

# Adding to the HIV Prevention Portfolio – the Achievement of Structural Changes by 13 Connect to Protect® Coalitions

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Key Words: HIV prevention, adolescents, community mobilization, structural change, coalition

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#### Abstract

Opportunities to control risk factors that contribute to HIV transmission and acquisition extend far beyond individuals and include addressing social and structural determinants of HIV risk, such as inadequate housing, poor access to healthcare and economic insecurity. The infrastructure within communities, including the policies and practices that guide institutions and organizations, should be considered crucial targets for change. This paper examines the extent to which 13 community coalitions across the U.S. and Puerto Rico were able to achieve "structural change" objectives (i.e., new or modified practices or policies) as an intermediate step toward the long-term goal of reducing HIV risk among adolescents and young adults (12-24 years old). The study resulted in the completion of 245 objectives with 70% categorized as structural in nature. Coalitions targeted social services, education and government as primary community sectors to adopt structural changes. A median of 12 key actors and six new key actors contributed to accomplishing structural changes. Structural change objectives required a median of seven months to complete. The structural changes achieved offer new ideas for community health educators and practitioners seeking to bolster their HIV prevention agenda.

Key Words: HIV prevention, adolescents, community mobilization, structural change, coalition

# INTRODUCTION

Because human immunodeficiency virus (HIV) is primarily acquired through volitional behavior (e.g., unprotected sexual intercourse and needle sharing), prevention efforts have largely focused on modifying personal behavior to reduce risk of HIV exposure (Coyle et al., 2006; Peterson & DiClemente, 2000; Johnson, Scott-Sheldon, Huedo-Medina & Carey, 2011). However, as we progress further in the field of HIV prevention, complementary interventions that address the broader social and structural determinants of HIV risk, such as unstable housing, poor access to healthcare and economic insecurity, must be considered (Raymond, Chen, Syme, Catalano, Hutson & McFarland, 2014; Dean & Fenton, 2010; Denning & DiNenno, 2010). The National HIV/AIDS Strategy acknowledges the role community and contextual factors have in enabling the spread of HIV, particularly in communities hardest hit by HIV where individuals may experience a myriad of debilitating issues that compromise their overall well-being (The White House Office of National AIDS Policy, 2010). Of concern, 26% of all new HIV infections in 2010 occurred among youth ages 13 to 24 years and within this same age group, 60% of new infections were among African American youth and 20% were among Hispanic youth (CDC, 2012; CDC, 2010). In response, structural change interventions that are focused on the physical, social, cultural, political, economic, legal, and/or policy aspects of the environment can play a necessary and significant role in addressing HIV acquisition and transmission (Gupta, Parkhurst, Ogden, Aggleton & Mahal, 2008; Frieden, 2010).

Unlike interventions targeting individual or group behavior, structural change interventions have the potential to be sustained over many years and can reach large groups of people. They don't seek to directly influence the decisions or actions of individuals but rather attempt to modify the environment in which individuals live, work and socialize (Sumartojo, 2000; Blankenship, Bray & Nerson, 2000). The range of structural change interventions that have been adopted within HIV prevention is limited and has typically focused on influencing risk factors that are proximally related to HIV transmission and acquisition, such as mandatory condom use in bath houses and laws allowing clean needle exchange (Abdul-Quader et al., 2013; Ko et al., 2009; Sakondhavat, 1997). However, as the field moves toward addressing broader contextual factors that influence HIV risk, developing a deeper understanding of the types of structural change interventions that are feasible to achieve and the process involved can enhance the efforts of coalitions focused on community change.

The purpose of this paper is to describe how 13 Connect to Protect® (C2P) coalitions located in urban areas across the U.S. and Puerto Rico were able to develop and achieve structural change interventions focused on HIV prevention for youth 12-24 years old by utilizing a community mobilization model. The findings are an intermediate step toward a longer term goal (not examined as part of this paper) of influencing HIV risk behaviors. This research sought to answer the following questions:

1) Were coalitions able to achieve structural changes that met the study definition and, if so, what types of structural changes were achieved?

- 2) Among the structural changes achieved, which community sectors (e.g., government, healthcare, education) were targeted (i.e., where did coalitions find opportunity and buy-in for structural-level change to be adopted)?
- 3) What level of community mobilization (e.g., amount of activity, number of people involved) was required to achieve structural changes?

# Connect to Protect® (C2P)

In 2002, the Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN), a National Institutes of Health research network, initiated Connect to Protect® (C2P). The coalitions described in this paper are located in Baltimore, MD; Los Angeles and San Francisco, CA; the District of Columbia; Chicago, IL; Miami, Ft. Lauderdale and Tampa, FL; Philadelphia, PA; New Orleans, LA; Bronx and Manhattan, NY; and San Juan, Puerto Rico. With one paid coordinator, ATN sites launched a local C2P coalition in 2006 with the primary focus being to advocate for structural level changes, defined as new or modified practices or policies that reduce HIV risk for 12-24 year olds. Details related to coalition development and partner formation are provided in previously published papers (Ziff, Harper, Chutuape, Deeds, Futterman, Francisco & Ellen, 2006; Geanuracos, Cunningham, Weiss, Forte, Henry-Reid & Ellen, 2007; Straub, Deeds, Willard, Castor, Peralta & Ellen, 2007). A national coordinating center (NCC) provided technical assistance, training and support. The study was reviewed and approved by each participating ATN site's Institutional Review Board and by Johns Hopkins University, the home institution of the Principle Investigator of the C2P study.

#### **METHODS**

Development of "Structural Change Objectives"

Coalitions used the VMOSA strategic planning process of defining vision, mission, objectives, strategies and action steps. Objectives were written using the SMART format (specific, measurable, achievable, realistic and timely) (Fawcett, Francisco & Paine-Andrews, 2000; Kansas University Work Group for Community Health and Development, 2007). A four-part definition was used to define and classify an objective as a "structural change:" (1) a new or modified policy, practice, program or change to the physical environment; (2) logically linked to reduction in HIV transmission or acquisition; (3) directly or indirectly impacts the target population; and (4) sustainable beyond the involvement of the coalition.

To assist with developing structural changes, a C2P logic model depicted in Figure 1 was created to illustrate the linkage between coalition objectives and the core risk factors contributing to HIV acquisition (e.g., number of sex partners, high-risk sex partners, and sex partner concurrency) and transmission (e.g., condom/clean needle

use, sexually transmitted infection [STI] co-infection, and viral load) (May & Anderson, 1987). The logic model was used initially during the coalition's strategic planning meetings where local issues were identified and objectives developed. The logic model served as a mechanism to prompt coalition members to (1) review and understand the six primary risk factors that contribute to HIV transmission and acquisition (2) prompt brainstorming around HIV risks that youth experienced locally and (3) discuss solutions that could minimize or eliminate these risks, and ultimately lead to better health outcome. To encourage consideration of multiple targets for change, a list of 12 possible "sectors" was used to prompt coalition dialogue. Sectors were derived from the Community Tool Box and are classifications of various groups of organizations or people from the larger community into smaller groups represented by common social, political, economic, cultural, religious or other mutually shared interest. (Kansas University Work Group for Community Health and Development, 2007).

Figure 1: Connect to Protect (C2P) Coalition Logic Model

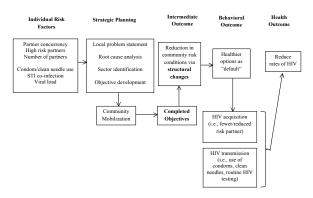


FIGURE 1 CAPTION: The C2P coalition logic model depicts the steps contributing to the intermediate outcome of achieving structural changes via a community mobilization process. Over five years, the C2P coalitions completed 245 objectives, 70% of which targeted structural determinants of HIV risk within the community, such as access to health and social services.

#### **Analysis**

Study Sample and Inclusion/Exclusion Criteria

The study sample is the total number of objectives (N=245) completed by the C2P coalitions over five years. Objectives were considered "complete" when a series of actions led to the adoption of the intended change (i.e., acceptance of a new policy) or integration of a new or modified practice by the entity, organization or system that was targeted. In total, the 13 coalitions initiated work on 522 objectives over the course of the study period; of these, 186 were ultimately discontinued by the coalitions and 91 were still active or pending at the close of the study period. Discontinued and active objectives were not included in the analysis.

Data Sources

C2P Coordinators completed study forms to track the status of the objectives (i.e., open, modified, completed or discontinued); describe action steps taken towards achieving an objective (action steps were defined as being sizable and significant with an outcome that supports completion of the objective); and identify the sector targeted to make the change and the number of existing and new coalition members responsible for completing an action step.

#### Description of Variables

#### *Type of Objective*

In order to assess the success of C2P coalitions in achieving the study goal of identifying and achieving structural changes, we developed a dichotomous variable to represent the 'type of completed objective.' Objectives directly seeking to modify individuals' risk behavior (e.g., distribution of educational brochures) were classified as "individual changes" whereas objectives seeking to modify a program, practice or policy that influences a contextual feature of the community were classified as "structural changes." A systematic review and cross-coding process involving study team members and in some instances. C2P Coordinators, was used to classify the completed objectives. Approximately 80% of the team's coding was consistent. Any inconsistencies resulted in follow up discussion, collection of additional information if needed, and a second review for consensus.

We found it helpful to consider four questions to distinguish between 'structural' (S) changes and 'individual' (I) changes. First, does the objective work by distributing information or resources, such as brochures, to the target population (I) or does it affect a feature of the environment that affects risk level, such as a policy to require shelter beds designated for youth (S)? Second, does the objective require the target population to make a behavior change to receive benefit of the change (I) or does the change target other individuals who influence the youth's environment, such as teachers or providers (S)? Third, does the scope of the objective affect a single entity (I), two or more entities (S) or a government system (S)? Fourth, is the objective linked to a specific event, such as an annual conference, thereby suggesting an infrequent "dosage" (I) or is the objective tied to an ongoing practice or timeless change tied to the environment (S)?

#### Diversity of Community Sectors

Coalitions targeted various sectors of the community for change in order to address underlying issues related to HIV risk such as access to health care, housing security and prioritization of health department prevention funding. Sectors targeted by the coalitions' objectives were analyzed as a way to assess where coalition members were able to gain entrance and develop buy-in for their ideas.

#### Community Mobilization Variables

In order to assess the level of community mobilization and engagement needed (e.g., people, resources and time) to achieve objectives, we examined five indicators that were captured as part of the ongoing documentation process. Mobilization indictors included the action steps taken towards completing each objective, the number of people ("key actors") who played a significant role in the completion of an action step, the number of new key actors joining the coalition's work for the first time, the sector that key actors represented and the duration of time to complete each objective. Recording the number of key actors was a proxy for measuring the levels of community engagement and the number of new key actors served as a proxy for determining the expansion of mobilization in the community (in contrast to relying on the same individuals to complete the work).

Univariate and bivariate descriptive analyses were run on all variables of interest to examine the overall profile of completed objectives and the comparison of the characteristics for individual versus structural changes. Statistical tests of association were performed to investigate potential differences between individual and structural change objectives. Fisher's exact tests were used for categorical variables and non-parametric Wilcoxon tests for continuous variables.

#### **RESULTS**

### Structural Change Objectives Completed

The majority of the objectives (172/245 or 70%) completed were classified as structural changes, while 30% (73/245) were classified as individual changes. Within every coalition, there was significant focus on structural change objectives, which comprised 50% to 97% of each coalition's total objectives. Common types of structural change objectives focused on creating new linkages between two or more organizations to increase youths' access to HIV or health-related services, modifying organizational policies to increase provider competency around youth and LGBT culture, modifying policies within schools, detention facilities and faith-based institutions to increase availability of HIV prevention resources, reducing barriers for youth seeking healthcare and modifying policies related to data collection and allocation of HIV resources.

Examples include establishing health and wellness centers at all public high schools in San Francisco, eliminating parental consent requirements for individuals under 21 years who are seeking HIV/STI testing in Puerto Rico, mandating HIV risk reduction classes for all 9<sup>th</sup> graders in the District of Columbia and establishing a state-level board to oversee mandatory cultural competency training for public school staff. Additional examples of structural change objectives across four sectors (social service,

schools, government and legal/justice) are provided in Table 1. In general, objectives classified as individual

changes sought to develop brochures, resource directories or websites, or were one-time events, such as a health fair.

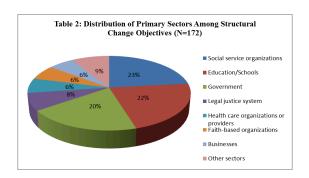
Table 1: Examples of Structural Change Objectives by Sector Achieved by C2P Coalitions (2006-2011)

Sector		Examples	
Social Service	Two social service agencies located in neighborhoods with high STI/HIV morbidity rates provides 'safe space' for LGBT youth to socialize and access structured activities.  Youth drop-in center, transitional housing program & agency serving minority youth partner to offer health screenings and support groups to clients.	<ul> <li>Homeless shelter employs a youth navigator to link youth to support services.</li> <li>Agency serving youth released from juvenile detention formalizes a HIV counseling and testing referral process with local HIV testing agency</li> <li>Children's Center collaborates with local health department and hospital to start offering free health screenings, including HIV counseling and testing, to individuals 18 years and older.</li> </ul>	<ul> <li>Foster care agency provides HIV education to youth entering group homes.</li> <li>Staff of state-wide housing provider begins to receive annual training on LGBT issues.</li> <li>AIDS service organizations serving high-risk youth with unstable housing will begin practice of providing hygiene kit to youth clients.</li> <li>Shelter links homeless youth clients with social services.</li> </ul>
Schools	Community college establishes a task force to assess and address students' health needs.     State-wide ACLU & state-level Department of Education established an anti-bullying and harassment board to ensure statewide implementation of cultural competency training for school staff.	<ul> <li>School district allows HIV/STI testing on school grounds.</li> <li>School district opens Wellness Centers to provide health education services at all city high schools.</li> <li>School-based Health Centers have a new protocol for linking HIV+ youth to care.</li> <li>Alternative school registered as an HIV testing site with the Department of Health.</li> </ul>	<ul> <li>Public schools mandate HIV risk-reduction classes for 9<sup>th</sup> grade.</li> <li>School district health advisory committee establishes a subcommittee to provide technical assistance to staff responsible for teaching the sexual health curriculum.</li> <li>City teachers receive routine training on issues related to sexual minority youth.</li> </ul>
Government	Department of Health Surveillance Office uses maps with geographic HIV/STI data to coordinate outreach and prevention efforts.      State Aids Administration collaborates with a hospital to coordinate state-funded HIV prevention services      Code of state regulations now includes addressing needs and protections of sexual minority youth in group homes, independent living and treatment facilities.	<ul> <li>Office of Aids Programs and Policies develops new protocols for: (1) referring HIV+ youth to care and (2) transitioning HIV+ youth to adult care.</li> <li>Department of Mental Health opens three satellite offices for youth.</li> <li>Local law amended to allow (1) allied health staff to offer HIV counseling and testing; and (2) youth under age 21 to receive HIV test without parental consent.</li> <li>Department of Human Services grantee funding is contingent on adherence to best practices for serving sexual minority youth. Site monitoring visits include best practices checklist.</li> </ul>	<ul> <li>Office of Aids Programs and Policies offers youth specific training for HIV counseling and testing staff.</li> <li>Child and Family Services require foster care parents to receive training about sexual minority youth.</li> <li>Department of Parks and Recreation requires after school staff to be trained about sexual minority youth.</li> <li>Department of health clinics provide referrals for employment training to youth tested for HIV/STI.</li> </ul>
Legal Justice	Department of Health registers Departments of Juvenile Justice and	Depts. of Juvenile Justice and Juvenile Services link HIV+ detainees to medical care upon	Department of Juvenile Justice offers HIV education to all detained youth.

	Juvenile Services as HIV testing sites.	release. • Dept. Of Juvenile Services offers HIV testing when processing youth into detention.	At discharge from juvenile detention, youth are sent to medical services and receive HIV education discharge packets from trained medical staff.
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#### Diversity of Community Sectors

All of the 12 sectors were targeted by at least one completed objective; however the three most common sectors were social services (23%; 40/172), education/schools (22%; 38/172) and government (20%; 34/172), as illustrated in Table 2. Social service organizations typically included organizations providing basic needs, such as housing, HIV support services or job training, as well as those providing youth-oriented services (i.e., mentoring). The government sector included objectives targeting city agencies and offices, such as the Department of Health, Department of Child & Family Services, City Council and the Mayor's Office. The least common sectors targeted by coalition objectives were youth not representing a particular organization or agency, civic organizations, law enforcement, media, and parents/guardians/other family members. Given the small number, these sectors are collapsed within the "Other" category in Table 2.



Note: The category "other sectors" includes the following sectors: youth individuals not representing a particular organization or agency; civic organizations; law enforcement; media; parents/guardians/other family members; and objectives classified by the coalitions as "other sector."

#### Community Mobilization Indicators

For structural change objectives, a median value of three action steps was required to complete the objective. Twelve key actors and six new key actors contributed to accomplishing the change. Key actors represented a median value of three sectors. A median of seven months was needed to complete a structural change objective. Key actor

contribution to completion of individual changes was the only mobilization indicator that was statistically significant, with a median value of 10 key actors.

#### DISCUSSION

Researchers have acknowledged the need for expanding the portfolio of HIV prevention interventions to address contextual factors contributing to HIV risk behavior (Gupta, Parkhurst, Ogden, Aggleton & Mahal, 2008; Prado, Lightfoot & Brown, 2013). Structural change has been identified as a powerful and necessary complement to existing interventions. To be effective, however, the development of structural change interventions must be localized to the environmental context and include a diversity of community stakeholders to contribute to the process. Unlike behavioral interventions targeting the knowledge, attitudes and skills of a specific cohort of individuals, structural change interventions target community systems and structures and thus have the potential for modifying the risk environment.

Expanding the Range of Structural Changes for HIV Prevention

We present a community mobilization study that promoted the development and completion of 245 objectives with 70 percent identified as structural changes. The C2P process involving root cause analysis aided coalitions in thinking deeply and broadly about the types of structural changes that could contribute to meaningful change in their community (Willard, Chutuape, Stines & Ellen, 2012). One benefit of this approach was that coalitions often pursued multiple objectives targeting one goal, thereby increasing the likelihood of penetrating a defined problem. For example, one coalition identified a need to create better services and policies to support homeless sexual minority youth in the city. Their discussion led to three root cause areas: lack of culturally competent homeless providers, limited safe shelter spaces and a need for supportive housing programs and funding for youth. This prompted the creation of four structural change objectives. Three objectives targeted government agencies that oversee public shelters and foster care to ensure that, as a funding requirement, approved cultural competency practices are adhered to by case managers, housing staff and foster care parents. Another objective formalized a shelter procedure to ensure that youth clients are actively referred to agencies that provide housing and support services for sexual minority youth.

There was a learning curve for coalitions to move from considering behavior change outcomes (focused on individuals) to structural change outcomes (focused on community structures). We observed that it was challenging for coalitions to develop structural objectives that targeted risk factors linked to HIV acquisition (i.e., number of sex partners, high-risk sex partners and sex partner concurrency). Examples of objectives that attempted to address these factors focused on creating alternative safe social spots for youth at a business, recreation center or school. Some coalitions were able to work with a government entity, such as the Department of Recreation, to institute city-wide changes related to safe spaces.

Coalitions with a higher percentage of objectives classified as structural focused more on the government sector to make policy or practice changes, such as efforts by one coalition to advocate for HIV testing as part of the detention facilities intake and discharge process. Whereas, coalitions that had a higher concentration of objectives focused on individual behavior change were more likely to target the social service sector. These objectives often involved providing education about where youth could receive testing, rather than creating more testing opportunities. While both approaches are important, the policy changes that target systems and agencies to deliver their care and services differently may ultimately have broader scope and impact, as well as potentially be more sustainable than those utilizing behavior change strategies.

#### Engaging a Diversity of Sectors

Addressing the myriad of social and structural factors related to HIV risk requires practitioners to look beyond the traditional HIV prevention and health service sectors. We found that one benefit of pursuing structural change is engagement of a diversity of sectors in the mobilization process. This has the collateral benefit of elevating the importance of HIV prevention among a broader array of community members and organizations and increasing awareness and acceptance of issues impacting at-risk youth. Some sectors did prove difficult to engage (e.g., family members, unaffiliated youth) likely because they are not organized entities with formalized structures, practices and budgets in place. A sector such as media was more likely to be utilized by the coalition as part of a broader strategy to achieve an objective (e.g., hosting a press conference or meeting with a reporter to discuss coalition work) rather than as a target for change.

Within the social service sector, our study demonstrates a traditional focus on increasing access to HIV testing, condoms and educational resources with several objectives establishing unconventional venues, such as the public library, as places that began offering HIV-related services. Other objectives within this sector sought to form a new partnership, such as uniting a cultural center with a service agency to offer HIV testing on routine basis. Examples of

objectives that moved beyond agency scope and were more likely to modify the contextual environment included state-level coordination of state-funded HIV/AIDS prevention services for men who have sex with men and sexual minorities throughout central Maryland. Not surprisingly, the education sector was also a popular target for change. In this area, objectives included working with secondary schools to start teaching health education at an earlier grade (e.g., in 7<sup>th</sup> rather than 9<sup>th</sup> grade) and working with a Board of Education to permit on-campus HIV testing via a mobile testing unit. The majority of coalitions completed at least one objective targeting a government entity, which we found encouraging given the inherent challenges of influencing larger systems.

#### Community Mobilization for HIV Prevention

Coalitions often serve as effective vehicles for engaging in community mobilization by creating a framework for community stakeholders to actively pursue mutually desirable goals (Roussos & Fawcett, 2000; Wolff, 2001). Our findings show a low number of action steps needed to complete a structural change but a fairly high number of individuals (key actors) involved in completing action steps. This suggests that structural changes rely on engaging multiple stakeholders in the community in order to reach the "right" people, such as decision-makers, who can approve a structural change idea. The low number of action steps is unexpected and points to an issue of variation across sites as to which action steps were recorded in the study database. More action steps may have been completed by a coalition partner but not reported to the C2P Coordinator for data entry. In addition, we would have assumed that structural change would require significantly more time to complete, given that structural changes often involve modifying organizational policies or altering the way business is conducted. While that may be the case for some objectives, we were encouraged to see that it took a similar amount of time to complete a structural change objective (seven months) as it did an individual change objective (six months).

#### Limitations

We recognize that classification of the objectives as either "individual changes" or "structural changes" is subject to bias. There are no scientific benchmarks that clearly place an objective in one category or the other and our coding may not have adequately taken into account the full range of implications. However, we worked with concepts previously discussed in the literature, such as sustainability, and scope and barriers targeted, to better understand and describe what a community driven initiative may produce in terms of structural changes. Furthermore, the full implications of completed objectives may not have been known at the time (e.g., how many and which sectors are ultimately impacted by change). Also, this analysis does not present individual coalition results and, therefore, does

not fully represent the variation in local coalition capacity and achievement of C2P goals. Finally, while we believe this research fills a gap in knowledge, we recognize that a next step requires examination of how structural change interventions may contribute to longer-term behavioral and health outcomes.

#### CONCLUSION

Opportunities to control factors that contribute to HIV acquisition and transmission extend far beyond individuals. The infrastructure within communities, including the policies and practices that guide institutions and organizations, should be considered crucial targets for intervening as public health professionals seek to expand their repertoire of HIV prevention strategies. Through this research, a range of achievable structural changes emerged and provide a platform for communities to pursue a holistic HIV prevention agenda.

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