

The Seattle RARE Project: Executive Summary

Background

In Seattle-King County, as in the U.S. as a whole, epidemiological data indicate that HIV and AIDS are disproportionately affecting African Americans and foreign-born Black immigrants (hereafter referred to as Blacks). Overall, the percent of HIV/AIDS cases among people of color has risen steadily since the early years of the epidemic in King County, going from 13% of cases in 1984-86 to 26% in 1993-95 and 35% in 1999-2001. Blacks, increasing 4.5 times more likely to be infected with HIV than whites, are the most disproportionately impacted racial group. About 2% of Black men and 1% of Black women in King County are currently living with HIV/AIDS. Foreign-born Blacks comprise an increasing share of the infections among Blacks in King County. In light of these data, Public Health—Seattle & King County decided to assess the HIV prevention needs of the Black community in order to provide more effective prevention services.

At the request of Executive Ron Sims, King County applied for and received money from the Department of Health and Human Services to conduct an in-depth HIV prevention needs assessment of the local Black community called the RARE Project (Rapid Assessment, Response, and Evaluation). RARE draws on the resources of both the Public Health agency and the community for an effective data gathering process. The project was overseen by a Community Working Group (CWG) comprised of local service providers, leaders, and community members with unique experience and expertise in HIV prevention. The purpose of the assessment was to gather information from the community about barriers to receiving HIV prevention services, and to find out how to more effectively address these barriers.

RARE Methodology

By design, RARE projects focus on two geographic sites, with each site being no larger than 22 square blocks. A combination of community expertise and analysis of HIV/STD surveillance data for Blacks in King County quickly focused attention on the two sites selected for study: the 23rd Avenue corridor in the Central District of Seattle (CD) and the south end of Rainier Avenue from Orchard to Henderson. These two sites were selected based on community expertise and because they have the highest rates of HIV and STD infections for Blacks. Using the standardized RARE methodology, a team of 6 field investigators undertook mapping and ethnographic observations of the sites and conducted interviews, focus groups, and street intercepts with members of the priority population, service providers, and policy makers.

Barriers to HIV Prevention

The 84 one-to-one interviews and 18 focus groups provided the comprehensive information about the community's current knowledge and perceptions of HIV prevention in their neighborhoods. Street intercept surveys with 109 community members provided additional detail on specific issues raised during the assessment. Overall, community experts, service providers, and community leaders from both sites were cohesive in their assessment of current HIV prevention efforts and suggestions for improvement. The assessment yielded the following findings:

- 1. People know the basics of HIV transmission, but myths remain:** Although participants expressed a basic knowledge of HIV transmission through unprotected sex and injection drug use, many also related varying levels of transmission myths that kept them from feeling personally at risk for HIV or getting an HIV test.
- 2. Stigma and fear drive community attitudes:** Participants clearly identified the powerful sense of stigma and fear surrounding HIV as the root of HIV prevention barriers for their community. Many cited the church's historically negative stance as both a cause and perpetuating factor of the shame around HIV.
- 3. Distrust and mistrust of HIV prevention work:** Participants expressed a great deal of distrust of HIV information and testing efforts. In particular, they did not trust information distributed by the government or by white people – often citing the belief that HIV was designed as a tool for the “genocide of black people”.

4. **Invisibility of HIV and lack of services:** The community perceives a distinct lack of accessible HIV prevention information and testing services in their neighborhoods, and cites the invisibility of the HIV as a major factor in the epidemic's growth.
5. **Educate Educate Educate:** The community overwhelmingly supported the need for HIV education "anywhere and everywhere". Specifically, closely matched peer education was seen as the key to effectively promoting HIV prevention.
6. **Confidentiality is essential:** Confidentiality is an overriding concern for the community when considering HIV testing. Because of the stigma associated with HIV, community members do not want to be seen getting tested or, in some cases, actively seeking information about HIV.
7. **The Testing Catch-22:** The counseling and testing aspects of HIV prevention remain the most difficult to provide in the Black community because of prevailing community norms, the lack of accessible and acceptable testing facilities, and fears of confidentiality.
8. **Need for leadership:** Participants described the urgent need for leadership around HIV prevention, so that the issue would move to the forefront and be addressed. They identified two main sources of potential leadership: churches and mosques, and a community-wide effort led by trusted elders and teachers.
9. **Subpopulations present their own barriers:** While several community subpopulations at risk for HIV share the overarching report findings, particularly those related to the need for peer education and outreach, they also presented barriers unique to their background or circumstance. The subpopulations included in RARE were formerly incarcerated men, African immigrants, women, youth, and gay men.

Recommended Action Steps

Based on the findings, the Community Working Group recommends the following action steps. [More detail on these action steps can be found in the body of the report.]

Action Step 1: Incorporate RARE findings in 2004-05 HIV Prevention funding cycle.

- 1.1 Encourage programs funded through Public Health to use the RARE findings to guide program development.
- 1.2 Fund a program that specifically focuses on the HIV prevention needs of African Immigrants.
- 1.3 Ensure that Allocation Panel for 2004-05 HIV Prevention funding considers the RARE Project findings and actions steps in their funding recommendations.

Action Step 2: "Back to Basics" outreach: Increase the presence of one-to-one HIV prevention/ education outreach in each of the RARE Project sites.

- 2.1 Emphasize outreach in the current funding cycle.
- 2.2 Generate additional resources to increase peer outreach.

Action Step 3: Implement a media campaign to increase the visibility of the epidemic.

Action Step 4: Adapt HIV Counseling and Testing to increase availability and enhance confidentiality.

- 4.1 Increase availability of HIV Counseling and Testing (HIV C/T) at multi-use service centers and as part of general health screening services.
- 4.2 Increase availability of HIV C/T in publicly funded clinics that serve the needs assessment sites.
- 4.3 Increase availability of rapid testing in the African American community.

Action Step 5: Increase leadership and clergy involvement in HIV prevention efforts.

Action Step 6: Increase the level of HIV prevention services available in both RARE sites.