for African Americans aged 25-44.

Durham also has one of the highest rates of STDs in North Carolina. Syphilis is an STD that significantly increases a person's risk of acquiring or transmitting HIV. For 2008, Durham ranked 4th for the number of early syphilis cases in North Carolina. There continue to be serious racial/ethnic disparities in STD rates. In Durham, in 2007, the rate for gonorrhea, the most easily transmitted STD, was 12 times higher among Blacks than Whites (650.2 per 100,000 in Blacks as compared to 54.6 per 100,000 among Whites and Chlamydia rates were 11 times higher than Whites (911.5 per 100,000 in Blacks as compared to 82.8 per 100,000 among Whites). The reasons behind these racial/ethnic disparities nationwide are complex, but are likely due to the interplay of contributing factors including poverty, unequal access to health care, stigma and social networks. These challenges were identified in the 2007 Durham County Community Health Assessment, in which 57% of adults surveyed believe that these diseases are a major problem in Durham.

The biological and epidemiological synergies between the HIV and STD epidemics are well recognized, and preventive approaches addressing co-infections are crucial. For example, the recent HIV epidemic among young Black men in North Carolina has been accompanied with a concerning 4-7% rate of co-infections with early syphilis (Sena, et. al 2008). Although rates of acute hepatitis B and C have declined nationwide, a high proportion of cases are known to occur among injection drug-users, men who have sex with men (MSM), and persons with multiple sexual partners. According to the CDC, as many as 10%–40% of adults in STD clinics have evidence of past or current hepatitis B infection, and approximately 25% of HIV- infected persons nationwide are also infected with hepatitis C. Therefore, despite the observation that only 9 cases of acute hepatitis B and 2 cases of acute hepatitis C were reported in Durham County in 2007, these diseases deserve attention due to the significant morbidity and health care costs incurred in their chronic phases.

Environmental Components. Environmental components and underlying causes of this disproportionate impact of HIV and STDs on African Americans in Durham are individual, relational, and societal in nature. Individual risk behaviors, which are not unique to racial/ethnic minorities, include lack of HIV knowledge, unprotected sex, multiple sex partners, and sex with commercial sex workers, substance use, and sharing injection equipment. Beyond individual risk factors, relationship dynamics also can increase risk for HIV and STDs, especially among women. Even with sufficient knowledge of HIV prevention, some women may not be able to demand that their partners use protection. Condom negotiation can be compromised by power imbalance, partner violence and abuse (sexual, physical, emotional, financial), and fear of abandonment. Finally, there are societal factors that affect HIV and STD risk in the African American communities in Durham. Across the globe, poverty has been shown to have a direct correlation with HIV and STD rates. Durham County has a large gap between rich and poor, and racial/ethnic minorities are more severely impacted by poverty than Whites. Current census data shows that nineteen percent of African Americans in Durham are living below the poverty level, compared to fifteen percent of the population of Durham overall. Poverty is associated with low educational attainment, fewer job opportunities, discrimination, less social support, substance use and trade, and higher rates of teen pregnancy—all of which contribute to HIV/STD risk. Studies have shown that racial/ethnic minorities with HIV/AIDS tend to receive diagnosis and treatment later in their course of illness compared to Whites, which leads to a shocking and unacceptably large disparity in preventable, premature AIDS deaths among African Americans.

Unmet Needs. Although the STD burden appears greater in numbers than HIV, the cost of HIV care and the chronicity of this infection create a larger public health dilemma, especially when a significant proportion of HIV disease occurs among persons with limited access to health care. There are no exact assessments of the “unmet needs” for HIV-infected persons in Durham County (defined as those who are aware of their status, but are not accessing HIV primary health care), but the North Carolina HIV/STD Prevention and Care Unit (NC Department of Health and Human Services, 2008) estimated that 38% of state residents with HIV disease are not “in care,” using data from the HIV/AIDS reporting system (HARS), Medicaid and the AIDS Drug Assistance Program (ADAP). Based on the same estimated proportion for the unmet HIV needs and the reported 1,240 persons living with HIV disease in Durham County, there are approximately 471 individuals with known HIV infection who are not in care in our community.

In addition to those with “unmet needs”, the Centers for Disease Control and Prevention (CDC) also estimates that 25% of persons living with HIV infection in the United States are unaware of their status. In 2006, the CDC expanded their recommendations to include routine HIV screening of all adolescents and adults in healthcare settings, regardless of perceived risk. However, the 2007 Durham Community Health Assessment found that 23% of residents do not have a personal health care provider, and that only 46.8% of persons under 65 had ever been HIV tested. Therefore, expanding HIV screening

in non-clinic based locations, including community centers or in neighborhoods, merits further consideration in order to reach high-risk individuals that have very little contact with Durham County health care systems. The development of new strategies to integrate HIV screening with other preventive services such as STD and hepatitis testing is likewise needed.

The challenging economic environment exacerbates already difficult situations among lower income residents of Durham. Typically in a serious economic downturn, health indicators can be expected to worsen, as people devote their limited resources to other, more immediate needs such as food, housing, and transportation. Accessing health care, particularly preventive services even if offered free of charge, becomes a lower priority as people dedicate their time, resources, and attention to more immediate needs, such as employment, food, housing, and transportation. Creative approaches and incentives may be needed to link community members' immediate concerns with opportunities to access public health education and information, testing, referrals, and services.

Table 1. HIV and STD infections, Poverty and Uninsurance Rates, Durham County, NC, and USA

	HIV infections	HIV rate	HIV – AA	Chlamydia	Gonorrhea	Poverty Rates	Uninsured
Durham June 09	37	29.2	19	823	303	18.3%	18%
NC June 09	834	20.1	584	22,683	7,585	14.3%	16%
USA 2007	337,590	---	1,030,832	1,108,374	335,991	13.2%	15.3%

Key Health Metrics. There are a number of key health metrics that can be used for baseline data and to judge improvement in health of the next five years, including the following parameters:

- Incidence rates of HIV infection, STDs and hepatitis B and C in Durham
- Percentage of youth and adults in Durham who have undergone HIV, STD and hepatitis testing
- Percentage of HIV-infected persons who enter care (receive a medical evaluation following their diagnosis) and remain in medical follow-up
- Utilization of health care services including outpatient clinics, emergency department visits and inpatient hospitalizations.

BUILDING THE TEAM & COMMUNITY ENGAGEMENT

- ◆ How did your team come together?
- ◆ What is the full complement of existing programs, resources, and partnerships in Durham County relevant to your team's primary focus?
- ◆ How did the existing programs, resources and partnerships shape your team's thinking?
- ◆ How did you ensure broad community input and involvement?
- ◆ What input/assistance did you get from the Oversight Committee and the technical assistance cores?
- ◆ What did the community engagement process teach your team about the problem and about each other?

History. The HIV/STD/hepatitis planning team formed readily due to decades of partnership and collaboration between community groups, faith-based organizations, and health providers and service organizations. Planning group members participated actively in the planning process throughout and

sought additional community input through presentations and discussions with existing community coalitions and organizations, which include community members and health care consumers, as well as agency staff, in their membership. These include the HIV/STD Committee of the Partnership for a Healthy Durham, the Duke University AIDS Research and Treatment (DART) Center Community Advisory Board, the Lincoln Community Health Center EI Clinic Community Advisory Board, the Durham Coalition on Adolescent Pregnancy Prevention (DCAPP), North Carolina Central University's Project SAFE (a youth peer education program), Family Health International's LINC2 Durham HIV Prevention Participatory Research program, and the Durham Faith Community on HIV/AIDS.

Working Groups. In May, the Planning Group formed two working groups - a Community Outreach Working Group and a Clinical Working Group - which were tasked with bringing the community or clinical perspective (respectively) to the planning process. They each sought to identify methods to establish a baseline for key variables in a 5-year plan, to identify methods to increase coordination between existing HIV/STD/hepatitis services, to identify methods to increase coordination between services, and to assess the needs of special populations. The groups met from May through August. Full planning group meetings resumed at the end of July, and have continued to meet regularly.

Focus Groups, Key Informant Interviews, Town Hall Meeting. To solicit community input regarding the issues of HIV/STDs/hepatitis, we conducted focus groups, key informant interviews, a pastor's meeting, and a community town hall meeting. Focus groups were held with youth, Spanish speaking Latinos, HIV-infected clients of the Lincoln Community Health Center's Early Intervention Clinic and the Duke Infectious Diseases Clinic, adult students at North Carolina Central University, and members of an African American church in East Durham. Key informant interviews were held with three HIV-infected clients who had been lost to care and are currently back in care, and receiving support from a care bridge coordinator. The pastor's luncheon meeting included 23 pastors and 2 lay persons serving Durham churches of many different denominations. About half the participants were African-American and half were white.

Detailed information from the focus groups, interviews and meetings are included in the Appendices. Some of the main findings from these include:

1. Stigma is still a very large barrier to getting tested and for getting care.
 - a. Some people wouldn't want anyone to know.
 - "If I see someone who knows me, I won't want to get tested."
 - "I didn't want *anybody* to know. ... People talk about you so bad. When people know, they don't want you to use their bathroom; they think [the virus] will jump on them."
 - b. Some people wouldn't want to know their own status.
 - "Everyone thinks, 'Nobody will love me, everyone will reject me.'"
 - c. Fear that the medications don't work, don't trust doctors and health care
2. Cost and/or fear of cost is a barrier
 - "Cost is a BIG problem. I've got a lot of bills to pay and no money coming in. I hear from collection agencies, and get bills in the mail."
 - "If I cannot pay the co-pay, if I don't have the money for that, I will wait."
3. Transportation is a barrier to getting care
 - "Most of my friends don't have cars. My relatives don't have time and charge me for a ride."
 - "It takes half a day, and I would take 2 buses. I had to wait 40 minutes for one, and 40 minutes for another one. Now I use a bicycle, it takes up much less time. When I was sicker, I couldn't go by bicycle."

4. Pastors feel they need help in discussing HIV/STDs/hepatitis with their congregation
 - Pastors said congregants don't discuss HIV, "My father's youngest brother passed away from HIV/AIDS, but it was kept quiet in our family, and we still do not discuss it.
 - "HIV is today's leprosy."

Approximately 65 people attended the Town Hall forum that was held at the Hayti Heritage Center despite rainy weather. During informal conversations prior to the presentations, several people commented how unique and important it was to be giving the information back to the community. People were attentive during the presentations, and there were lively discussion periods after the presentations of our research findings and our proposed model of care. In response to our focus group findings, some Town Hall participants expressed surprise that stigma to HIV and STD testing was still a major issue, and that youth in the community were self-conscious about HIV and STD testing. Other participants provided suggestions, such as drawing on highly motivated HIV-infected patients in helping engage other people with HIV infection into care, and using their church as a resource in teaching pastors how to provide faith-based sex education to youth in the congregations. Participants agreed that our work with focus groups should be continued, and that additional data is needed from injection drug users, commercial sex workers, and recently incarcerated persons. In response to the model of care, Town Hall participants were unanimous in their support of a highly integrated, collaborative network model for HIV/STDs/hepatitis that provides individualized support to persons who are not in care or who have fallen out of care. Participants made detailed suggestions as well, such as increasing awareness and funding dollars for hepatitis C testing.

Oversight Committee Assistance. The HIV/STD/hepatitis team participated in meetings of the Project Directors, Cluster C technical assistance, and co-leads as arranged by the Oversight Committee. The team was provided feedback by the Oversight Committee following presentation of the team's process and care model. Presentations and discussion by members of the Oversight Committee with the Project Directors and Co-Leads facilitated understanding of DHI's process, intent, and expectations as well as supported development of the team's process and care model.

The Implementation Core assisted in developing the care model and identifying common elements and synergies across DHI teams. Issues identified included health reform, integrated health records, integrated care models, focus groups and key informant interviews, care bridge coordination and patient navigators, and social marketing. The vision provided through discussion with key Oversight Committee members provided clarification and guidance on potential and expected project outcomes. Consultation was held with Bobbie Berkowitz about our planning process and team structure.

The Data Analysis Core (DAC) assisted in developing IRB protocols, identifying plans for and abstracting and analyzing DSR data including geo-spatial mapping and statistical analyses. Additionally, support included defining outcomes for quantitative data analysis, and clarifying ICD-9 (diagnosis) and v-codes. Geo-spatial mapping included HIV infections overlaid with HIV testing sites, crime incidence such as prostitution and a composite of violent crimes, and several other publically available data sets made available to all DHI teams. The DAC addressed issues of access to and security of DSR-generated data. This core also supported qualitative data gathering that includes focus groups, key informant interviews, and a town hall meeting.

Team Lessons. The community engagement process taught our team about key issues regarding HIV/STDs/hepatitis. We knew that stigma was an issue, but it appears to be a much bigger concern than we had previously realized. We were surprised that concerns about cost were still a barrier, despite that a

lot of free testing is already available for HIV and STDs in the community, and that both Duke Infectious Disease Clinic and Lincoln Community Health Center's Early Intervention clinic provide patient assistance to help cover costs. However, patients in the Duke system do get frightening calls about their bill from the business office (that may lead them to drop out of care) even though the ID clinic has identified resources to cover their care. We acknowledged the frustration that despite all the work that may be done to keep a patient with HIV in care, one call regarding the cost of services can result in losing that patient to care.

The community engagement process also taught us about the need to develop more trust between institutions like Duke, UNC and other community agencies. On several occasions, we learned about programs or resources that have been in existence for some time in the community, but were unknown to our participants.

We heard from many community members that expressed their lack of trust in the Duke University system and their intentions:

- People believe that the people/staff of Duke don't want to talk to the community until there is money involved (e.g., a grant).
- Duke does not have the best community relationships, and the community is mistrustful of Duke's motivations.
- Pastors feel that Duke and community people (including churches) need to do a better job at building a level of trust with the community they are serving.
- Churches are not just a fly by night project because there is money or a grant at hand. The community needs to know that what Duke is presenting will be around for the long term and not because of a short term grant.

However, many planning team participants over time began to express optimism that Duke is really increasing in awareness and understanding of community needs and issues. Some expressed that "Duke may really be beginning to get it," to understand that it's not just utilizing community members to meet the requirements of a certain grant. Participants started to see that changing power dynamics (power sharing) and creating freer flow of communication can lead to better results and better outcomes in addressing community health needs (in partnership with community members and community agencies) and can also lead to cost containment and financial sustainability for health systems.

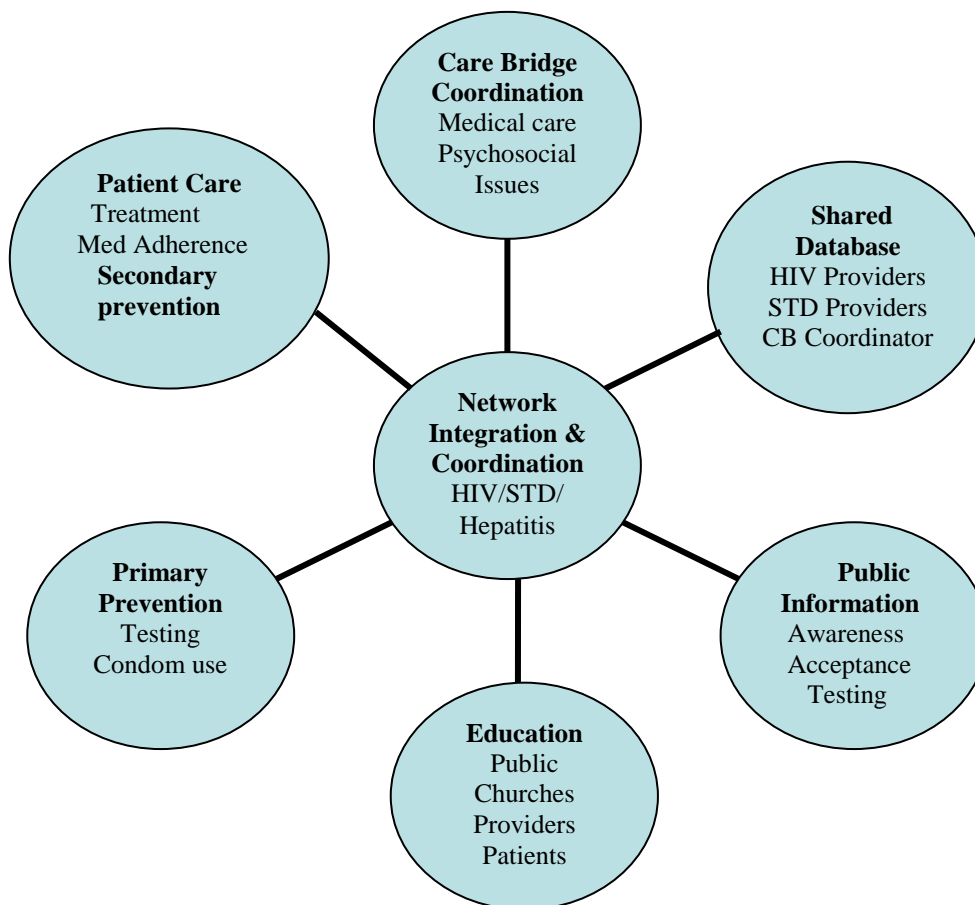
MODELS OF CARE FOR 10 EMPHASIS AREAS

- ◆ What is the model of care that your team is proposing?
- ◆ What services will be provided?
- ◆ What populations does your proposed model seek to serve?
- ◆ Who will provide the services?
- ◆ Where will the services be provided?
- ◆ What volume of services is associated with your alternative model of care?
- ◆ What are the estimated incremental costs of delivering your alternative model of care assuming that the primary connected care model is in place?
- ◆ What evidence currently exists that this model is viable – particularly in Durham County?
- ◆ Economic analysis – in current state of affairs, who bears the burden and what are the economic implications of the proposed changes in the model of care?
- ◆ What providers (both physician and non-physician) and community stakeholders would be involved in delivery of your alternative model of care?

- ◆ How do the health metrics identified by your team align with your proposed alternative model of care?
- ◆ What regulatory/policy changes (national/state/local) would facilitate your proposed alternative model of care?
- ◆ How could the proposed model of care be evaluated in terms of processes, impact, and outcomes?
- ◆ What are the critical components to the longterm sustainability of the proposed model of care?

Services to be provided: The main goals of care coordination are to improve care, promote independence, and reduce unnecessary service utilization, and have been predominantly applied for chronic disease management. Our proposal applies the care coordination model for persons with infectious diseases including HIV/STDs/hepatitis, and has recognized the need to combine both medically-oriented and social (community-based) models under a network approach. While the term “integrated” can refer to a care coordination model with both medical and social components, we also use the term as an approach to care and prevention of HIV/STDs/hepatitis due to shared risk factors. A network approach between agencies providing services for persons at risk or diagnosed with these infections is also critical to our integrated care coordination model in order to facilitate the exchange of information about client needs and available services and to minimize the frequency of individuals not available to access care or lost-to-care by establishing an interagency “safety net” of resources for the community.

Figure 1:



We therefore identified the key components of our model of care based on the needs and gaps identified from our community and clinical working groups, focus groups, key informant interviews and pastors' forum (Figure 1). Our model of care is contingent upon inter-agency networking of comprehensive prevention and care services for HIV/STDs/hepatitis in Durham County, which involves the following key medically-oriented and community-based components: 1) coordinated and accessible patient care for persons with HIV/STD/hepatitis in the community including after hours, with a focus on secondary prevention of infections (i.e. STDs in HIV-infected persons, HIV infection in patients with hepatitis C), 2) care bridge coordination (CBC) for persons newly diagnosed with HIV or HIV-infected persons who are lost-to-care in order to link them with medical and psychosocial assistance; 3) a shared database between providers with basic client information to facilitate quality care and CBC; 4) integrated clinic and community-based testing for HIV/STD/hepatitis with screening for other infectious and chronic diseases; 5) combined approach to education for the public, faith-based organizations, healthcare providers and patients "bundled" with other chronic or communicable diseases; and 6) coordinated public information activities for HIV/STD/hepatitis to increase awareness and acceptance of these diseases and primary prevention activities. The model of care in essence will include both care coordination of services (medically-oriented model) and community coordination (social model), with the assumption that the care of individuals at risk for or with HIV/STDs/hepatitis cannot be successfully attained without optimizing the information and prevention strategies available in the community and the individual's sociosexual network that may be hindered by lack of awareness, information, or stigma with regards to these infections.

The CBC program is a key component of our model in order to provide services to HIV-infected persons not in care, which is different from standard HIV case management in which social and medical assistance to HIV-infected persons *in* care. The CBC program will utilize social workers or nurses in non-traditional roles to conduct home visits and tracing of newly diagnosed persons and patients lost-to-care, with an initial goal of having every HIV-infected person receive prompt psychosocial services, medical evaluation and consideration of early medical treatment through coordinated efforts between DCHD, Duke and UNC ID Clinics and the Lincoln EI Clinic. Care coordination will be provided by CBCs who work for DCHD, Duke, and UNC but function under a network with common resources, community linkages, and a basic shared database. CBC would be expanded to strengthen the connections with other medical and social support agencies in the community. Persons with HIV infection frequently encounter spiritual, mental or substance abuse challenges that are barriers to care, so the CBC program will be optimized by creating linkages with faith-based organizations and programs that can provide spiritual and psychosocial support. The CBC program will work closely with disease investigation specialists (DIS) from the NC STD/HIV Prevention and Care Unit, who do partner tracing and notification for persons with HIV infection and STDs. Over time, the CBC program has the potential to be applied to persons with other "chronic" diseases such as syphilis or hepatitis B/C who are not in care and face similar barriers as individuals with HIV infection.

Coordination of community services is another key component of our model. Our focus groups and pastors' forum underscored the power of the community and social support to the care of individuals with HIV/STD/hepatitis. Integration and coordination of testing among health care providers and community-based programs is critical to identifying more infections in the community and linking them to care. Bundling of educational messages with other health issues important to the community would complement the medical model by increasing public awareness and acceptance of HIV/STDs/hepatitis as a public health issue not limited to only high risk groups. Along with screening for secondary prevention, community-level or individual behavioral interventions to reduce secondary infections and to reduce risk behaviors among persons with HIV/STDs/hepatitis will be developed as a part of the educational initiatives of the model.

Population to be served. The populations that our services will target will be primarily Black, Hispanic and MSM adult populations (≥ 18 years of age) who represent persons at highest risk for HIV infection and STDs in Durham County. While substance abusers, sex workers, incarcerated persons and the homeless comprise the most marginalized population in the community at-risk, other groups included in our target population include adolescents (age 15-24 years) and young adults (age 25-29 years) with risky behaviors and multiple sexual partners. Sexual minorities, including lesbian, gay, bisexual, and transgendered individuals also experience health disparities, and their inclusion among our populations will be important.

Provision of services. The tenet of our model is the continuation of a core inter-agency network consisting of lead organizations in Durham County already providing HIV/STD/hepatitis care and primary prevention services. The key provider and community stakeholders who will provide these services and be included in this network are described further below. We propose that the care of patients with HIV/STDs/ hepatitis and coordination of community services be centrally coordinated in physical locations such as the Health Department or in neighborhoods clinics that are trusted by the community and situated in areas close to our target populations. Integrated services can be provided in neighborhood health clinics representing a “one-stop shop,” whereby residents can receive HIV/STD/hepatitis screening in addition to screening for other health conditions (i.e. blood pressure, cholesterol, or family planning services), and infected patients can seek non-urgent care or psychosocial support after-hours when clinics or other programs are typically not available. Potential alternative sites for primary prevention activities including HIV/STDs/hepatitis testing and education include community centers, churches, housing complexes, homeless shelters, etc, where DCHD and other community agencies already provide limited services.

The NC HIV/STD Prevention and Care Unit estimated that 38% of state residents with HIV disease are not in care (NC Department of Health and Human Services, 2008). Based on the same estimated proportion for the unmet HIV needs and the reported 1,240 persons living with HIV disease in Durham County, there are approximately 471 individuals with known HIV infection who are not in care in our community. Of those in care at Lincoln EI and Duke Infectious Diseases Clinics, approximately 15-16% of their population is lost-to-care over 6 months. We therefore estimate that the volume of services to be provided by care bridge coordinators could include 600-800 individuals if the referral process can be maximized for this program.

An estimated 14 – 15,000 HIV antibody tests are performed at Duke University Hospital System annually, and the numbers tested for HIV at Durham County Health Department is approximately 6000 per year. Several other agencies already provide HIV testing in the community include the Alliance for AIDS Services-Carolina, CAARE, Inc. and UNC Student Health Action Committee. Although coordination of community services would not directly involve provision of HIV testing in the community, expanding the volume of testing currently provided by health care providers and community based programs, and creating opportunities to combine STD and hepatitis testing with HIV testing initiatives would be provided under our model of care.

Incremental costs. We propose that our model be implemented in incremental phases that can build on the components of the network model in Figure 1. Our costs will be estimated in three phases; Phase 1 (year 1-2), phase 2 (years 3 – 5), phase 3 (years 5-10). Phase 1 will focus on hiring a care bridge coordinator for Duke Infectious Diseases and a health educator to coordinate existing community services for primary prevention activities and education for the public. In addition, phase 1 will focus on coordination of care through a centralized database with basic clinical information that can be shared between providers. Phase 2 will focus on strengthening the CBC program and its linkages to faith-based organizations and other community agencies that can provide psychosocial support to persons with HIV

infection. In addition, phase 2 will include the establishment of a neighborhood clinic staffed by a mid-level clinician that can provide general health services for persons seeking evaluation and care for HIV/STDs/hepatitis after hours and weekends. The mid-level clinician can also assist with the greater coordination of care between Duke, Lincoln and UNC, and supervise the care bridge coordinator program activities. Phase 3 will expand the CBC program to other diseases including STDs and hepatitis, and intensify the activities to develop and implement new integrated and coordinated testing and outreach for HIV/STDs/hepatitis in Durham County.

	Personnel	Annual Costs	Operational	Annual Costs
Phase 1	1 CBC, 1 HE, ½ DM	\$140,000	Office space, educational materials, travel	\$20,000
Phase 2	1 CBC, 1 HE, 1 NP/PA, 1 DM	\$250,000	Clinic space, educational materials, travel	\$30,000
Phase 3	2 CBCs, 2 HE, 1 NP/PA, 1 DM	\$370,000	Clinic space, educational materials, travel	\$50,000

CBC= care bridge coordinator, HE=health educator, DM=data manager, NP/PA= nurse practitioner or physician assistant

Viability of model. Durham County Health Department currently has 1 care bridge coordinator funded by the UNC Chancellor for Health Affairs and supported by the NC HIV/STD Prevention and Care Unit to ensure that newly diagnosed HIV-infected persons reported to the Durham County Health Department enter medical care soon after diagnosis, and that Lincoln EI Clinic patients who are lost to follow-up return to care. Since April 2008, the UNC-DCHD CBC program has received 194 referrals including 52 adults with newly diagnosed with HIV infection, and 143 HIV-infected patients who were lost-to-care to the Lincoln EI clinic. The care bridge coordinator has conducted 394 client visits, and linked 137 patients to care or back to care.

Economic analysis. Our proposal to integrate services for HIV/STDs/hepatitis will have both financial and operational impacts on providers of clinical services for HIV, STDs, and viral hepatitis (e.g., DUHS, DCHD, Lincoln EIC) as well as economic impact on the community. Our primary model of maintaining persons in care will result in both costs and benefits, though the overall net impact will yield significant cost savings. Components of the model can be generalized to other urban communities experiencing high morbidities of HIV/STDs/hepatitis as the problems noted in Durham County are not unique to the area and could be improved through a coordinated multidisciplinary approach to serving the target populations encountering health disparities with these infections.

Care Bridge Coordination (maintaining continuity of care). In general, it has been shown to be cost-effective to maintain people in care and treatment for HIV (Schackman et al., 2001; Schackman et al, 2005; Walensky et al, 2007). At the broadest level of analysis, comparing the costs for those in-care with those not in-care will demonstrate the cost savings of our model. The overall savings to DUHS would be the number of HIV-infected persons served through DUHS times the cost savings per person. (# HIV served x cost-savings/person = total cost savings).

Cost savings, however, are expected in several areas. Those HIV-infected persons who are lost-to-care may experience progression of disease, with resulting increases in opportunistic infections, patient encounters, length of encounters, and severity of encounters, including both ED and inpatient visits. Costs are borne by payors (private and public such as Medicaid, Medicare, Ryan White), DUHS, public health (DCHD, NC DHHS), and the community at large.

Increased numbers of infections in the community would result in increased costs to public health (DCHD, NC DHHS) for disease surveillance (e.g., partner notification, testing, surveillance). Indirect costs to the community include lost productivity, lost quality of life, and increased mortality.

For HIV-infected patients, average daily charges range from \$6.1 to \$31.1 for categorically-eligible patients and \$8.8 to \$35.9 for medically-needy patients (Whetten & Zhu, 2004). Evidence from a large sample of uninsured patients indicated that initiating antiretroviral therapy earlier, when they are healthier, results in a five-year savings of \$11,500 to government payers and an incremental cost-effectiveness ratio of \$17,300 per quality-adjusted life-year gained, compared with no therapy. Initiating care earlier through improved testing and linking those testing positive to care results in fewer deaths and fewer opportunistic infections (Schackman et al., 2001). The discounted lifetime cost of comprehensive treatment per HIV-infected person was \$385,000 for this survival benefit (undiscounted cost, \$618,900). Antiretroviral therapy accounted for 73% of the total cost, inpatient care accounted for 13%, and outpatient care accounted for 9%. (Schackman et al, 2006). In another study of direct medical costs of treating HIV infection that included lost productivity, of treating the estimated 40,000 new HIV infections each year in the US, the undiscounted total lifetime cost of illness was approximately \$53 billion. Medical care accounted for only \$8 billion of the total, whereas lost productivity accounted for the remaining \$45 billion. (Hutchinson et al, 2006). Diagnosis of HIV infection can, when followed by prompt linkage to medical care, lead to a sequence of events, including initiation of ART, that yield substantial survival benefits. (Walensky et al, 2007). Thus, costs for medications increases, however, societal costs including cost of treatment are significantly reduced.

Connected Care. Various synergies of care and treatment as well as economies of scale will result in overall cost efficiencies. Those at-risk for or infected with HIV/STD/hepatitis will likely have most commonality with maternity, adolescent, and substance abusing populations, though demographically, those at greatest risk for infection continues to be men who have sex with men, though the greatest rate of increase in HIV infections are Black females.

Providers and community stakeholders. Medical care coordination will need to be provided by the agencies that can provide care and treatment for HIV/STDs/hepatitis among Durham County residents, which include DCHD, Lincoln Community Health Center, DUMC, and UNC-CH. Care coordination for HIV/STDs/hepatitis will consist of 1) coordinated patient care; 2) care bridge coordination, and 3) a shared database. Health care providers would need to be engaged in this model of care bridge coordination across institutions providing HIV care in order to facilitate a noncompetitive referral process for care and to share client information regarding newly diagnosed persons with HIV or HIV-infected patients lost-to-care in their clinics. Other community stakeholders in our model include the Duke University Schools of Nursing and Law, the Duke University Health Inequalities Program, DUMC Pastoral Services, the Piedmont HIV Health Care Consortium, the Alliance of AIDS Services - Carolina, CAARE, Inc., NC Central University and El Centro Hispano of Durham.

Alignment with health metrics. Our alternative model of care will improve the key health metrics by coordinating primary prevention services including integrated testing for HIV/STD/hepatitis and the percentage of HIV-infected persons in care. Although the volume of testing in the community may not substantially increase from its current volume, coordination of primary prevention services should increase efficiency of activities to reach populations not well accessed by existing programs (i.e. intravenous drug users, commercial sex workers). Care bridge coordination will assist by providing a safety net for HIV-infected persons in the community who are not in care due to psychosocial issues that cannot be addressed by healthcare providers alone.

Regulatory or policy changes. Current NC HIV policies indicate that HIV-infected persons detected by confidential name-based testing in the state are to be reported to state or local health departments. However, no legislation exists regarding referral of HIV-infected persons for care. A network of care bridge coordinators would likely need to be sanctioned by the North Carolina HIV/STD Control Program in order to give them the authority to obtain more referrals regarding newly diagnosed HIV-infected persons from HIV testing sites in the community and to share client information with other coordinators and providers.

Evaluation. The processes of our model will be evaluated beginning the second or third year of Phase 1-2 through client focus groups and key informant interviews with community partners involved in the program. Evaluation of the impact and outcomes of our model will be performed quantitatively beginning in Phase 2 using agency specific and county-wide data for some of the intermediate- and long-term outcomes we already identified in our planning grant. See Logic Model in Appendices.

Sustainability. In the absence of external funding sources, the sustainability of the program will be highly dependent on maximizing existing infrastructure, resources and programs already in place in the community, and public health funding from the North Carolina HIV/STD Prevention and Care Unit, which shares similar objectives for the state as this Partnership Team. Additional opportunities to sustain this model of care will be sought through the NIH, HRSA, the CDC, and private foundations such as the Kate B. Reynolds Charitable Trust and the Duke Endowment.

KEY ELEMENTS OF A CONNECTED CARE MODEL FOR SUCCESS OF PROPOSED TEAM MODEL OF CARE

- ◆ What functions would your team want a CC model to contain?
- ◆ How would workflow and processes ideally work within the CC model
- ◆ How can we ensure that Durham County residents and patients remain engaged in the Connected Care system and the more formal health system where appropriate?
- ◆ How can we ensure that residents/patients have an opportunity to understand their health care treatment options, as well as how their own behavioral choices affect their health outcomes?
- ◆ How can we maximize the probability that residents/patients will adhere to the plans that are agreed upon between providers and residents/patients?
- ◆ How can we ensure that critical patient information (medications, allergies, etc.) is shared efficiently across the multiple components of the CC system?
- ◆ What information systems (functions) would your team want as part of the CC model?
- ◆ What information does each component of the system need?
- ◆ How should that information be shared?
- ◆ Who are the stakeholders for this model in Durham County?

Key Stakeholders. A Connected Care model for HIV/STDs/hepatitis must facilitate coordination and communication across multiple entities within health care systems and the community. The key entities/stakeholders should include;

- Direct care providers to persons diagnosed with HIV/STDs/hepatitis, including the Duke University Health System, the Durham County Health Department and Lincoln Community Health Center
- Direct care providers who address common co-morbidities associated with HIV/STDs/hepatitis, especially mental illness, substance abuse and metabolic disorders such as diabetes and hypertension
- Coordination with the other DHI teams especially the Adolescent Health, Pain Management and Substance Abuse, Senior's Health, Diabetes and Cardiovascular Disease Teams

- Communication with primary health care providers to encourage the routine incorporation of HIV/STDs/hepatitis testing into health evaluations, and foster the acknowledgement that a diagnosis of HIV, STDs or hepatitis should prompt evaluation for the others given their common modes of transmission
- Use of well-established community networks, such as faith-based organizations, to disseminate messages on health, prevention of HIV/STDs/hepatitis, and support for persons living with HIV/STDs/hepatitis.

Key Functions. Based upon the need to facilitate coordination and communication across these entities, the key functions of the Coordinated Care Model should include;

- A medical record system that is accessible to care providers throughout the Durham community
- Care Bridge Coordinators who remove obstacles to care and ensure that all diagnosed persons follow-up in care
- Community-based clinics that are easily accessible and open during evening and weekend hours
- Readily available services to address co-morbidities of mental illness and substance abuse
- Minimization of stigma associated with the diagnosis of HIV/STDs/hepatitis through protection of patient confidentiality, community education and incorporation of testing into routine health care examinations.

Care Bridge Coordination. Fundamental to this model is the need for Care Bridge Coordinators in the community to ensure that barriers to outpatient care are minimized. In the Duke Infectious Diseases Clinic, 16% of HIV-infected patients have been lost to follow-up in the past 6 months. These patients are likely not receiving antiretroviral treatment or prophylaxis against opportunistic infections, placing them at high risk for complications associated with progressive HIV infection. In a review of the Duke University Health System database, Emergency Department visits for HIV-infected persons rose significantly in 2008 to 643, increasing from 403 in 2004. In further analyses of HIV-infected persons lost to follow-up from the Duke Infectious Diseases Clinic, we found that their utilization of expensive Emergency Department and inpatient hospitalization services was high and increasing. In 2008, these 96 lost to follow-up patients had 75 Emergency Department visits (increased from 20 visits in 2004), with a mean of 4.2 visits/patient during 2008. Furthermore, in 2008 there were 49 DUMC and 22 DRH hospitalizations among HIV-infected persons lost to follow-up, increased from 25 and 6 respectively in 2004, (mean 2.3 DUMC hospitalizations/patient and 2.4 DRH hospitalizations/patient in 2008). These data suggest that lost to follow-up patients represent a significant cost to the Duke University Health System. We suggest developing a cadre of Care Bridge Coordinators who will serve in the Durham community and assist patients to access outpatient services, enhancing the health of those HIV-infected persons and avoiding the more expensive Emergency Department visits and inpatient hospitalizations.

The Durham County Health Department and UNC-CH currently have a Care Bridge Coordinator in the Durham community to assist with this function. This Care Bridge Coordinator has successfully linked 137 clients to care or back to care. With funding from the North Carolina HIV/STD Prevention and Care Unit and the Ryan White Care Act, the Duke Infectious Diseases Clinic is adding a second Care Bridge Coordinator focused on Durham County. Pending an evaluation of the performance of these Care Bridge Coordinators, additional personnel in this category could be added in the future. It is possible that Care Bridge Coordinators may be able to facilitate access to care across multiple chronic disease diagnoses beyond HIV/STDs/hepatitis, and focus on a specific geographic region within Durham where they could build trust with the local neighborhood and serve as an advocate for patients in reaching needed health care. Such relationships will help to build an informal contract with patients that they will adhere to treatment plans and achieve optimal health outcomes.

Faith-Based Network. The HIV/STD/hepatitis team also recommends consideration of creating a Health Education Coordinator position to liaison with the faith-based community. Clear need was identified by Durham pastors for additional health-related education, and the faith-based network in Durham represents a unique opportunity to disseminate information regarding health. The Health Education Coordinator position could be housed jointly within the Health System and the Divinity School, and would oversee health-related education in faith-based locations throughout Durham County. Our team believes that health-related education through these venues will help Durham County residents understand concepts of healthy behaviors, disease prevention, early diagnosis, and disease management.

Electronic Medical Record. It is essential that a communications system that includes the electronic medical record be available and utilized by Durham County health care providers. This system must be accessible throughout the Duke Health System, the Lincoln Community Health Center, and the Durham County Health Department. Care Bridge Coordinators must also be able to enter their observations into this system so that health care providers are aware of the obstacles to care. This communications system must be robust and secure, especially given the significant concerns about stigma related to HIV/STDs/hepatitis. A careful public relations campaign within Durham County would be helpful to engender community trust in this system.

Integrated health information systems (HIS) are critical components of effective health reform efforts as evidenced by significant emphasis and subsequent funding through federal ARRA economic stimulus legislation and by long-term efforts at DUHS and other groups such as the NC Health Care Information and Communications Alliance (NCHICA) which seeks to accelerate the adoption of health information technology and enabling policies. Among other features, information systems must be interoperable and secure. Interoperability allows the secure exchange of information between health care providers. Security assures that protected information is not shared inappropriately.

Components of an HIS for HIV/STD/hepatitis include: service coordination, pharmacy, labs, and data normally found in a personal health record (PHR). Service coordination should include key medical information (e.g., CD4 counts, viral loads, HCV status), appointment history, referral information including appointments (made, missed, re-scheduled), demographic and contact information, lab reports (most recent and historical), and clinical procedures. Comprehensive PHR data (see below) would be useful for service coordination. Pharmacy information should include all medications prescribed, and the dates that prescriptions are dispensed to patients. Laboratory information should include all lab results, including those performed internal and external to DUHS.

The PHR is an electronic, universally available, lifelong record of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. (source: American Health Information Association, www.ahima.org). A PHR would include: demographic information, general medical information, allergies and drug sensitivities, conditions, hospitalizations, surgeries, medications, immunizations, and clinical tests though the contents could be much more extensive (see http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1_027456.pdf).

Protected health information should be stored in a centrally-maintained, secure, data center with patient-oriented management and control in compliance with all applicable rules and regulations. This raises issues of provider oversight and responsibility for security and privacy of health information.

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APPENDICES

1. Logic Model 17


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DHI STD/HIV/Hepatitis Team - Logic Model

Inputs →	Activities →	Outputs →	Short-term outcomes →	Intermediate outcomes →	Long-term Outcomes
<p>Team members/Partners</p> <p>Service providers (DUMC, CBOs, DCHD, LCHC, NC DHHS)</p> <p>Community stakeholders (PLWHAs, community leaders)</p> <p>Community based testing sites (DCHD, AASC, CAARE, SHAC)</p> <p>Funding</p> <p>DHI planning grant</p>	<p>Network integration and coordination</p>  <p>1) coordinated/accessible patient care</p> <p>2) care bridge coordination (CBC)</p> <p>3) shared database</p> <p>4) integrated clinic and community-based testing</p> <p>5) public education/ coordinated public information</p>	<p>- reduce # new infections, decrease opportunistic infections, decrease hospitalizations, decrease ED/urgent care visits</p> <p>- link HIV+ to care,</p> <p>- improve coordination of services, improve quality of services, reduce errors, reduce un-needed and duplicate services</p> <p>- improve coordination of services, increase testing, reduce # new infections</p> <p>- increase testing, reduce # new infections, reduce stigma, increase awareness, increase knowledge</p>	<p>Decrease HIV+ lost-to-care</p> <p>Increase newly diagnosed HIV+ linked to care</p> <p>Increase testing for HIV/STDs/hepatitis</p> <p>Decrease 2° infections</p>	<p>Decrease morbidity</p> <p>- HIV/STDs/hepatitis incidence</p> <p>- ED and Urgent Care visits</p> <p>- Admissions</p> <p>- Severity/complexity of admissions</p> <p>- Loss of QALYs, productivity</p> <p>Decrease mortality</p> <p>Reduce health disparities (e.g., race, income, education, gender)</p>	<p>Decrease costs (DUMC, DCHD, CBOs, community/society)</p>

Appendix 2

Written comments from the Town Hall

Likes:

I love the integration of different members/ethnicities in the community and the interlocking regarding networking, community with one another.

The promotion of overall community involvement.

I like that it was thoughtful of the need for coordinated care.

Concerns:

"I think that there was a lack of representation of community agencies that are already attempting it. This is an ongoing issue. There should never be exclusivity when trying to address. I am concerned that instead of looking at what the community has done to address. As our issues you have sat in meetings and decided how you can fix them instead of seeing how you can assist and/or empower through resources. You mentioned that people wanted a "one stop shop" model, yet there is one comprehensive model that exists that was not included in Dr. Sena's presentation.

That the focus groups weren't effectively facilitated which caused facilitators to not have more answers or clarity for the discussion. I feel like more effective focus groups and research should be conducted throughout the community to get a clear understanding of what is needed.

How to gain acceptance from churches as well as school systems / any program catering to youth to give the information needed for in-depth prevention education.

I wanted to hear more about how you planned to reach out to the community and make it more accessible and culturally relevant to both non-English speakers and ethnic minorities. Also, it needs to incorporate IDUs, MSMs, young adults, youth, incarcerated people, etc.

Where were the translators for the Spanish speakers? Where were the people of color (specifically Black and Hispanic) members on the project? Where were the community members who had input on the design and implementation (not just focus groups)?

Other barriers:

Churches may want more presentations about HIV/STD but they limit the providers on what they can talk about.

Consistent communication between HIV patients and all of their care providers.
Kind, open, and receptive health care educators capable of being non-judgmental.

Money, not being able to find minority providers, not being asked to be tested when I go to the doctor, not being education about these things, especially how to navigate the healthcare system once I'm sick or before I get sick.

Other comments:

What would be the difference between care bridge coordinators and your traditional case managers? There is certainly a disconnect in recognition of those providing care and services and those who think they know who provides the services. People are not territorial (providers are). Silos exist for this reason only.

Are oral tests included?

I love Jackie's analogy of war!

Are pastors moved to open their door to be places to test (in high incidence areas of Durham)? What are partners willing to provide, in kind or for compensation?

This is a considerable achievement. I look forward to it coming to fruition for the Durham community.

Add funding for more collaborative “one stop shop” events.

The presentation were too science-jargon filled. They were dry and not culturally relevant. The presenters seemed uncomfortable and defensive when answering questions and the woman who spoke at the end was best.

Wonderful and insightful presentations.

Appendix 3

Audience Comments from the Town Hall

There were comments from ten individuals during the discussion following the presentation of qualitative results by Rae Jean Proescholdbell and four individuals following the presentation of our innovative model by Arlene Sena.

Comments include the following:

- Some people were surprised that our focus group participants reported stigma being so strong.
- Some people were surprised that our youth reported being so private and self-conscious, and others wondered how youth could want more information in a county that has comprehensive sex education.
- People were surprised that homophobia concerns did not emerge from the focus groups.
- People were surprised that needle exchange did not come up.
- People wanted clarification on the difference between care bridge coordination and case management, a clarification which Arlene made later, but which tells us that we always need to convey this difference clearly (i.e., in grant proposals, etc.).
- Suggestion: to use engaged patients as models of success (local celebrities) for Durhamites
- Question: do people with HIV really want more support groups composed of other people with HIV, or to they want social groups and activities (for which funding has dried up)?
- People wanted to hear the perspectives of sex workers, injection drug users, and recently incarcerated people. Also possibly more from MSM.
- Comment: our model seems to be too HIV-centric.
- Comment: our model should include needle exchange.
- Suggestion: need more money to test for hepatitis.
- Some people were interested in focus groups for men who have sex with men and active injectors.
- Some people were interested in the perspective of HIV+ individuals who have successfully navigated the service system.
- Some people were interested in discussing support groups.

Appendix 4

HIV/STD/Hepatitis Team

Durham Health Innovations Focus Group and Key Informant Results

By Rae Jean Proeschold-Bell and Genevieve Ankeny, with input from Mary DeCoster

Methods

Between August 15, 2009 and October 8, 2009, a total of 6 focus groups and 3 interviews were conducted. The groups were chosen through several steps. First, the Community Outreach Committee of the HIV/STD/Hepatitis Team of Durham Health Innovations brainstormed potentially important groups of people from whom to hear. Second, an executive committee prioritized seven groups of people: youth, Spanish-speaking Latinos, Whites, African-Americans, HIV+ people successfully in care, HIV+ people who have had difficulty staying in care, and men who have sex with men. Third, Mary DeCoster and others identified community partners working with each prioritized group. In the case of wanting to hear from African-Americans and Whites in the community, mapping was used to identify the neighborhoods in Durham with the highest concentration of locations of sex crimes (i.e., prostitution and pornography) and drug crimes.

The focus groups were with:

1. Youth (peer educators ages 15-20 recruited through Durham Coalition on Adolescent Pregnancy Prevention);
2. Spanish-speaking Latinos recruited by El Centro Hispano;
3. HIV+ patients of Early Intervention Clinic;
4. HIV+ patients from Duke ID Clinic, many of whom were men who have sex with men;
5. NCCU adult students; and
6. Members of an African-American church in East Durham.

The 3 interviews were with HIV+ patients being visited by the Care Bridge Coordinator. All of these participants had previously had a lapse in HIV care.

Community partners were asked to help organize and facilitate the focus groups, and also recruit participants using a verbal script. Participants received lunch and a \$5 gift card.

Focus group and interview questions concentrated on STDs, HIV, and hepatitis C. They specifically asked about barriers to testing and solutions to overcome those barriers, and barriers to treatment and solutions to overcome those barriers. After hearing barriers and solutions that were spontaneously mentioned by participants, the facilitators then probed for specific barriers that the HIV/STD/Hepatitis Team of Durham Health Innovations suspected might exist: clinic hours, clinic locations, services being offered at different places rather than all under one roof, cost, stigma, fear of being diagnosed, trust in medical providers, and belief that treatment might not work. Finally, facilitators asked the group to think about any cultural (e.g., Latino, African-American) or experiential (e.g., men who have sex with men, youth, being HIV+) issues that we should know about in seeking solutions to barriers to testing and treatment.

Focus groups lasted approximately 90 minutes, and interviews lasted approximately 60 minutes. All procedures were approved by the Duke University Medical Center Institutional Review Board.

Results

Demographics

A total of 53 people participated in the focus groups and interviews. Each group was attended by between 7 and 12 people. All participants completed the brief post-focus group survey. From this, we know that participants were 55% male, 77% African-American, 15% Latino, and 9% White. On average, they reported having lived in Durham for 13 years, with a range of being new to Durham (0 years) to having lived here for 53 years. Twenty-five percent reported not having any form of health insurance, with an additional 6% reporting having Ryan White coverage only. Thirty percent reported having private insurance and 40% reported having public insurance. Fifty-two percent of participants reported having been unemployed for at least the past 6 months. Over half (64%) reported regularly attending religious services.

We also asked participants where they had previously received services, and their responses are summarized in Table 1. Note that about half of the participants had received services from the Durham County Health Department, and that we heard from Duke ID Clinic and Lincoln Early Intervention Clinic patients beyond patients recruited for those specific focus groups.

Table 1. Sites where participants ever received health care

Clinic	% ever received care at clinic (n)
Durham County Health Department	53% (28)
Duke ID Clinic	34% (18)
Duke Liver Clinic	4% (2)
Other Duke Hospital Clinic (other than ID or Liver)	66% (35)
Lincoln-Duke satellite clinics	6% (3)
Lincoln Early Intervention Clinic	26% (14)

We wanted to hear from people of varying health, and it seems we were successful in this. Overall, 26% of participants reported having excellent health, 40% reported “very good” health, 25% “good” health, and 9% “fair” health. No one reported being in “poor” health.

Responses to focus group and interview questions

Before reporting on the responses to the open-ended questions, we’d like to comment that from the data, it is hard to know the extent to which participants responded about HIV versus hepatitis vs other STDs. Our questions lumped these diseases together, and the responses seemed to come back with a focus on HIV. In all fairness, all 3 interviewees and 2 of the focus groups were held specifically with HIV+ people. However, even for the African-American church focus group, it appeared that many of the responses were in reference to HIV rather than other STDs. In the future, we might want to separate out questions by disease, or probe about diseases other than HIV.

Site of most recently received medical care

To help participants open up in the focus groups, we began with an easy-to-answer question about the site that participants last received medical care. Here are the responses (the most common responses have asterisk):

Duke*
Lincoln Community Health Center*
Lincoln Early Intervention Clinic*
Durham County Health Department*
Raleigh

Reasons Why It Was Possible to Receive Medical Care

We then asked participants what made it possible for them to receive that medical care. This was one attempt at looking for community strengths or aspects important to receipt of care. The responses centered on:

- 1) services being free or low-cost, or the ability to pay in installments;
- 2) having transportation in the form of bus passes, a friend giving a ride, or being able to walk; and
- 3) having good clinic hours or multiple times of the day available for appointments.
- 4) In the case of youth, it helped to have appointments made by a parent.

In many ways, these responses portend the later discussion on barriers and possible solutions. Participants struggle with cost and transportation and need extended or at least flexible clinic hours in order to receive services when they are able to get transportation to the clinic site and when they are not working (with time off work being a kind of cost issue).

Barriers to Testing

We asked participants, “What goes on in Durham that makes it hard for people to get tested for HIV, hepatitis, or sexually transmitted diseases?” Below is a list of all barriers named, with an asterisk next to those most frequently named.

*Fear that if you find out you have HIV that you will be stigmatized

*Ignoring the possibility of having HIV in hopes that one never gets sick and doesn’t have to face the consequence of having HIV (Making a conscious decision not to know because not knowing and its consequences seem better than knowing and possibly being positive and having those consequences)

*If symptoms of any STD go away, then people assume they are OK and don’t need to get tested

*Belief that if you don’t find out that you have HIV, that you won’t pass it on to anyone else

Fear of abandonment by partner (“*A couple of my friends ... did not know how to tell their partners—so that became the issue—how do you tell because they think if they tell them , they’ll leave them or won’t have anything to do with them.*”)

Stigma of having a disease that was transmitted through sex

Feelings of shame or embarrassment

No reason to get tested (for HIV) because meds don’t work or because of not liking to take medication

Mistrust of doctors and health care

Fear of violence from partner if they returned with a positive HIV test (only one group said this)

Fear of their spouse or partner being told by Disease Intervention Specialist that their partner has HIV

Fear they will binge on drugs if they get a positive HIV test (“*Some people will go harder on the drugs if they find out. They feel they might as well go out and go hard...*”)

Fear that the health worker telling them of the diagnosis won’t be sensitive or won’t be able to help them enough to cope with the diagnosis

Lack of information about HIV and/or other STDs

People are preoccupied with paying bills

Fear that someone working at the clinic will tell your test results to others—lack of confidentiality

Clinic hours not long enough

Comments: We had an overall sense of people not testing because they fear that with a positive diagnosis they would be overwhelmed or unable to cope, or stigmatized in ways that would intimately affect their relationships and lives. We had expected that clinic hours might be a barrier. Interestingly, only two people--both in the Latino group--mentioned clinic hours being a barrier to testing. It could be that clinic hours are more of a barrier to treatment than to testing.

Barriers to Treatment

We asked, “What keeps people in Durham who know that they have HIV, hepatitis, or sexually transmitted diseases from getting treatment?” As with testing, we report below a list of all barriers named, with an asterisk next to those most frequently named.

Denial of positive status (“We all know our bodies—we know something is not right –you are simply not ready to accept what it is going on.”*)

Feelings of helplessness and hopelessness (“People may set it up like there’s no hope for you, and thinking there is nothing I can do. I know I went though that for a minute.”*)

*Shame, embarrassment

*Lack of education, lack of literacy and education of medical terminology

*Fear of unknown

*Invincibility

*Cost

*Transportation

*Not wanting to take meds

Lack of insurance

Personal insurance (medications are very expensive and a person may have to choose one medicine over another)

Substance abuse gets in the way

Psych issues

Trust issues (*“You tend to go into a shell—also it’s how you are raised-- family, culture, some people are taught not to go to doctors. A doctor don’t know what they talking about.”*)

Comments: Participants seemed to focus on barriers for HIV, as opposed to other STD, treatment. Frequently named barriers centered on stigma, cost, transportation, and low self-efficacy in understanding medical terminology and navigating systems such as insurance and health care systems.

Other than these practical barriers, other barriers to treatment seemed to come from deep-seeded places. Many of the barriers stemmed from fear, such as fear of being ostracized, stigmatized, or abandoned in relationships. Although not always articulated, it seemed that participants' deepest fear is that of losing vitality, specifically living with a chronic illness, losing love/sex/intimacy, and the possibility of death. Perhaps because of these fears, there seemed to be a lot of denial about the possibility of having a disease, and living with that denial was preferred to being tested and facing the consequences of a positive test result. Many of the HIV+ participants shared that it takes a long time to accept being positive status.

Solutions for Testing and Treatment Barriers

We further asked for suggestions of how to address testing and treatment barriers. We asked for testing solutions separately from treatment solutions, but often participants did not make this distinction. We therefore report solutions for both testing and treatment barriers combined, with an additional list of solutions that we know were named to address treatment barriers. Solutions with an asterisk identify solutions named during more than one group. We thought it would be interesting to pair up suggested solutions and barriers; please refer to Tables 2 and 3 below for this comparison.

Testing and Treatment

- *Celebrity public service announcements and celebrity getting tested (named in 3 groups)
- *Medical literacy (*"folks need to have information in language they understand"*)
- *Media campaigns
- *Sex education for youth
- *Birth control and condoms available to youth
- *Counseling and support for someone newly diagnosed and for people waiting for STD results

Central large clinic in downtown Durham with full lab

Parent training on how to talk to their children about HIV, STDs, and sex

More public service announcements about HIV and STD risks, prevention, testing, and treatment

Incentives for testing

Play up desire to know what is wrong with you

Make wait time at clinics shorter

Mobile van

Free services for people without insurance

Combined services to avoid the stigma of any single service

Hotline where you could share symptoms and get advice about going to the doctor

Health department advertise differently; talk about things other than HIV/STDs, including overall health, blood pressure, diabetes, cholesterol, and nutrition

Health department talk about other things (blood pressure, diabetes, etc), and not just STDs during outreach

More outreach to colleges and high schools about STDs

Free condoms at more places

Doctors in the media discussing testing and treatment, especially in high profile media spots (e.g., BET, MTV)

Fewer scare tactics

Universal testing of teens

Treatment Only

Generate a more positive outlook for people (Remember quote from Barriers above: *"People may set it up like there's no hope, and thinking there is nothing I can do, I know I went through that for a minute."*)

"Having a treatment plan and doctors helping ...takes a lot of burden off us"

Improved transportation

Doctor's schedules need more availability

Less wait time for an appointment to be scheduled, especially at Duke ID

Better staff sensitivity to patients

Sensitivity of staff toward Latinos
 More follow-up after patient visits, especially for people newly testing positive
 Better urgent care (*"They tend to act like 'urgent' is nothing."*)

Table 2. Testing and treatment barriers and solutions

Barriers to Testing and/or Treatment	Solutions
*Ignoring the possibility of having HIV in hopes that one never gets sick and doesn't have to face the consequence of having HIV	*Letting people know if they are infected there is treatment and it is not a death sentence *Better health care in the US *Public Service Announcements
* Belief that if you don't find out that you have HIV, that you won't pass it on to anyone else	*More sex education *Celebrities normalizing having a STD and treatment
*Belief that if you don't find out that you have HIV, that you won't pass it on to anyone else	*More public service announcements
Fear of their spouse or partner being told by Disease Intervention Specialist (DIS) that their partner has HIV	*More or better counseling at pre-test counseling to help lessen fear
Fear they will binge on drugs if they get a positive HIV test	See additional solutions
Fear that the health worker telling them of the diagnosis won't be sensitive or won't be able to help them enough to cope with the diagnosis	*Training for health care workers and increased counseling and bridge counseling
Clinic hours	*Expand hours to include evening and weekend
Mistrust of doctors and health care	Doctors talking on media about STDs
Fear of abandonment by partner	*PSA and media campaigns on real people with STDs and how they continue to have relationships
Stigma of having a disease that was transmitted through sex	See additional solutions
Fear that someone working at the clinic will tell your test results to others—lack of confidentiality	*Assurance of confidentiality from all persons at HD, medical facilities Improved training in privacy and confidentiality for all levels of health care workers
Lack of information about HIV and/or other STDs	*More sex education Parent training on talking to one's children about STDs
Fear of violence from partner if they returned with a positive HIV test	More public service announcements about how to test, where to test, and privacy—more info on Domestic V
People are preoccupied with paying bills	Free testing and more testing sites *More PSA See additional solutions

Barriers to Treatment	Solutions
Transportation	*Better localized treatment in downtown Durham, with lab in-house.
Urgent care is not seen as urgent	Sensitivity training for staff, pt rights and responsibilities should be made clear at all visits
Denial of positive status “We all know our bodies—we know something is not right – you are simply not ready to accept what it is going on.”	Intensive counseling for those in newly diagnosed Someone to check on them multiple times after diagnosis, between appointments.
Feelings of helplessness and hopelessness “People may set it up like there’s no hope for you, and thinking there is nothing I can do, I know I went through that for a minute.	*More education, more sex education in schools *Media campaigns *Increase condoms distribution and include better sex education in schools. Media campaigns about condom use and protection.
Shame, embarrassment	Play up desire to know what is wrong with you Free STD Hotline offers anonymity
Cost	*Low cost and free testing and treatment Sliding scale fees More legal assistance to get disability Being billed later Reminder calls that mention the co-pay Paying in installments Discounted medication Knowing in advance how much a visit will cost Education that treatment for HIV is not always expensive
Invincibility- “ <i>You tend to go into a shell—also it’s how you are raised--family, culture, some people are taught not to go to doctors.</i> ”	*Celebrities talking more about treatment and role models and doctors talking openly about having a STD *Media Campaigns
Long wait times at clinics/difficulty with getting appointments especially at Duke ID	Better schedules for docs
Denial of positive status “ <i>We all know our bodies—we know something is not right – you are simply not ready to accept what it is going on.</i> ”	*More PSA *Media campaigns

Barriers to Treatment, continued	Solutions, continued
Lack of insurance	*Low-cost and free treatment
Lack of literacy and education of medical terminology	*Step-by-step counseling and bridge counseling See more on additional solutions
Fear of unknown	*More PSA
Transportation	Care Coordinators Mobile van

Comments: Focus groups and interviewees did not give specific solutions for each barrier, rather, they provided a large list of possible solutions. However, an examination of the tables indicates that there may be more than one solution per barrier and some solutions can fit multiple barriers (e.g., media campaigns can address both stigma and knowledge gaps).

Participants focused on solutions that would raise awareness and educate. While these solutions may increase testing and decrease stigma, they do not address the barriers of cost and transportation that were so passionately spoken about. The participants who were currently in the care of a Care Bridge Coordinator revealed that they experienced the triumvirate of barriers named in the barriers section: stigma, cost, and transportation. These participants further testified that the Care Bridge Coordinator helps them overcome all three of those barriers.

Other suggestions included decreasing stigma and normalizing testing and testing positive. There appeared to be many ways to make this happen, including: more openness about sexuality and living with STDs, as well as more education, more sex education for youth, and more availability of condoms and birth control. Later in this report there is a more detailed section on stigma.

Another theme was confidentiality. Participants commented on a need for increased confidentiality, or at least improved perceptions of staff maintaining confidentiality at health departments, clinics, and medical centers.

In addition, a theme arose on people who get lost in the cracks and do not seek services outside of their neighborhoods. Practical solutions such as a mobile van and care coordinators were mentioned.

A Shift In Questions....

All of the responses thus far have been spontaneously given by participants; in other words, we asked open-ended questions and did not suggest possible answers. In qualitative analysis, one generally gives more weight to this kind of participant-generated content. We are now going to report on the responses to particular issues that we the researchers were curious about and raised ourselves. These issues are: clinic hours, clinic locations, services being offered at different places rather than all under one roof, cost, stigma, fear of being diagnosed, trust in medical providers, and belief that treatment might not work. In interpreting these data, we looked for insights into why each might be a barrier and how they might be addressed, without assuming that these are the most pressing barriers. We looked to the spontaneous responses to the barriers questions above to identify the most pressing barriers, from the perspective of participants.

Barriers That We Asked About: Clinic Hours

When we asked participants about clinic hours, they unanimously agreed that they would like clinic hours to include 6:00-8:00 pm on at least some weekdays, and also some weekend hours, with both Saturday mornings and Saturday afternoons being specified. However, we need to consult with the community about the priority of increasing clinic hours, because no one spontaneously named clinic hours as a barrier when we began the focus groups and interviews asking about barriers to treatment. Only two people, both Latino, mentioned clinic hours as a barrier to testing. It may be that extending clinic hours are a lower priority for Durham residents, or it may be that they did not mention clinic hours because they did not think that extending them would be a possibility. Of

note, some youth said that the hours were already accessible and that they preferred to go during the day to avoid being seen by parents.

Barriers That We Asked About: Clinic Locations

Participants endorsed the idea that convenient locations assist in treatment, particularly given transportation barriers. They suggested locating clinics at pharmacies and malls, noting that all locations need to be on the bus line. Duke ID Clinic participants thought a different site might provide more anonymity. Lincoln Early Intervention Clinic participants thought the current sites were already convenient but needed more advertising. Focus group participants in the youth group indicated that more clinics inside of schools, like the Hillside and Southern clinics, would be helpful. Youth also suggested a mobile van.

Solutions That We Asked About: More Services Under the Same Roof

The idea of “one stop shopping” was spontaneously mentioned by the Duke ID Clinic group and by one of the HIV+ key informants as a way to provide convenient services, and it was also spontaneously mentioned as a way to decrease stigma of HIV and/or STD services. When asked about the idea of offering multiple services at the same place, it was unanimously embraced by the Latino and African-American church participants. The Latino participants said that such an idea would “help the self-esteem of everyone,” and noted a need to be able to bring their children. The African-American participants suggested locating such a place “in the heart of Durham.”

Interestingly, youth preferred doctors’ offices where “you feel like you are being cared for.” They also preferred strip mall clinics as opposed to indoor mall clinics for fear of being seen entering a clinic by peers and parents. They thought this fear might be addressed somewhat by having a clinic that offers many different kinds of services, not just STD services.

Overall, the idea of offering multiple services under one roof was well-received.

Barriers That We Asked About: Cost

Although no participants mentioned the cost of testing being a barrier, the cost of treatment was universally seen as a problem and was spontaneously mentioned (by youth and Latinos) as well as elaborated upon in detail at our probing. For example, one HIV+ interviewee said, “Cost is a BIG problem. I’ve got a lot of bills to pay and no money coming in. ... I hear from collection agencies, and get bills in the mail.” An HIV+ participant of the Lincoln Early Intervention Clinic group said, “If I cannot pay the co-pay, if I don’t have the money for that, ... I will wait.” Both the African-American and Latino focus group participants indicated that they felt it was fair for patients to pay something for treatment, but they (and the other participants) wanted to see arrangements that allowed for affordable treatment. A variety of such arrangements were mentioned, including sliding scale fees, more legal assistance to get disability, being billed later, rescheduling until they have the money, reminder calls that mention the co-pay, paying in installments, and discounted medication. Participants noted that not knowing in advance how much a visit would cost prevented them from going in the first place. It was also noted that some people assume treatment for HIV is very expensive.

Barriers That We Asked About: Stigma

Stigma was spontaneously mentioned as a barrier to testing, for example, “Makes you kind of scared, a lot of people are afraid,” and “[It would help] if people were educated better on it ‘cause there is a bad stigma.” The youth participants agreed that stigma plays a very large role in preventing testing, because youth fear being seen at STD clinics. Some participants at the NCCU focus group indicated that they thought males are more embarrassed than females to get treated for STDs. Although no Latino focus group participants spontaneously mentioned stigma as a barrier to testing or treatment, when asked, they universally agreed that stigma was a problem, saying for example, “If I see someone who knows me, I won’t want to get tested.”

Participants who were living with HIV spontaneously offered that they sometimes cope with high levels of stigma. For example, one said, “I call it the Mayberry Syndrome...lived here all your life, it goes back to people feeling stigmatized, confidentiality, privacy.” Another said, “I didn’t want *anybody* to know. ... People talk about you so bad. When people know, they don’t want you to use their bathroom, they think [the virus] will jump on them.” Yet another said, “It’s *very* important that people don’t know I have HIV.” Participants also mentioned that the stigma they feel at times is so great that it can develop into feelings of embarrassment and shame. In contrast to most participants, one participant with HIV indicated that “it’s a big concern, everyone thinks, ‘nobody will love me, everyone will reject me’”, and yet he also said that he personally was very open about his HIV status, and “no one rejects me.”

Participants gave a number of suggestions to address stigma, including the health department advertising about things other than STDs; universal STD testing for teens; multiple services offered in one location; celebrities being open about testing and encouraging testing and treatment; and friends going together to get tested or treated. An overall theme that surfaced was a desire for more information about sexuality, relationships and safer sex, as well as testing and treatment for STDs, to reach the community. Participants suggested that this information needs to be distributed in various forms, and that messages have to normalize getting a STD—ANY STD. Participants desired a saturation in communities and society at large. It was noted that other countries have health care which costs much less than in the U.S. Our own knowledge of HIV and STD campaigns informs us that other industrialized countries have been more successful than the U.S. at increasing condom use because they were more explicit about using them. The campaigns taught real skills; they showed people how to use condoms, to negotiate condom use, and to talk about sex.

Barriers That We Asked About: Fear of Being Diagnosed

Because many group members and interviewees spontaneously stated that fear of being diagnosed prevents testing, we did not have to probe for this question in all focus groups and interviews. It appears that fear of receiving a positive diagnosis is universal. Most of the time, participants seemed to be referring to fearing a diagnosis of HIV.

Participants in the youth focus group were unanimous in believing that fear of being diagnosed plays a large role in preventing testing for HIV, STDs, and hepatitis, saying for example, “People don’t want to find out they got it.” Youth also thought fear of how a positive diagnosis might change their life plays a role: “You might think like man, I can’t do this anymore because I got it.” Latinos agreed that fear of diagnosis prevents testing, and the HIV+ participants in the Lincoln Early Intervention Clinic focus group reflected back on their pre-HIV days: “Ignorance is bliss,” and “Do I want to know?” Participants in the Duke ID Clinic focus group also expressed that there is fear of partner violence if someone tests positive for HIV and their partner finds out.

Barriers That We Asked About: Trust

In contrast to the answers about clinic hours, cost, and stigma, we received more nuanced responses to our questions about trust. We heard stories of both very positive and very negative interactions with medical providers, leading accordingly to higher levels of trust or mistrust. Not all of these stories had to do with HIV, STDs, or hepatitis, and yet were raised because trust in medical providers is probably a more general phenomenon. For example, one participant from the NCCU focus group related a story in which he was told by one doctor that he needed surgery for a broken nose, and told by another doctor that he would be fine, leading to lower perceived trust in all doctors.

Cultural respect and understanding was also seen as playing an important role in trust. Some of the Latino focus group members indicated that discrimination against immigrants is pronounced in Durham overall, and that many health care workers likewise discriminate against Latinos and/or immigrants. They said that being treated well at a clinic gained their trust to return. One participant commented that Anglo doctors might pay more attention to you and your health than Latino doctors; this comment was based on the experience of once having a Latino

doctor pay attention to their shoes (attending to their income or social status) rather than to their health. Thus, complicated class and race issues enter into health care and can affect trust.

The participants in the youth focus group indicated that they had quite a bit of trust in doctors, and those who didn't trust them received medical care anyway because their parents made them go to the doctor. However, youth also said that they did not know of a "good clinic" to refer a friend to and seemed less trusting of health departments than other clinics.

The Lincoln Early Intervention Clinic focus group participants named a lot of things that keep them in care, and many of these things touch on trust: treating the total person, knowing you by name, giving reminder phone calls that are personalized, good information, welcoming demeanor, having compassion, and breaking down technical language. The trust held by the Lincoln Early Intervention Clinic participants came through in their comments about the clinic: "It is like a family thing here." "Whatever it is, we can work through it." "You are not client number 50, they call you by name."

The Duke ID Clinic participants thought trust was important and could develop through a relationship with doctors, but also that you have to advocate for yourself and "do your homework."

One of the key informants who had fallen out of care said he trusted the doctors because they give him good advice, are concerned about him, and always want him to follow-up. However, in going to the clinic, he expressed concern about who might see him there. Another key informant who had had a prior disruption in care said that he trusts his HIV medicine (and by implication, doctors) because he has seen the meds work for him, but that he thinks many other people do not trust the doctors or medicine. He indicated that feeling rushed in the clinic decreases trust for him.

In sum, trust is a particularly complicated issue that is universally seen as related to seeking testing and treatment, although there is neither a universal lack of trust or experience of trust. It appears that trust could be higher but that many micro-interactions would need to change to enhance trust. These micro-interactions range from doctors taking time with patients to addressing patients of various cultures with the modes of respect recognized in their culture to personalized reminder and follow-up calls from clinic staff.

Barriers That We Asked About: Not Believing That Treatment Will Help

Overall, disbelief that treatment (at least for HIV) will help was seen as a barrier to seeking testing and treatment, and participants spontaneously included this issue among their barriers. However, they seemed to have less passion for this issue than for issues of cost, transportation, and stigma.

Not believing that treatment will work was considered to be a barrier in the African-American church group. The Lincoln Early Intervention Clinic focus group participants mentioned "mistrust" of medicine and concern about treatment in general due to Tuskegee. One HIV+ Latino key informant spontaneously indicated that there needs to be more communication with the community "that the medications have a positive effect, that you can have a full life." He also said, "It takes a lot of discipline to take the medications every day," and later in the interview he said, "I would tell people: above all, *take your meds,* eat breakfast, and get your sleep. Because if you don't, you're killing yourself. Now your life has changed." When asked, another HIV+ key informant indicated that he was initially unwilling to take medications for HIV because "I thought that the medication wouldn't help me...back then, it was bad, everyone was dying, and the medicine made them so sick. ... People thought that ... the medication would kill you. ... Now I know that you have to get used to it. Your head gets to spinning, you feel weak all over. The doctor told me you have to take 3 weeks to get used to it. I was so sick, I hurt all over. ... It was terrible."

It seemed that participants perceived medication side effects as just as much of a barrier to treatment as not believing that the medications will work. Both the youth and the Duke ID Clinic group participants discussed the side effects of the medications as being a barrier.

Related to medication adherence, two key informants stated that substance abuse problems initially made it difficult for them to adhere to medication. One person at the Lincoln Early Intervention Clinic mentioned that it was hard adjusting to the idea of needing to take medicine, because they previously had never had to take medication.

Issues That Seemed Different for Specific Groups

Insights from the Youth Focus Group

It was apparent from the discomfort displayed in the youth focus group that being different and expressing an opinion counter to that of the group, can be quite difficult. This is true for many young people. These youth expressed their views very clearly by what they *did not say and through signs of discomfort*. They appeared very self-conscious. The inference from this and other things they said is: youth do not want to go anywhere where they can be seen in public or, worse, be identified as living with an STD. This embarrassment can feel excruciating to them. Youth were even unable to articulate barriers to testing. This means that solutions for this age group would be very different from those of, say, the 25-44 age range. There were specific solutions suggested from the youth also worth noting. Many youth said that they would suggest to a friend who confided in them to also talk to a parent/trusted adult. Youth also said they would offer to go with a friend to get an STD test. Other solutions that arose were specifically about role models such as celebrities. It was suggested that celebrity status and crushes that adolescents have on celebrities hold a lot of weight. Celebrities who would talk openly about STDs and testing could shift attitudes for fans.

Insights from the African-American Church Group

Unfortunately, the tape quality for the African-American focus group was poor, such that we could not hear the questions asked by the facilitator and different points of the focus group were not taped at all. Fortunately, African-Americans comprised 77% of our total focus group participants, and so it is likely that we have captured other good content on their perspectives. Some slightly different ideas were raised in this focus group, however. For example, the sense of people preferring to live in denial about possibly having an STD or HIV, rather than seeking testing, was strong. Participants also discussed at length the need to talk to your children about sex, and the desire for a media campaign that teaches parents how to talk to their kids about it. Further, they indicated that they believe that there is a lack of understanding about diseases, symptoms, and long-term effects, and that they want a high visibility campaign to make their community more aware and stir them into action. For HIV+ people, group participants indicated that they need support groups and “to go through the treatment process with the doctor or counselor and understand step-by-step.” There was at least one recovering substance abuser in the group who made several substance-related points: concern that if you are a drug user that information is withheld from you; that it is difficult to convince active drug users to get tested, even though they especially need it, because they are focused on their next fix; and that drug users are worried that if they test positive they will “go harder on the drugs.”

Insights from the Latino Group

From the Latino focus group and key informant interview, we surmise that the Latino experience in accessing health care is different in some ways from that of other Durhamites. First of all, participants reported language being a barrier, with a need for more Spanish-speaking providers or translators. Latinos also spontaneously gave accounts of both positive and negative experiences in receiving health care from White providers, as well as from Latino providers. We asked for differences in opinion and got them; there is not a consensus on preference of the culture of one's provider. However, there was consensus that Latinos desire respect when interacting with health care providers and staff. It is possible that many people in Durham do not know culturally how to show respect to Latinos. For example, one person said, “More Latino clinics where you can go with trust and in your language –

not with a gringo ‘What’s up?’”. In Latino culture, el respeto is often shown through terms of address employing the formal “you” (Usted) and Señor and Señora. Finally, some Latinos expressed that they felt they were being treated differently due to their race or perceived immigrant status. One said, “My Latino friend who does not speak English had a terrible experience [at the Durham County Health Department]. I don’t know if it was because he looks humble and maybe she was racist. But it’s not fair that she bruised him with the needle.” Reading into this example, it may be racism that led to rough handling, or it may be an unfortunate blood draw and the patient needed more sensitivity and more explanation around what may happen during blood draws.

It was also unique to the Latino group that some thought that there is fear around being deported if you are here illegally and test positive for HIV. One participant suggested having Latino case managers; another suggested making brochures that explain that people will not be deported if they test positive for HIV. Interestingly, at least 2 of the Latino focus group participants perceived that there are clinics just for African-Americans and expressed interest in having a clinic just for Latinos. Latinos reported that language is a barrier for many of them. They also indicated that men may not get tested because taking care of yourself and getting tested and possibly having health problems is equated with being weak. Finally, one person indicated that the culture in some Latino countries is not to complete a medication regimen and that we may have to “create the habit” of taking medication regularly or completely.

Some policy implications from the Latino data are: 1) Durhamites may need training around how respect is demonstrated in Latino culture, and the need for patient education; 2) Latinos may benefit from having patient advocates at health care centers whom Latino patients may express their concerns to, and who may inform the centers’ leaders about Latino needs and perceptions; and 3) more Spanish translation is needed.

Insights from the Interviews with the Care Bridge Coordinator Patients

Three themes clearly emerged from the interviews with patients reached by the Care Bridge Coordinator: transportation, stigma, cost, and co-morbidities. They also uniformly appreciated the assistance that they receive from the Care Bridge Coordinator.

Transportation. One of the participants made it clear that transportation is the #1 barrier, in his opinion, to seeking treatment. In terms of his own situation, he said, “Most of my friends don’t have cars. My relatives don’t have time and charge me for a ride.” Another participant uses a bicycle for transportation, and currently that works well, but it did not work for him when he was feeling sick. Another participant used to ride the bus until she got too sick to do so. For many of these patients, receiving rides from the Care Bridge Coordinator is essential.

Stigma. All key informants discussed the role of stigma. It appears, sadly, that HIV stigma is alive and well. One person talked about enacted stigma (“people don’t want you to use their bathroom”) and another talked about felt stigma (“[Stigma] is inside them – it’s not reality. I tell everyone [about my HIV], nobody has a problem with it.”) Real or perceived, stigma appears to play a role in preventing people with HIV from seeking treatment.

Cost of visit, meds. The key informants discussed how important it is to have cost barriers removed for them.

Co-morbidities. The interviews (versus focus groups) allowed for more personal information to be revealed. The personal stories in the interviews served as a reminder that many people with HIV have histories of trauma and co-morbidities with TB, substance abuse, and mental health issues. Substance abuse relapse is one reason why people fall out of care. Having a Care Bridge Coordinator seemed important to keeping people with HIV and co-morbidities in care. Of note, two of these key informants had gotten deathly ill (“didn’t know if I was gonna live”) before re-entering care. One stated the lesson as: “You’ve got to learn to ask for help and let them help you.”

Insights from HIV+ Patients Successfully in Care at Duke ID Clinic and Lincoln Early Intervention Clinic

These HIV+ patients indicated that reliable transportation, low cost/no cost arrangements, and appointment availability made it possible to get care. However, when these aspects were not in place, the participants missed

out on their care. For example, the participants described times when their transportation fell through, or when they wanted an emergency appointment but were not given one.

At Lincoln Early Intervention Clinic, participants had a long list of things that kept them in care, including personalized outreach (e.g., personalized reminder phone calls, multiple calls, staff noticing when they miss appointments, knowing you by name); a warm environment (e.g., family atmosphere, treating the total person, compassion); support groups; and clear explanations from providers.

At Duke ID Clinic, participants indicated that support groups and social workers, combined with a strong will to live, kept them in care. Duke ID patients in particular wanted to see mass media campaigns emphasizing HIV risks, testing, and treatment. In this way, their group sounded a lot like the African-American church focus group.