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## Understanding Motivators and Challenges to Involving Urban Parents as Collaborators in HIV Prevention Research Efforts

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### SUMMARY

This study was designed to explore the experiences of urban parents in their role as Collaborative Board members as part of the CHAMP (Collaborative HIV prevention and Adolescent Mental health Project) Family Program Study. The CHAMP Collaborative Board is comprised of urban parents, representatives from schools and community-based agencies and university-based researchers and is charged with overseeing the design, delivery and testing of a family-based HIV prevention program for pre and early adolescent youth. The current qualitative study, guided by the Theory of Unified Behavior Change, is meant to elucidate: (1) pathways to involvement by urban parents; (2) benefits and costs of participating in this collaborative HIV prevention research effort; and (3) the role of social relationships in influencing initial and ongoing participation by parent participants. Twenty-nine parent Collaborative Board members were interviewed for this study. In-depth interviews were audio recorded and ranged from 30 to 90 minutes in length. Transcripts were coded and analyzed using NUD\*IST, computerized software used for examining narratives. Findings include community parent members identifying social support and learning opportunities as major reasons for involvement with the Collaborative Board. Prior involvement with other community-based projects and knowledge of at least one other person on the Board also influenced members to join the Board and remain involved over time. Further, recommendations for future collaborative partnerships are made. Findings have direct implication for participatory HIV prevention research activities.

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## Keywords

Pathways to involvement by urban parents; family-based HIV prevention; programming; influential social relationships; community narratives; urban pre and early adolescent youth

As the HIV epidemic enters its third decade, the demographic characteristics of those most likely to be infected and affected by the disease have also changed. Rates of new infections are climbing for urban minority youth and low-income women of color (Centers for Disease Control, 2001; 2000; 1998). Factors associated with living in urban, low-income neighborhoods, including higher overall rates of neighborhood prevalence, along with poorer access to preventive health care, early detection and treatment services appear to be fueling rates of HIV infection in these emerging risk groups (Centers for Disease Control, 2001; Institute of Medicine, 1997; Miller, Clark, & Moore, 1997; Minnis & Padian, 2001; Rotheram-Borus, Mahler & Rosario, 1995; Wilson, 1987).

Over the last decade, a number of HIV prevention programs have demonstrated efficacy in reducing HIV risk behavior among women or adolescents (Centers for Disease Control, 2001). However, efforts to transport empirically supported prevention programs to a larger number of urban communities have encountered numerous obstacles, including, insufficient school and community-based resources, poor community participation or tensions and suspicions between community residents and outside researchers (Dalton, 1989; Galbraith, Parcel et al., 1989; Galbraith, Stanton, Feigelman, Ricardo, Black & Kaljee, 1996; Thomas & Quinn, 1991). As a result, it is becoming clear that community-based HIV prevention programs targeting urban minority youth or low-income women are likely to fail if they attempt to provide interventions in a non-collaborative manner (Aponte, 1988; Boyd-Franklin, 1993; Fullilove & Fullilove, 1993; Secrest, Lassiter, Armistead, Wychoff, Johnson, Williams, & Kotchick, 2004; Fullilove, Green, & Fullilove, 2000; Schensul, 1999) or neglect to design and implement programs which do not appreciate stressors, scarce contextual resources or target groups' core values (Boyd-Franklin, 1993; McLoyd, 1990; Sanstad, Stall, Goldstein, Everett, & Brousseau, 1999).

One model for maximizing community participation within a HIV prevention research project has been offered, that of a Collaborative Board structure that is responsible for overseeing all aspects of a HIV prevention research project (McKay, Hibbert et al., 2004; Madison, McKay et al., 2000; McKay, Chasse et al., 2004; McKay, Baptiste et al., 2000). More specifically, a Collaborative Board, consisting of urban parents, representatives from community schools and youth-service agencies and university-based researchers, has been funded by that National Institute of Mental Health and charged with overseeing all aspects of the design, delivery and testing of the CHAMP Family Program.

The CHAMP Family Program is intended to impact three interrelated outcomes for pre and early adolescent youth: (1) time spent in situations of sexual possibility; (2) initiation of sexual activity and; (3) sexual risk taking behavior. The program was designed specifically to address the prevention needs of urban youth of color living in communities with high rates of HIV infection (see McKay, Baptiste et al., 2000; Madison, McKay et al., 2000; McKay, Chase et al., in press for a detailed descriptions of this program).

In addition, the CHAMP Family Program study was designed to address some of the serious difficulties that prior HIV prevention research efforts had encountered within urban communities, particularly low rates of participation, community misgivings about the appropriateness of HIV prevention programs for children and mistrust of program and project staff. Thus, a strong community collaborative research method was employed by

investigators of the CHAMP Family Program study that draws upon key elements of participatory research paradigms (Israel et al., 1998). However, as the investigative team was organizing this community/research partnership and developing the Collaborative Board structure, little guidance was available to understand mechanisms to involve community members in this effort. In addition, little knowledge was available regarding the experiences of urban community members in prevention research partnerships, specifically reasons behind choice of participation, barriers to involvement, perceptions of ongoing community/research collaboration and recommendations for future collaborative arrangements.

Thus, this article presents the results of a study designed to explore the participation of urban parents as Collaborative Board members as part of the CHAMP (Collaborative HIV prevention and Adolescent Mental health Project) Family Program Study. The current qualitative study, guided by the Unified Theory of Behavior Change, is meant to elucidate: (1) pathways to involvement by urban parents; (2) benefits and costs of participating in the collaborative HIV prevention research efforts; and (3) the role of social relationships in influencing initial and ongoing participation by parent participants.

## THEORETICAL UNDERSTANDING OF INVOLVEMENT IN COMMUNITY COLLABORATIVE PREVENTION RESEARCH EFFORTS

In order to guide the current study, a framework for understanding collaborative behavior, referred to as the Unified Theory of Behavior Change, was employed to offer guidance regarding potential motivators and challenges to involving urban parents in a collaborative HIV prevention research effort and specifically to participating as members of a Collaborative Board. By way of background, in 2001, the National Institute of Mental Health (NIMH) convened a meeting focused on relevant theories of behavior change, including the Theory of Reasoned Action (Ajzen & Fishbein, 1975; 1981), Social Learning Theory (Bandura, 1975, 1986), the Health Belief Model (Janz & Becker, 1984; Rosenstock, Strecher, & Becker, 1988) and Triandis' (1972) Theory of Subjective Culture, and Self-Regulation Theories of Behavior (e.g., Kanfer, 1987). The primary architects of each of these theories (Bandura, Becker, Fishbein, Kanfer, and Triandis) met for intensive interactions to develop a common theoretical framework that integrated the core constructs of each approach (Fishbein, Triandis, Kanfer, Becker, Middlestadt, & Eichler et al. 2001). A general framework emerged, the Unified Theory of Behavior Change, (Jaccard et al. 1999), forming the basis for the conceptual framework guiding the current study.

The core variables of the model are organized into two sequences. The first sequence focuses on the immediate determinants of behavior and is illustrated in Figure 1.

Behavior is hypothesized to be influenced by five core variables. First, an individual must be *willing to perform or intend to perform the behavior* in question in order for behavior to occur. Second, the individual must have the requisite *knowledge and skills* to enact the behavior. Third, there must be no *environmental constraints* that render behavioral performance impossible. Fourth, the behavior must be *salient* to the individual so that the person does not forget to enact it. Finally, *habitual and automatic processes* may influence behavior.

These five variables are believed to interact in complex ways to determine behavior. For example, a positive behavioral intention will generally be a necessary, but not a sufficient condition, for behavioral performance to occur. Behavior is most likely to occur when each of the variables coalesce toward behavioral performance. For example, for community/university collaboration to occur, an individual will be most likely to collaborate if he/she intends to collaborate, if he/she has the skills to do so, if the environmental constraints

against doing so are absent (e.g., meetings take place at convenient times and familiar community locations), if he/she remembers to do so, and if he has done so in the past. To understand a given behavior, it is important to consider and explicate each of these facets of the theory, namely collaborators' intentions to engage in partnerships, their skill levels relative to collaboration, features of the environment that are constraining (or facilitating) collaborative efforts, the salience of prevention oriented collaboration, and relevant habitual and automatic processes (Jaccard et al., 1999).

The second aspect of the theoretical framework focuses on the determinants of an individual's willingness, intention, or decision to perform a behavior (summarized in Figure 2).

There are six major factors that serve as the immediate psychological determinants of one's decision to perform a behavior. The construct of *attitude* refers to how favorable or unfavorable the individual feels about performing the behavior. *Normative beliefs* reflect the idea that the more pressures an individual feels to perform a behavior, the more likely it is that he will decide to perform the behavior. *Expectancies* refer to an individual's perceived advantages and disadvantages of performing the behavior. *Self-concept* refers to an individual's conception of self and whether performing the behavior is consistent with that self-image. *Affect* refers to fundamental affective and emotional reactions to behavioral performance. Theories of emotion emphasize two core facets, the degree of arousal and the affective direction of that arousal, positive or negative (Ekman & Davidson, 1994). In general, individuals who have a strong negative emotional reaction to a behavior will be less inclined to perform it and those who have a strong positive emotional reaction will be more inclined to perform it. *Self-efficacy* is derived from Bandura's social learning theory and refers to one's perceived confidence that he or she can perform the behavior.

To understand community parents' intentions to engage in key leadership roles as Collaborative Board members, we considered attitudes about becoming involved with university-based partners, expectancies about the advantages and disadvantages of prevention oriented collaborations, the normative pressures and social support influences that were brought to bear on parent members with respect to becoming community leaders, their emotional and affective reactions to the prospects of being a deliverer of HIV prevention programming, and their perceptions of their abilities to become an effective collaborator. Within the current study, we hypothesized that attention to these factors would potentially yield large returns in terms of explaining in urban parents collaborative behavior.

## METHODS

The current qualitative study, guided by the Theory of Unified Behavior Change, is meant to elucidate: (1) pathways to involvement as Collaborative Board members by urban parents; (2) benefits and costs of participating in this collaborative HIV prevention research effort; and (3) the role of social relationships in influencing initial and ongoing participation by parent participants.

## PARTICIPANTS

Twenty nine parent Collaborative Board members were interviewed for this study. These participants were urban parents serving as part of the oversight Collaborative Board of the CHAMP Family Program study. This study is set within a low-income, inner-city community with high rates of poverty and overlapping psychosocial stressors, including high rates of poverty, community violence, substance abuse and HIV infection.

Demographic characteristics of study participants are summarized in Table 1.

The average age of parent Collaborative Board members is 42 years (s.d. = 10.02). Approximately 41% ( $n = 12$ ) of participants were Latino and 41% ( $n = 12$ ) were African American. Finally, the vast majority of participants were female with five male Collaborative Board members also represented in the current study. The average length of time as a Collaborative Board member was 3.5 years (s.d. = 0.9).

## DATA COLLECTION PROCEDURES

The first author of this article presented the purpose of the current study at a Collaborative Board meeting. The Board reviewed the general interview questions, data collection procedures and met the research assistants who would conduct the interviews. Informed consent was obtained along with Institutional Review Board approval.

Next, research assistants contacted each parent member of the Collaborative Board to schedule an interview. All interviews were scheduled at the convenience of the participant and generally took place at community-based sites, although a few occurred at the university or over the telephone. Every parent Board members agreed to participate in the study. At the start of each interview, the procedures and goals of the study were re-explained by research staff. Interviewers reminded participants that involvement in the study was entirely voluntary and offered to answer any questions that participants had. Interviews ranged in length from 30 to 90 minutes.

Interviews were semi-structured, consisting of open-ended questions meant to elicit narrative responses. Each question was followed by prompts in order to elicit further information and clarifications when necessary. Six general content areas were covered in each interview: (1) history of involvement with the CHAMP Family Program study and the Collaborative Board; (2) perceptions of the Board and its' work including, sources of motivation and challenges to initial and ongoing participation; (3) social support and network among Board members; (4) social support and network outside the Collaborative Board, including support and discouragement offered by family and members of formal and informal social support networks related to participation in the collaborative research effort; (5) consistency and conflicts between commitments and priorities in participants' lives and involvement with the Collaborative Board; and (6) advice or recommendations for researchers about collaborating with communities on future prevention research studies.

Interviewers attempted to elicit self-generated accounts of participants' experiences as part of the Collaborative Board and their opinions about their work as part of the Board. For example, during the part of the interview that related to history of involvement with the CHAMP Family Program Study and the Collaborative Board, interviewers specifically asked participants to "tell me the story about how you became involved in the Collaborative Board." This question was followed by several prompts, such as "Is HIV/AIDS what inspired you? Could you tell me more about that?" and "Is there a person who may have influenced you to join the Board?"

All interviews were audio taped and transcribed verbatim. Total transcribed qualitative data approximated 900 double-spaced pages of text. Interview data were analyzed to explore the appropriateness of applying the Unified Theory of Behavior Change (Jaccard et al., 1999) to understanding community collaborative behavior. First, using a ground theoretical approach, in-depth qualitative interviews were coded based upon key constructs identified in Figures 1 and 2. These interviews were next analyzed using the QSR NUD\*IST software package (QSR NUD\*IST 4.0, 1999). The use of NUD\*IST (Non-numerical Unstructured Data Indexing Searching and Theorizing) software package was chosen in the current data analysis for two primary reasons. First, the NUD\*IST software facilitates the effective organization and analysis of large amounts of textual data. Second, this software package is



considered particularly adept in the analysis of theories through the manner in which textual data may be structured (Gahan & Hannibal, 1997). More specifically, the NUD\*IST program allows the researcher to create an outline or a coding structure of primary and secondary fixed headings to which participants' comments may be copied and categorized. Primary fixed headings, called index nodes, represent the central outcome under analysis that the applicable theory proposes to explain. The secondary fixed headings, called sub-nodes, are a series of smaller categories that are ascribed to each index node and reflect salient aspects of the index node construct.

Data analysis proceeded using standard NUD\*IST software protocol, where each individual interview was prepared as an electronic rich text document file and then imported into the NUD\*IST database (QSR NUD\*IST 4.0, 1999). Two index nodes were created. The first index node was named "behavior" and the second "behavior intention," which reflected the two primary outcomes of the Unified Theory of Behavior Change (Fishbein et al., 2001; Jaccard, Dittus, & Litardo, 1999; Jaccard, Dodge, & Dittus, 2001). The first index node was ascribed five sub-nodes reflecting the constructs (i.e., willing to perform or intend to perform the behavior, knowledge and skills, environmental constraints, salient and habitual and automatic processes) that are theoretically believed to influence behavior. The second index node was ascribed six sub-nodes reflecting the constructs (attitude, normative beliefs, expectancies, self-concept, affect, self-efficacy) that are theoretically believed to influence behavioral intention. In analyzing the data, participant responses were broken down into individual phrases that reflected a single aspect of the Theory of Unified Behavioral Change. Each phrase was then copied into the applicable sub-node of the theoretical dimension that the participants' comment reflected. A single phrase could be coded in multiple sub-nodes, if it were relevant to more than one theoretical construct.

Coding reliability was established by having transcripts coded by multiple coders and comparing the codes. Two individuals were involved in coding the transcripts and a conservative approach was taken to establishing agreement. Any code for which there was not agreement by both coders was discussed; if agreement could not be reached, the code was not assigned. Once reliability was established, as indicated by consistent agreement among the coders (> 85%), transcripts were coded by individual coders. Reliability checks were then conducted periodically to ensure that reliability was maintained.

## RESULTS

Community parents identified several key factors that served as the foundation for their intention to begin involvement and stay involved with the community/research partnership. For example, in relation to *intention* to continue involvement in the collaboration, strong endorsements were revealed.

Every little bit I could give to this community, I will.

There's a lot of drugs, gangs, murders, and rapes (in the community). If I have anything to give to help the community, I would like to share it with them.

*Salience of involvement with CHAMP, normative social pressure and supports* created within the partnership and *emotional response* to involvement were consistently identified as prime motivators to remain actively engaged in the community/research partnership. For example, for community parent partners, *salience* was described in these ways:

My brother and sister died of AIDS and I need to teach my 13 year old daughter about disease and pregnancy.

I lost a nephew and a couple of friends to HIV...I figured if I could help someone else, I would be doing something for the people I lost.

Programs are needed to help parents deal with their children and make them more aware of what's going on.

There are a lot of people that I know (in the community) that do unprotected sex... and I liked to let them know and try to inform them...so that they learn to protect themselves a little better.

When I learned that a lot of kids don't know information about STDs, HIV and AIDS, I realized that we had to get the word out.

I wanted to sit in the same room and work together with people of all nationalities from my community.

Further, community partners described other members of the partnership as providing additional encouragement to remain involved and social support when faced with obstacles to involvement. For example, community partners described *normative social pressures and supports* in these ways:

The Board has become like a family...anything goes wrong and we call each other.

...recently, I had a girlfriend who committed suicide. She was pregnant and I spoke to (one of the Board members) about this and she kind of made me feel a little better.

(another Board member) helps me with things sometimes, like if I don't have money, uh, she'll loan me money or she'll treat me to breakfast or lunch.

I really like working with our university partner...she gets so animated and when you are working with a person like that, it makes you want to give more of yourself.

*Social support outside* the collaborative partnership also was cited as an important influence on ongoing collaborative involvement.

My husband looks after the baby when I attend meetings...if he did not, I would not be able to go.

My wife and the boy are the exact same, pushing me and giving me confidence in what I could do (in CHAMP).

Finally, members of the Board described their *emotional response* to HIV prevention research efforts in these ways:

I noticed the commitment and seriousness of the board coming together to help the community...I really loved it and was happy to be there.

CHAMP is an amazing program....how families reach out to each other and I am excited to see everyone connecting well. The program made me a believer of the need to educate children on the issues of HIV prevention and sex education.

Feelings of *personal self esteem* and respect for other Collaborative Board members were also noted.

I like the feeling CHAMP gives me, you know, helping other people, and helping where you live at, it feels good.

People in CHAMP are down-to-earth, they're friendly, and they really dedicate themselves to doing wonderful things.

Many Collaborative Board members described their participation in the research partnership as feeling natural to them (*habitual or automatic response*) because they had prior experience with community-based projects.

I was involved in my kid's school...volunteering to help kids read or helping the teachers.

All my life, I've volunteered to counsel or do anything I can to help children.

In addition, participants identified the building of knowledge and skills (*self efficacy*) in key areas as being highly influential in their decision to remain involved with the Collaborative Board. For example, benefits to self included development of personal attributes.

CHAMP has helped me to be a little more patient, and they offer workshops, like for listening skills.

CHAMP helped me to be more open when I'm around a lot of people.

In addition, participants identified involvement in the collaborative partnership as assisting in the acquisition of HIV/AIDS knowledge.

I knew certain things about HIV, but there was more stuff that I didn't know...so CHAMP was another opportunity for me to learn more about HIV/AIDS.

Despite so many positive endorsements to participation in the collaborative partnerships, some costs (*environmental constraints*) to members were also identified.

My little girl says, 'Ma, you're not home no more,' but, I take her to meetings with me...and she stays with her father...it makes me feel bad because she's used to me being there all the time...and I love being around my kids...but, the Board is only until 7...but, she says that she's used to seeing me home all the time.

## DISCUSSION AND IMPLICATIONS

Results indicate that the Unified Theory of Behavior Change (Jaccard et al., 1999) did help identify key factors that influenced urban parents to decide to join and remain as members of the Collaborative Board, thereby, supporting a community-wide HIV prevention research partnership. Given that concerns regarding the consequences of early and high risk sexual behavior for urban minority youth have been constant over the past several decades and infection rates continue to rise in young people and women of color, prevention programs designed specifically for urban youth and women are critically needed (Centers for Disease Control, 2000). Though collaboration with communities has been emphasized as a necessary component of building successful preventative interventions, not much is known about the factors critical to the development of such partnerships. We believe that the current study contributes to the field by defining specific factors that motivate urban community members to collaborate with HIV prevention researchers.

Implications of the current findings include the possibility that if consideration is specifically given to the factors that motivate and retain community participants in collaborative prevention efforts, then recruitment of community partners could be facilitated. Further, future research might focus on ways that bolstering these factors could enhance rates of ongoing involvement, satisfaction and productivity of community/university prevention partnerships. Finally, the current study may shed light on the foundation of effective community-based prevention oriented groups.

## Acknowledgments

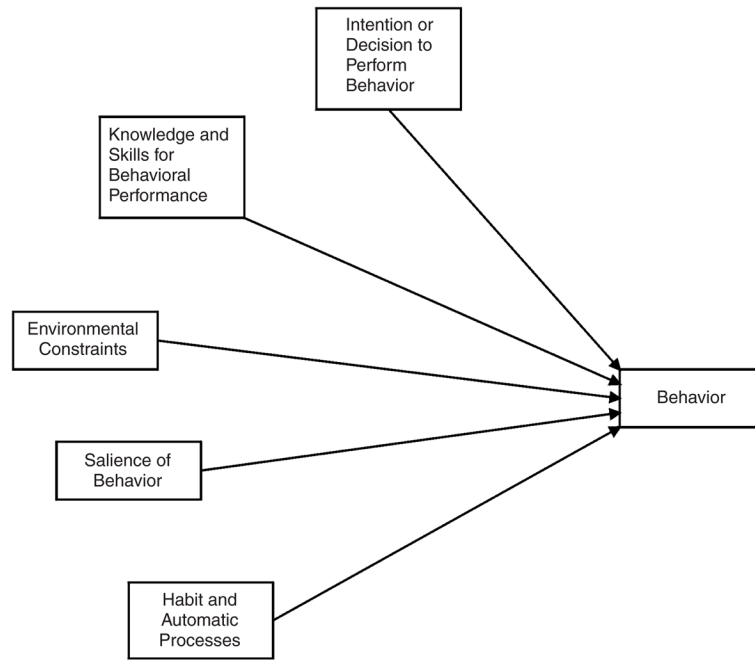
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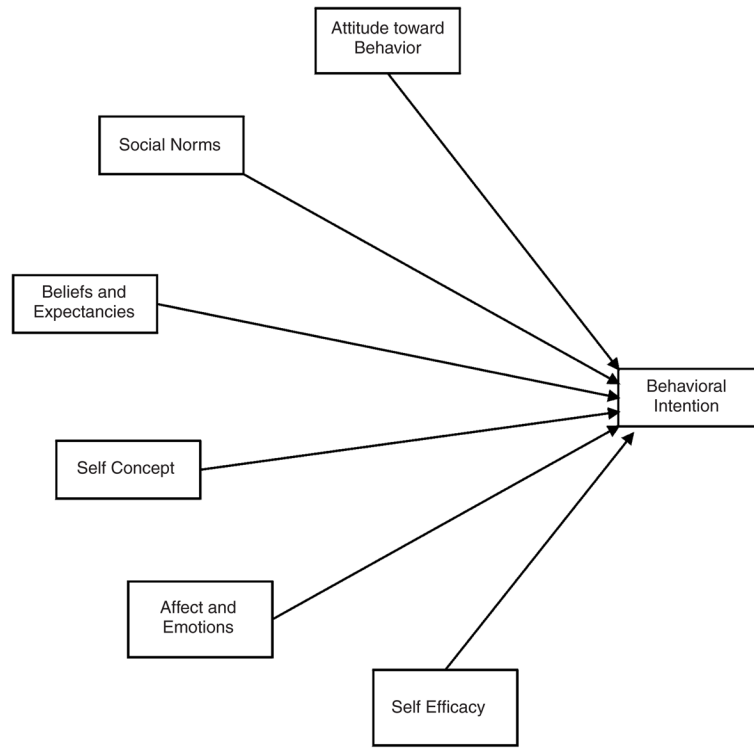
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**FIGURE 1.**  
Determinants of Behavior



**FIGURE 2.**  
Determinants of Intentions to Perform a Specific Behavior

**TABLE 1**

Summary of demographic characteristics of study participants

	Mean	Standard Deviation	<i>n</i>
Age	42	10.02	29
Length of time on Board	3.5	0.9	29

	Latino	African American
Ethnicity	41% ( <i>n</i> = 12)	41% ( <i>n</i> = 12)
Gender	Male	Female
	17% ( <i>n</i> = 5)	83% ( <i>n</i> = 24)