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Central city youth and HIV/AIDS an emerging community construct: Finding the best fit of prevention and intervention service

Michael David Black

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CENTRAL CITY YOUTH AND HIV/AIDS
AN EMERGING COMMUNITY CONSTRUCT:
FINDING THE BEST FIT OF PREVENTION AND INTERVENTION SERVICE

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Michael David Black
June 1998
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Approved by:

Dr. Marjorie Hunt, Project Advisor, Social Work

Dr. Rosemary McCaslin, Chair of Research Sequence
Department of Social Work

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ABSTRACT

The study is a community research project that examined HIV/AIDS prevention and intervention with youth in a Southern California Central City neighborhood. The research was community centered to facilitate a good fit between agencies providing services and the neighborhood. A constructivist paradigm was used to uncover and discover strategies that will work best in the area, and to discard those that are not working. In order to reveal the best possible prevention and intervention for the Central City neighborhood a hermeneutic dialectic circle was used that consisted of at-risk youth, community members, and current service providers. A bi-phasic model emerged. While the constant comparative method was used to construct a shared concept and salient points of the respondents, a working group formed from a nucleus of respondents to explore the possibility of providing a needle exchange program to prevent the spread of HIV in the neighborhood. A consensus of the need for an exchange was based on the high rate of IVDU coupled with the unprotected sexual cross over between teens and IVDUs. An early vision of the researcher was that continued dialogue would result between the stakeholders. This was accomplished through the Needle Exchange working group that launched a neighborhood coalition. The research uncovered the need to operationalize vague terms such as comprehensive prevention services, both primary and secondary prevention and what priorities are funded. It discovered an “essential” prevention concept, the need for interactive educational presentations, and the use of indigenous workers to reach diverse enclaves. It discarded the idea that legitimacy must come from legal sanctions and that language, religious, and cultural barriers are best overcome by agencies, schools, or researchers not the community.
TABLE OF CONTENTS

ABSTRACT ......................................................... iii

TABLE OF CONTENTS ........................................ iv

Introduction .................................................... 1

Literature Review ............................................. 5

Research Design and Methods ............................... 13

Results ............................................................ 21

Needle Exchange .............................................. 21

Concepts and Salient Points ................................. 29

Discussion ....................................................... 37

APPENDIX I: Research Questions ............................ 41

APPENDIX II: Informed Consent .............................. 42

APPENDIX III: Debriefing Statement ........................ 44

REFERENCES ..................................................... 45
Introduction:

This research project is a community practice constructivist study. It addresses HIV/AIDS prevention and intervention with youth in an impoverished neighborhood of a mid-sized Southern California City. Strategies for community intervention have been explored which were designed to enable the tailoring of service delivery to the community’s unique characteristics.

The problem of impacting the HIV/AIDS epidemic in a particular neighborhood and a particular age group has led to many strategies (that may, or may not, be relevant for the youth of the area being studied). There are also many barriers specific to both age group and neighborhood. These barriers can be the socioeconomic status of the community members, multicultural considerations, and the special problems of certain at-risk populations that make up the population of the youth in the community.

Services are currently being provided in this community. These resources have been examined for their contribution to the overall efforts of HIV/AIDS prevention and intervention in the neighborhood and some of the service providers are included as stakeholders in the community. They have not, however, been scrutinized as in the case of a traditional program evaluation. What they currently do, and how they go about providing services have been examined from the perspective of integration into a network of community intervention strategies that are reflective of community self determination. Their perception of the contribution they make to the effort and the perception of youth in the neighborhood
of their services have been explored.

The study may be conceptualized as a community needs assessment. It is assumed, however, that programs already in operation will have conducted their own needs assessments. Although the research is on the neighborhood, agencies that operate there may naturally evolve as part of the research focus. A community / agency study combination that explores needs assessment as a goodness of fit will be successful if it identified gaps in service, or areas that may require emphasis. The emergent design proceeded in the path of needs assessment, and prior efforts in this neighborhood will continue to be studied to facilitate an understanding of how past interpretation of needs have impacted, failed to impact, or have exacerbated the problem.

The research studied HIV/AIDS prevention with youth and its goal was to involve the community in responding to the many problems that contribute to a high risk environment. One of the roles that the research foresaw as indispensable was that of serving as a catalyst for creating a forum for dialogue about the issues. Included in this research were representatives from the neighborhood and from the agencies providing services there.

The neighborhood studied was a Central City area that included the least desirable living conditions in a city with a population of approximately 200,000. The boundaries included a corridor of old businesses and gangs on the west side, and an impoverished housing project to the east. The Boundary extended to a major boulevard on the north end where many sex industry workers and
their customers met and south to an industrial tract that was long ago deserted and currently occupied by a transient and homeless population. Poverty and blight are calling cards of the neighborhood that is inhabited by large populations of minority cultures. Hispanics and African Americans are over represented in the area. The area is home to two county welfare departments. Poverty, crime, drug addiction, prostitution, and unemployment permeate the streets. Other than the downtown business and government district its' infrastructure was in poor repair. It was distinctly different from the big city ghetto, characterized by tenement slums and crumbling high rises. In contrast, it is more the sprawling ruralized Central California style dilapidated old towns next to dirt floor migrant worker camps interspersed with run down apartment buildings.

From the inhabitants of this neighborhood the researcher sought how the community's HIV/AIDS prevention and intervention service providers for young people attempted to facilitate the elimination of high risk behaviors? This was another of the survival questions for a neighborhood that has many survival questions to answer. It was proposed after initial investigation of the neighborhood, that the best way to phrase the general question (in research interviews) was to ask the stakeholders to “tell me about youth and HIV/AIDS prevention efforts in your neighborhood?” The term “youth” for the purpose of this study included adolescents 12-17 years old and the population of young adults 18 to 24.

The working hypothesis for this study was that; we can discover the specific barriers in the neighborhood to HIV/AIDS high risk behavioral change by in-
volving the community served and service providers in identification of conditions that create and maintain the development, change, and elimination of high risk behaviors.
Literature Review:

When considering prevention in the HIV/AIDS arena there are two main areas of priorities to focus on which are primary and secondary prevention efforts. Primary prevention occurs when a person who is not infected is motivated to take action to protect themselves or when action is taken in their behalf. Secondary prevention is attempting, at different levels, to encourage people who are already infected to take action to refrain from infecting others (California Community Planning Working Group, 1995; Los Angeles County HIV Prevention Planning Committee, 1996). A continuum of efforts exist in both primary and secondary prevention. Primary prevention may include essential environmental action that facilitates the development of individuals who are more inclined to protect themselves to changing ingrained at risk encounters. Secondary prevention include support for behavior change in people aware of a positive diagnosis to efforts to intervene in the progression of HIV in an infected person, or partner notification. Essential to prevention efforts is the understanding that every transmission is related to passing the virus from an infected person to a non-infected person so elements of primary or secondary prevention are important. This fact implies that it is important that primary and secondary prevention be linked as in the case of educational presentations, where testing is done on site, primary prevention in the form of education and pretest counseling are offered. Upon disclosure of the results of the test primary prevention counseling may be given if the test result is negative and secondary preventive case man-
agement including support for behavior change and partner notification is initiated if the test result is positive (Los Angeles County Prevention Planning Committee 1996; T. Pendergast and M. Haupert, 1998; California Community Planning Working Group, 1995).

There are many special challenges that face the community trying to prevent HIV/AIDS. Not the least of which is the population of homeless youth. These children are runaways, throwaways, and former members of families who became homeless. Both primary and secondary prevention are essential in this population (M. Rotherman-Borus, C. Koopman, and A. Ehrhardt, 1991; J. Athey, 1991; T. Sullivan, 1996). There are significant barriers to receiving services that include housing, meaningful support of a reference group, means, and a pervasive distrust of adults. Their own health needs and the prevention of infecting others are concerns which are often superseded by immediate survival needs. Homeless youth are targets for sexual predators who may be infected and take advantage of this vulnerable population as they engage in survival sex for food or temporary shelter (J. Athey, 1991; California Community Planning Working Group, 1995).

These children who expect that life will bring them nothing in terms of housing, economic opportunity, education, and access to medical care internalize the message that their life is worth nothing. They don't care about the future or preservation of their health (D. Romer et al., 1994; V. Solonim-Nevo et al., 1996; T. Sullivan, 1996). Further internalization of feelings of worthlessness
come from histories of sexual abuse from either their family of origin or in institutional care coupled with their vulnerability to being a victim of rape while living on the streets (J. Athey, 1991; California Community Planning Work Group, 1995).

There are many reasons why condoms are not used. Education about unsafe sex becomes secondary to sexual gratification when children do not have condoms. If they are unavailable, children, just like adults will seldom forego sexual activity. Financial need has been cited as a reason for nonuse, or discontinuation of use in high risk youth. (A. Stiffman, P. Dore, and R. Cunningham, 1994; T. Sullivan, 1996). The influence of parents, and shared basis of communication with parents and partners are essential to a commitment to use condoms (G. Breakwell, L. Millward, and C. Fife-Schaw, 1994; D Shoop, and P. Davidson, 1994; S. Middlestadt, et al. 1996). Because of limited life experience, and a lack of a relational reference point to illness and death, and a lack of a sense of delay of gratification young people have a pervasive sense of invulnerability that is apparent in their unwillingness to use condoms (T. Prendergast, and M. Haupert, 1998; California Community Planning Working Group, 1995; Los Angeles County HIV Prevention Planning Committee, 1996). The high rate of teen pregnancy and Sexually Transmitted Diseases is an indicator that consistent condom use is not the norm (T. Prendergast and Haupert, 1998).

Prevention efforts in AIDS/HIV historically aimed at youth education usually ignore the population of young men who have sex with each other, or young
men who have sex with men. Most education and intervention efforts assume that if the young people are having sex it is of a heterosexual nature (T. Prendergast, and H. Giese, 1997; T. Prendergast, and M. Haupert, 1998; G. Goldberg, T. Perdue, and D. Higgins, 1996; D. MacKellar, et al., 1996). Research suggests that young gay men are also distanced from interventions that are targeting the exclusively gay community. They may not circulate in the gay community because of parental disapproval, not being "out", or continued struggles with sexual identity (D. MacKellar, et al., 1996; G. Goldbaum, I. Stulberg, and M. Smith, 1988). In neighborhoods like the site of this study, where there are high populations of African American and Hispanics, the denial of homosexual intercourse fostered by fundamentalist Protestant and Catholic ideologies is a barrier to facing the reality of the need to educate this population.

Cultural competence of intervention workers is important to Hispanic, African Americans, and Gays (T. Prendergast, and H. Giese, 1997; D. Higgins, et al., 1996). It is important that target groups are considered for their unique cultural and ethnic components. Intervention should be culturally appropriate and address the bicultural issues that confound the process of accepting interventions (D. Higgins, et al., 1996; I. Stulberg, and M. Smith, 1988).

The use of substances by youth in all of the sub categories of the at-risk behavior groups raises the possibilities of HIV transmission (J. Athey, 1991). By lowering inhibitions the participation in unsafe sex is facilitated by some who might otherwise protect themselves or, as in the case of secondary transmis-
The population of youth who are IVDU (Intravenous drug users) present a problem of access for intervention because of the illegal status of drugs, and the social stigma attached to IVDU's (California Community Planning Working Group, 1995). Not only are IVDU's at risk but sexual partners of this population, and their sexual partners also are at risk. A general lack of concern for IVDU's is evident when we consider that the essential intervention procedure in public health, eliminating the vehicle of transmission (in this case contaminated syringes), is secondary to political considerations for the "war on drugs" as it is apparent in paraphenalia laws (California Community Planning Working Group, 1995; The United States Conference of Mayors, 1997; P. Lurie, and A. Rein-gold, 1993).

Injection drug users may acquire HIV just like anybody from unprotected sex, or from their use of contaminated needles. They may transmit the virus either through unprotected sexual relations or through sharing needles. The best way to prevent primary or secondary transmission is to give up injecting drugs; the next best way is to use sterile, needles, syringes, and other "works" each time; next is not sharing any equipment; and the least effective method is cleaning equipment after each use. Needle exchange programs are effective in increasing the availability of sterile equipment, and contrary to their critics accu-
sations do not promote increased drug use (California Community Planning Working Group, 1995; The United States Conference of Mayors, 1997; P. Lurie, and A. Reingold, 1993).

The use of condoms, bleach kits for IVDU's, and other prevention measures have been emphasized, through education of at risk populations since the beginning of the AIDS epidemic. Because of the view of AIDS as a plague, the gay disease, the curse of a vengeful God, and it's mental image of certain death there has been a great need for education efforts (Sontag, 1989; I. Stulburg, and M. Smith, 1988; L. Lockhart, and J. Wodarsky, 1989; T. Prendergast, and H. Giese, 1997).

The next frontier after education is facilitating the application of the knowledge in behaviors that eliminate the risks of spreading the epidemic. Behavioral change does not follow the intake of knowledge. High levels of knowledge are often coupled with low levels of action consistent with the knowledge (G. Shields, and J. Adams, 1995; P. Simon, E. Morse, H. Osofsky, and P. Balson, 1994; M. Morton, et al, 1996). Behavioral Science theories, and technologies need to be integrated into public health education and prevention (L. Leviton, and K. O'Reilly, 1996; M. Fishbein, and M. Guinan, 1996; J. Curran, 1996).

Community intervention using multiple formats to deliver behavioral strategies that are successful can take many forms. The use of role model stories that portray members of the different categories of high risk populations (such as IVDU, gay men, the heterosexual partners of IVDUs or bisexual men, and
male or female prostitutes) is a format that may work in some communities (N. Corby, S. Enguidanos, and L. Kay, 1996; L. Leviton and K. O'Reilly, 1996).

Another format for community intervention is street outreach that includes screening, engagement, assessment, service delivery, and follow-up (J. Valentine, and L. Wright-De Aguero, 1996). Outreach services may be the only way to access some disenfranchised members of the target community. It may be conducted by professionals, para professionals, volunteers, or paid indigenous peers who use life experience and street skills that may, or may not, be grounded in theory (R. Cheney, and A Merwin, 1996; J. Valentine, and L. Wright-De Aguero, 1996; L. Levitan, and K. O'Reilly, 1996).

The use of Peer Educators is a format that has facilitated a sense of community ownership and pride in intervention programs (D. Holtgrove, et al., 1996; P. Simmons, et al., 1996; L. Levitan, and K. O'Reilly, 1996). Although much dropout is experienced with peer educators, most intervention networks maintain a core group of peers who become a conduit for the communities perspectives, and a constant gauge for effective monitoring of program success (L. Levitan, and K. O'Reilly, 1996; C. Gunther-Grey, D. Noroian, J. Fonseka, and D. Higgins, 1996). If Peer Educators are paid it empowers the individuals, keeps important resources within the community and may be an important asset in the recruitment of new individuals into peer education programs (Los Angeles County HIV Prevention Planning Committee, 1996).

Continued monitoring and adjustments to the changing contexts of com-
munities with their unique problems is an ongoing challenge for prevention and intervention in a neighborhood. Continued research that defines target populations of at risk groups, gathers information from inside the community about the groups, and applies theories and knowledge about the groups is needed. Planning for intervention should be in conjunction with people from the affected community. Prevention needs should be assessed based on epidemiology, resources, and knowledge about target groups so that decisions are made on sound information (D. Holtgrave, J. Harrison, R. Gerber, T. Aultman, and M. Scarlett, 1996; D. Higgins, et al., 1996; T. Prendergast, and H. Giese, 1997). Thus identification and scope of the problem, and the prevention and intervention goals are best determined by both the community and professionals.
Research Design and Methods:

A hermeneutic dialectic circle was employed to search for a best fit for the service providers and the community. In this form of constructivist naturalistic inquiry the research design is allowed to emerge through the process. The goal of constructivist research is to facilitate consensus that is the nucleus for collaborative work among stakeholders.

The design that emerged during this enquiry was a bi-phasic model. A consensus formed immediately surrounding the need for a needle exchange program in the community. This task group was formed shortly after the eleventh of sixteen interviews were completed when the 3rd and 4th respondent called the researcher to a meeting. We agreed to have a round table discussion at that time and overall five of the original eleven respondents have attended the working group meetings. The task group has expanded to include associates of the respondents who are from the Social Work faculty of a local college and individuals from a county office of Alcohol and Drug Programs. The group has currently met four times as it is engaged in the process of defining itself and its strategies for community action and building a coalition for needle exchange.

In the meantime continued interviews proceeded around the circle and skipping the first and second respondents five others were reinterviewed. Divergent perspectives, understandings, and priorities became apparent. Consensus on some concepts contrasted with differences. Member checking was used to help with accurate analysis of the data that was gathered. It was determined
by the researcher that further interviewing would not highlight more similarities and differences or contribute to forming a consensus. A round table discussion was held that was attended by three of the respondents. Of those who did not attend four sent their regrets referring to prior commitments as reason for not attending.

Respondents signed consents and were notified that their identities would not be kept from each other but every attempt to insure confidentiality, privacy, and anonymity at the level of this report and subsequent discussion would be made. Two of the interviews were conducted under the condition of total of anonymity with the understanding that their identity would not be conveyed to the other respondents, and that they would not be attending the round table discussion. Their interviews were added to the researchers body of knowledge.

The interview questions after the original research question of “Tell me about youth and HIV/AIDS prevention in this neighborhood?”, were designed to uncover themes of stakeholder claims, concerns, and issues.

Questions that explored claims asked “What is working in the neighborhood now?”, “What is ineffective?”, and “How is high risk behavior understood in this neighborhood, and what is it’s meaning?”

Questions that prompted expansion of concerns were “What is needed in the neighborhood?”, or “Is there a particular at risk behavior that needs emphasis?”, or “Are interventions, and preventions working as well as they should be?”
The uncovering of issues that the respondents had involved more pointed questions. For example, “What is the main barrier to intervention in the neighborhood”? or “Is that the problem, or a symptom of much deeper seated problems”? or the “miracle question”, “If you had the power to make one change in the neighborhood’s HIV/AIDS prevention effort what would it be”?

The first two interviews were anonymous upon request of the respondents. They were exploratory in nature, and added to the knowledge base of the community context of the researcher. They caused three additional more focused questions to be added to the interview which were; 1. “Would NEP’s (needle exchange programs) help in this neighborhood?”; 2. “What would a successful coalition to bring NEP’s into the neighborhood look like?”; 3. “How could availability of condoms in the neighborhood be increased?”

The interviews became more focused as constructs were presented to respondents for feedback until claims and concerns were reduced to only a few questions from each category. While all questions regarding issues were asked of all respondents.

Data was unitized across interviews and then across questions. Only data that matched in both unitizing processes were considered relevant for construction of categories and category attributes. After more focused questioning concepts were constructed according to the constant comparative method for presentation at the round table discussion (E. Guba, and Y. Lincoln, 1985; D. Erdlandson, E. Harris, B. Skipper, and S. Allen, 1993).
The identity of the respondents are not reported in this study. All were promised that tape recordings of their interviews would be confidential and protected until they were no longer needed then destroyed. The respondents were identified by number committed to memory by the researcher. The following are descriptions of the respondents.

The first respondent was a 24 year old gay male who was a former IVDU. He was a current resident of the community and has lived in the neighborhood off and on since his step father kicked him out of the house when he was 17 upon learning that he was gay. He shared that he was HIV positive and may have contracted the virus through unprotected sex or from sharing drug equipment.

Respondent number two was a 26 year old female who was a former sex industry worker and a former substance abuser who was now clean and sober. She reported that she has intermittently shared injection drug equipment especially when she had a boyfriend who was injecting drugs. She has lived in the neighborhood all of her life.

The third respondent was a 19 year old from the neighborhood. He graduated from the neighborhood high school a year ago. He has found employment at a CBO as a peer health educator and has concentrated in HIV prevention in the neighborhood.

Respondent number four was a minister who runs a small CBO in the heart of the community. He operated an after school peer education program that of-
fered peer health education. He has developed a transitional living home for homeless HIV positive community members.

The fifth respondent operated a drug and alcohol treatment facility in the neighborhood that was orientated to adults and included young women with children. As she stated it: “we get them later and deal with the results of their at-risk behavior as youths”.

Respondent number six was a community health outreach worker and satellite office manager of a large CBO who’s primary purpose was HIV/AIDS services. She had a long history of street outreach service to oppressed communities, and was highly skilled in street outreach especially to the Spanish speaking community.

The seventh and eight respondents were 18 year old males from the community who were currently students at the local high school. Both of these young men were contacted at the small CBO that operated a peer health education program.

Respondent number nine was a college professor of Health Science and Human Ecology at a small California university. He has been active in an advisory capacity in many of the agencies that operated in the community. He was involved in advocating for more access to HIV education for youth in schools and availability of the means of protection for youth.

Respondent number ten was a county child protective services worker and MSW who was assigned to operate an independent living program for children
who were approaching 18 years old. She incorporated HIV prevention into the childrens’ curriculum, and gave further HIV education as an adjunct to STD and substance abuse curriculum.

The eleventh respondent was an MSW who is county child protective services manager in the area. He was also on the board of directors of the large CBO that offered HIV services, and is a member of the local Ryan White HIV funding and advisory board. His experience reflected years of service in the field and his knowledge of the neighborhood was extensive.

Respondent number twelve was the county epidemiologist at the Department of Public Health. He was also a on the board of directors of the large CBO. He was responsible for public health clinics and outreach services in the area. He was on the local funding and advisory board and has been involved with the state HIV working group. He was the ghost writer for all of the county HIV publications of the County Health Officer, and was an occasional professor of public health at a local college.

Respondent thirteen ran another small CBO that used youth as peer street outreach workers to carry the message of HIV prevention to other youth in the neighborhood. They operated a community adolescent health office, as well as, outreach after regular business hours. He recently organized a youth summit in the area that facilitated group discussions on HIV, and featured a play entitled “Older men having sex with teenage girls” that had a HIV prevention message.

The fourteenth respondent was a homeless youth who was a 19 years old
male. He reported that he has been homeless off and on all his teen life when his family was displaced for economic reasons. The researcher was shocked upon learning the age or this teen as he presented as a much older person. The researcher came in contact with this respondent when the small CBO that was run by respondent number four hosted a meeting of the local homeless coalition. The meeting topic was HIV in the homeless population and the presenter was a street outreach worker from the large CBO.

The fifteenth respondent was a homeless woman who the researcher estimated to be in her late 30's. She claimed to have been homeless for 6 years when she lost her job as a parts person at a local junk yard after a divorce. She was also met at the homeless coalitions' HIV meeting that she had attended in order to advocate for her son who she stated is homeless and HIV positive.

The last respondent was a MSW from another office of the large CBO. She was chosen as the last respondent because of her expertise in providing services to youth and her expertise in the field of HIV services. She helped with verification of the concepts derived from other respondents and the researchers knowledge base.

There was a total of seven respondents from the community, one adult and six youth. Of these four people, three were African American, three were Caucasian, and one was Latino. There were five men and one female. From area service providers there were nine respondents two are from small CBO's, one from a local college, and one from a local substance abuse treatment prog-
ram. Of the remaining five, two were from the large CBO exclusively, two worked for local government and had ties to the large CBO, while one worked for local government and had no ties to any CBO's. Of the service providers interviewed, one was African American, one was Latina, and seven were Caucasian. There were three MSW's, and two with graduate degrees in public health. Four of the service providers were women and five were men.

An extensive literature review contributed to the researchers body of knowledge. Attendance at a day long seminar presented to an adjoining county mental health department by the large CBO (which included two of the respondents as presenters) added to the knowledge base. Participation at the homeless coalition meeting on HIV and involvement as a Social Work intern at one of the small CBO's coupled with attendance at a youth health summit by the second small CBO was helpful. The researcher monitored daily news reports and peer reviewed journals from the Centers for Disease Control via the internet for one full year.
Results:

A bi-phasic emergent model took shape after a task group formed surrounding the pressing need to develop a NEP. A decision was made by the researcher to continue with the original format while also attending to the task group. A hope was that the continued research questions might uncover other needs or action steps and that the concurrent studies would compliment each other. According to the constructivist research paradigm this is acceptable because of the complexity of the neighborhood and the ongoing goal of goodness of fit in prevention efforts. Flexibility is needed to accomodate the complexity (D. Erlandson, E. Harris, B. Skipper, and S. Allen, 1993).

Needle Exchange:

The pressing need for an NEP in the neighborhood and it's implications for prevention and youth were profound. Many respondents cited the high teen pregnancy rate and the high risk unprotected sex scenario of older men and young women. They claimed that older IVDU men victimize young women who are without the social skills to resist them. Others sited the IVDU and gay population crossover of both bisexual and homosexual addicts who have sex with young men or women. These children, who may feel unloved and insecure, may succumb to IVDU as a way to fulfill unmet needs when they see them as a bonding act with an older person. An IVDU may have a cultural bias in sexual relations that sees the use of a condom as minimizing the sexual act. Many young people experiment with drugs, and because of acceptance by drug using
peers or curiosity, might be situational IVDU's or one timers. These novice drug
users may have little knowledge about cleaning drug equipment. Some respons-
dents sited the combination of the youthful IVDU, who is an addict with little
hope of getting clean and sober, coupled with the pervasive ideas of limited ex-
pectation for a long life.

All of the respondents, both before and after the working group formed,
were in favor of needle exchange as a means of reducing HIV transmission to
the general population and to youth as a sub-group. The mobilization of that fa-
vor into a coalition to make it a reality in the community was an exciting chal-
lenge.

The working group meetings started when respondent four from the small
CBO phoned the researcher to inquire about our mutual level of commitment to
starting a NEP. After many conversations about possibilities, concepts, and con-
cerns a meeting was scheduled. In attendance were respondents three and
four, a social work intern from respondent four's small CBO, this researcher, a
HIV/AIDS program supervisor from the County Office of Alcohol and Drugs, and
a member of the faculty of the Social Work department at a local college. The
main questions that the group came up with was what the process is for having
an area declared a disaster area so that a variance to paraphanalia laws might
be obtained, and who would have the authority over approving a disaster dec-
laration or granting a demonstration project. The group decided to contact local
people in touch with political representatives, professors at the college, other
NEP's in the state, a former police officer (to assess the level of resistance to NEPs), and members of the large CBO who had formerly made a proposal for a variance to get an experienced perspective.

Political action versus civil disobedience was the theme of the next meeting with new members from the group of respondents that included the community health outreach worker from the large CBO (respondent 6) and the county epidemiologist (respondent 12). There was conflict as people aligned over whether to start covert needle exchange. The consensus was that underground operations are already in operation and that because of their illegal status they are destined only to serve a small circle of friends or drug networks, not the general population of IVDU's. A report on a historical attempt to create an NEP was given and the main reason given for not being successful was opposition from the County Board of Supervisors. A report on contacts with the current political power bases and local police were not encouraging. The political climate is conservative and opposed to NEP's and local law enforcement support enforcement of current paraphernalia laws. Local politicians embrace the popular idea that NEP's would promote drug use, law enforcement officers site fears of being punctured by needles during searches of suspects, and further, the state attorney general, (a current candidate for governor), has vowed to use state officers to override any leniency in enforcement of the law by localities. Since all NEP's start in environments that are oppositional and conservative a main question became how do we break through these bar-
riers. Letters were written to needle exchange programs throughout the state by
the researcher asking for input sharing their experience, strength, and hope on
how they became legitimate and inquiring about interest they might have in
helping to form our coalition.

From a working group to a coalition is a major transformation. Attempts
were made to incorporate community members through conversations in con-
tacts with the affected population and people who are recovered through local
self help groups. Another respondent (number nine), the Health Science pro-
fessor joined the group along with an additional professor from the local college
Social Work Department. It was decided that the coalition should be broad bas-
ed and should mirror associations that might oppose it. If a citizen, for instance,
opposed it on religious grounds we could point out that their minister, priest, or
deacon was a member of the coalition.

Other NEP’s did not answer letters asking for help with how to become a
legal program. In hindsight it seems somewhat naive to think that they would,
because even though programs may have local sanctions they are still illegal
according to state law. One response did come from a Northern California
“Harm Reduction” group leader that was involved in a locality that got local san-
ction. The insight that was shared was to get a lawyer to help analyze our op-
tions, and to ascertain the judicial climate of the area; to educate ourselves on
the history of NEP’s successes as they are discussed in the scientific literature
so that they can be passed along; to know the IVDU community and “street
elites'' who will use their respect in the community to vouch for us; and to make
friends with politicians or anyone with power or esteem who will support us.

The working group at a latter meeting decided to, first, build awareness of
the need for needle exchange through networking with local politicians and
providing empirical objective data from the neighborhood that will support that
need. The second decision was to plan an event that would show local power
elites that their peers in other regions are in favor of the NEP concept. And last
to take action to create a sample policy that the local politicians would feel com-
pelled to enact.

At another meeting the working group learned about state Senate Bill 885
sponsered by Senator Diane Watson. This bill would authorize the state Depart-
ment of Health to legalize needle exchange programs in certain areas on the
grounds that the lack of sterile needles and laws that restrict needle availability
promote needle sharing. The bill states that as of December of 1996, 32% of the
573,800 cases that met the criteria for full blown AIDS were attributed to injec-
tion drug use. Of the 49,764 cases that were presumed to be transmitted by het-
erosexual sex 44% were from the partners of IVDUs, and of the 6,891 pediatric
AIDS cases 59% were from IVDUs (Senate Bill 885, 1997). Upon calling the
office of Senator Watson the researcher learned that SB 885 had been intro-
duced four times and passed twice only to be vetoed by the governor.

The researcher then sent a letter on behalf of the working group to the
State Health and Human Services Committee and followed it up with three tele-
phone calls. The chairperson of that committee called back informing us that SB 885 would not be reintroduced until the current governor's term ran out at the end of this year. Regrettably none of the committee members were able to accept our offer to come to our meeting that would launch our coalition and relationship build with local politicians, but he did suggest a speaker from a nearby metropolitan city's Office of AIDS who subsequently accepted our invitation.

Other input from that office was that in other areas activist simply started overt operations then were subsequently sanctioned locally. Further, it was suggested that relationship building with local politicians was good but, when it came down to public health or moral issues politicians usually side with the moral issue. The key was to demonstrate that NEPs work because it would be very hard for a politician to oppose life saving measures.

Once the working group had a prestigious guest speaker from a nearby metropolitan area booked, fliers printed, and distributed it divided into two subgroups. One group was to further develop objective data that existed already and make plans for additional research that would support the creation of NEP's in response to needs in the neighborhood.

Another sub committee would work on developing a model for a substance abuse triage that includes NEP's. The model was envisioned as a bridge to services that would be administered in a user friendly (non judgmental) agency that put emphasis on confidentiality, anonymity, and accessibility. The program model would fit into a CBO that has credibility with the using population and
is orientated to outreach, as well as, being agency based. It would have a policy of cooperation and collaboration with other agencies that would include intensive relationship building leading to memorandums of understanding that would in effect pledge treatment upon request for IVDU who express a willingness to stop using with highest priority to pregnant women and teens. It would provide a variety of services in a client centered, rather than an agency centered services as exemplified by plans for 24 hour emergency response from non authoritarian staff. These staff are to be indigenous helpers, who are able to apply a combination of self help skills, coupled with professional training. Any CBO that incorporated HIV prevention through help for IVDU must offer a wide variety of services with the objective of changing the community, orchestrating the delivery of services, and developing collaboration with community members (Leukfeld and Battjes, 1992).

The model would be flexible and responsive with a basic three tiered level or services that would include linkage with total abstinence inpatient treatment, harm reduction and education services that would include outreach to partners of IVDU, and a NEP that would emphasize relationship building with contingency plans for crisis intervention and emergency treatment.

Staffing of the coordination of services could be done by MSW interns with support and training of indigenous workers done by Alcohol and Drug Interns from a local junior college. Volunteers from the community might first be recruited from self help groups to become paraprofessional, and community members
who are former peer adolescent health outreach workers who have prior training would be candidates. In this way the community would be growing its' own leaders who are committed to HIV prevention.

The future of the coalition should emerge further after the scheduled event with the guest speaker. A large turnout is expected given the response to promotions and the large quantity of flyers that were handed out in the community, other agencies, and colleges. The coalition might change directions from legitimacy to civil disobedience, identify new indigenous leaders, effect local politicians, become a committee that will coordinate funding proposals, or simply remain in place as an advisory committee.

The guest will address issues such as why have NEPs, do they work, the meaning of new federal guidelines, how NEPs can make a difference in IVDU, and stop the spread of HIV. It is envisioned that questions and concerns of the community will follow that will resemble a town meeting where various sectors of HIV prevention organizations can voice their opinion on the public health versus the political consideration of needle exchange. Where local politicians can listen to their constituency's response to solutions surrounding the discarding of used needles on public streets, the cost of prevention through needle exchange versus the lifetime medical costs of treating HIV, the opportunity cost to the neighborhood when the potential of these effected citizens are lost forever because of a preventable disease. It is hoped that it will include the dialogue about the opportunity to link NEP with drug triage, and make people aware that each
incidence of needle sharing may not include a junkie, but a situational user who may never use again. Hopefully it will build consciousness that these are people who have sex with, or have sex with people who have sex with our teens who may be in danger of initiating perinatal transmission.

Hopefully it will also become a forum where community members may be presented with the facts about NEP and where they may voice there claims, concerns, and issues in an agenda around which they will feel part of a collaborative effort thus empowering them through rebuilding their community, and a venting and advocacy forum for local substance abuse program personnel where they are able to feel a part of a process of humanizing the war on drugs.

Concepts And Salient Points:

All of the service providers in the neighborhood claim that they have comprehensive prevention services. For the Public Health Department and the larger CBO comprehensive services meant a breadth of services. Their main focus is on education and support for behavior change. HIV/AIDS prevention education for the population of youth in the community is mainly through school presentations and other presentations to youth at juvenile hall, probation, and at job corps. They relay a variety of messages to the population at large, and state that what they learn from youth is that they are most likely to be aware of HIV prevention messages that are in cartoon form. Priorities for these providers are the largest at risk groups, which are men having sex with men and IVDU’s. Youth is the third priority and it is claimed that the youth of the community re-
ceive prevention services as a natural adjunct to targeted high risk groups.

Other smaller CBOs and service providers claim comprehensive services to different target groups and believe that comprehensive services means depth of services to these subgroups. Both of the small CBOs claim that they provide comprehensive services in the field of HIV prevention with youth or comprehensive health education of which HIV prevention is a part.

Community members, including youth in the community, view agency efforts as insufficient. There is misunderstanding of the scope, depth, and availability of prevention service resources. There is a lack of knowledge in different priorities of at risk groups. Funding is limited and resource allocation may not be popular decisions to make. Unpopularity is fueled by a lack of awareness in the neighborhood of primary and secondary prevention services and the decisions made surrounding them.

A snapshot of HIV seroprevalence shows that 99.4% to 99.6% of the general population are HIV negative, while .4% to .6% are positive. When awareness of this is coupled with the need to get the most bang for the buck out of prevention dollars it makes more sense to give higher priorities to secondary prevention. The paradox in funding, and dilemma for agencies, is that secondary prevention efforts are not visible efforts. They include support for behavior change, usually in group treatment or in an intensive case management model.

Another problem with understanding what people mean when they say prevention is that the term secondary prevention is at times applied to the con-
cept of stopping or slowing the progression of the disease in people who are already HIV positive. When the general public, or citizens of an oppressed community, think of prevention they think of primary prevention not secondary. This is also a point of conflict between large service providers who get the lions share of funding, with the understanding that they will provide secondary prevention, and expectations of smaller under funded agencies who focus on primary prevention and unmet needs.

All of these circumstances are superimposed on an impoverished neighborhood who’s pervasive thoughts about government and agencies are that they really don’t care. This is further fueled by smaller agencies who see the power structure as withholding funding while wanting their cooperation in providing data for their own funding purposes. These agencies would propose an even more essential meaning to primary prevention. This would include a holistic meaning to the term comprehensive services that link services like school retention, finding jobs for community members, and family problems that lead to risk factors, or are in more obvious cases risk factors themselves.

Some salient points in this theme is that more collaboration between agencies that operate in the community is needed. The allocation of resources along with the sharing of power needs to be facilitated so that community members feel more like a part of the process in setting priorities. Agencies need to be more client centered than program centered and consider starting where the
community is at. Operationalization of the term prevention would help with clarity.

The concept of sharing in educational presentations to youth as opposed to lecturing in an authoritarian style was a major point with youth. More interactive learning such as role play, paired sharing, and small group forums give youth a chance to process ideas, feelings, and fears. They could also be a format for distribution of means of protection and dissemination of knowledge about when, where, and how they may get condoms, or other protection. Free, open, non-defensive, and non-judgemental communication is preferred over an authoritarian style that may be symbolic of a critical parental figure or preaching.

Another concept is that there are many assumptions based on denial. People want to believe that youth are abstinent, or that abstinence should be the goal in HIV/AIDS prevention. The high pregnancy and STD rates in teens are evidence that teens are not practicing abstinence. It came up often that a historic common sense perspective makes the likelihood that programs that push abstinence only will be unsuccessful, but that abstinence will be incorporated and promoted as an option.

There is denial about the exclusivity of heterosexuality in youth. Sexual orientation is not an open topic for discussion with youth and adults. Because of religious ideology and the historic mendacity of viewing homosexual sex as unnatural, institutions and individual community members deny that it occurs.

There is denial of alcohol and drug use by youth themselves that is partly
from protection from the law, and partly learned from a society that is permeated
with denial about substance use and misuse. It is denied by the power structure
because of the need to scapegoat the communities youth and if a problem is
acknowledged in the youth, it points to substance problems in the general pop-
ulation. A reoccurring theme in the neighborhood is that substance abuse is not
to be admitted because just being a community member brings a host of stig-
mas and there is no need to accept more.

Individual denial is a theme within the concept of youthful feelings of invin-
cibility. A presentation that gives youth the personal testimony of a person who
has been HIV positive for 10 years but looks healthy makes it easy to ignore
when 10 years approximates half of their lifetime. When an “it won’t happen to
me” attitude is adopted it allows for the pursuit of pleasure to prevail over per-
sonal responsibility.

Services to the neighborhood would find a better fit and start where the
neighborhood is if they viewed at risk behaviors as a way of fulfilling unmet
needs. In such harsh environments there is a lack of love, care, and concern.
When there is a lack of meaningful involvement at risk behavior becomes a sub-
stitute. It can also be seen as a respite from the stigma and prejudice in the
neighborhood. Status, esteem, and competency may be received from deviant
behavior, for example, in speaking about sex industry workers one respondent
commented that “those women take pride in what they do”.

These environmental effects contribute to the conditions that are condu-
cive to unprotected sex and sharing syringes. Alienation in the neighborhood may foster substance abuse, unsafe sexual encounters, and multi-problem families.

Because of the unsafe situations that the environment fosters, access to the neighborhood is impaired. Outreach workers feel threatened and may have little in common with the neighborhood. When safety is an issue it interferes with the delivery of services, or restricts the delivery of services to a 9-5 time frame, when people who are most likely to need their services, are not available. One respondent suggested having an interagency sweep at night that would cover citizens and areas that are currently missed.

Language, culture, and religious barriers must be resolved in order to reach the youth of the neighborhood. The most suggested strategy to accomplish this is to educate indigenous citizens to carry the message of prevention in other languages, cultures, and in diverse religious denominations.

A sense of community and facilitating resiliency building environments is needed to give youth the opportunity to develop self protection skills. This may be conceptualized as essential primary prevention. It is operationalized as a safe social space where children in the neighborhood can develop close, meaningful, and nurturing relationships while being guided through tasks in which they experience joy and feel competent. The environment must build self
esteem in the child so that they get a sense of satisfaction in who they are and feel worthy of acquiring skills, such as, negotiation skills in relationships where they must protect themselves. They need to develop a sense of situational self efficacy so that they take action to protect themselves when faced with decisions about risk behaviors. Children need pro social involvement in which they are engaged in giving to others and experience the spirituality of service. Finally they need a sense of hope for the future exemplified by operationalized goals.

Proponents of this essential prevention claim that children with the features that are attained developing in a nurturing environment are a very low risk for practicing at risk behaviors that will expose them to HIV/AIDS. They suggest that essential primary prevention should be funded in the neighborhood, but is not because the results cannot be easily quantified to receive more funding and since it does not specifically address HIV/AIDS it is in another realm.

More attention needs to be paid to diverse enclaves in the community, the population of young men who have sex with men, and public acceptance of needle exchange and human sexuality in all forms. There are many enclaves in the neighborhood who are isolated geographically because of little regard for neighborhoods when infrastructure is created, or are unique ethnic communities who may live in a single housing project. These pockets of citizens need to be considered when developing HIV/AIDS prevention strategies. Lack of acceptance for gay young men and needle exchange hinders open communication about safety and perpetuates the use of HIV as a weapon used against people.
in the political "war on drugs" and against a homosexual lifestyle. Attitudes that put up barriers and exclude, rather than include, people from prevention need to be changed whether they are social or individual attitudes.

Quality of services can be improved by fostering the development of indigenous helpers along the lines of neighborhood block representatives who would be the source of the dissemination of the means of protection, and information. These helpers could be recruited, trained, and supplied with supplies by agencies to outreach in their own enclaves. Consensus formed around the need for more resources and how they would impact service delivery for the neighborhood. Another salient point was that more collaboration and coalitions were needed to promote cooperation and facilitate coordination of services.

The concept of legitimacy in NEPs usually takes the form of legal concerns. The first legitimacy, however, must be with the people that are being served. Once that is established the only other thing to consider is honesty, in the sense of being true to what an agency as a service provider knows is the truth.

It is the same with the availability of condoms. The first legitimacy has an obligatory flavor to the youth in the community. In that sense, as a service provider in the community that makes condoms available to young people, a key function is validation of their worth as human beings. Nothing fosters care, concern, and cooperation in the communities youth than care, concern, and cooperation of their social environment.
Discussion:

Because of the absence of scientific procedures, constructivist research lacks the quantitative research attribute of generalizability. Rather than generalizability, this research project, hopefully, points out a subjective applicability to similar neighborhoods. If it can lend direction for finding the best fit for HIV/AIDS prevention by pointing out concepts and salient points for inclusion in decision making then it will have served its' purpose. Qualitative and subjective research has value in allowing a naturalistic emergent design that highlights the cares, concerns and issues of the community and service providers. In this project that design was biphasic as it continued the research after the NEP working group formed.

In this particular neighborhood, because of the epidemic magnitude of IVDU coupled with the crossover of teen and young adult unprotected sex, the need for a NEP was evident. A task group formed to explore the possibility of creating a coalition that would advocate for the creation of a legal NEP.

Some of the concepts that would be wise to consider when planning prevention strategies in the community studied would be to be specific when using terms like prevention (primary or secondary), or terms like comprehensive services (depth in certain populations or breadth to all populations that risks superficial services to some).

A salient point is that education with support for behavior change is the main prevention strategy being used in the neighborhood. It is recommended
that education be interactive sharing that includes the sharing of ideas, feelings, and fears rather than authoritarian in nature. It is also important to put emphasis on easy access to the means of protection for youth in the community as a support for behavior change.

Many assumptions made by individuals in the community and by service providers are based on denial concerning abstinence (in substance abuse and sexuality). This denial supports the phenomenon of invisibility in youth and disregard of personal responsibility toward self and others. It may have a reciprocal relationship with environmental factors that lead to alienation as exemplified by substance abuse, unprotected sex, and multi-problem families that inundate the community’s youth. Prevention efforts in the community must understand at-risk behaviors as a means of fulfilling unmet needs regarding a lack of meaningful involvement, prejudice, lack of love, care, and concern.

The concept of access is highlighted for the means of protection, as well as, barriers to intervention such as individual and social attitudes of cultures and religions. Access is limited by language barriers, and a concern of service providers for their safety in the community. This problem would best be addressed through collaborative efforts of service providers and community members that may lead to coalitions that take action to increase access.

With this in mind, attention to diverse enclaves in the community might be better facilitated by the development of indigenous helpers. Many strategies are being used that could benefit from more resources being allocated to HIV/AIDS
prevention in the area. Also more resources could be used to train community members to be service providers. This would give the benefit of empathetic prevention by concerned citizens at the same time engaging those citizens in meaningful work that impacts their own awareness of prevention. This strategy would go far in establishing legitimacy within the effected community.

The final concept is an aspect of primary prevention that may be labeled essential prevention. It targets the root of problems that lead to at-risk behaviors. Intervention is made to rebuild the sense of community in which health is fostered. This concept sees HIV/AIDS prevention beginning with a safe social space in which solid essential relationships are developed. It would facilitate the healthy psychosocial developmental stages of children that pays attention to environmental and developmental crisis. The paradigm may be understood as a resiliency building effort that gives children the opportunity to develop self protection skills. Some important components are building self esteem, situational self efficacy, positive social involvement, and instilling a sense of hope for the future. Currently efforts in this realm are not funded because they are not specific to AIDS/HIV prevention and are not easily quantified to support funding.

Implication for further research would be to address any of the concepts or salient points in quantitative data that would substantiate or disprove the subjective findings. In this way the findings would have the attribute of generalizability, and funding for innovative prevention strategies that are specific to success in oppressed areas could be funded such as essential prevention.
Implications for social work practice in finding the best fit for HIV/AIDS prevention is that the community should be involved in finding the best fit for services and how they are rendered. In the macro practice arena policy and planning should be orientated toward flexibility in application so that disadvantaged neighborhoods get the best prevention services for them. In community practice the emphasis should be on coordination of complimentary services and collaborative efforts that includes coalition building and incorporating community members in the process. For micro practice it is important that relationship building is highlighted so that services are provided in a non-judgemental, interactive manor, and with an inclusive spirit.
APPENDIX I

Research Questions:

"Can you tell me about youth and HIV/AIDS prevention in this neighborhood"?

"What is working in the neighborhood now"?

"What is ineffective"?

"How is high risk behavior understood in this neighborhood, and what are it’s meanings"?

"What is needed in the neighborhood to facilitate prevention"?

"Is there a particular at risk behavior that needs emphasis"?

"Are interventions, and preventions working as well as they should be"?

"What is the main barrier to intervention in the neighborhood"?

"Is that the problem, or a symptom of much deeper seeded problems"?

"If you had the power to make one change in the neighborhood's HIV/AIDS prevention effort what would it be"?

"Would nep work"?

"What would a coalition to bring a NEP to the neighborhood look like"?

"What would facilitate the availability of condoms in the neighborhood"?
Informed Consent:

I understand that I am being asked to participate in a research project concerning HIV/AIDS intervention and education with youth in the Central City neighborhood of a Southern California city. I am aware that the research is concerned with developing a shared understanding of the best combination of intervention and education for youth that participate in high risk behaviors in the community. I have been informed that the research hopes to facilitate a dialogue among myself and others to find the best fit for intervening with barriers to reducing high risk behaviors.

I am aware that high risk HIV/AIDS behaviors are very sensitive and controversial topics such as intravenous drug use, heterosexual sex, and homosexual sex. I agree to commit myself to honest and open conversation about sex and drug use because every case of HIV infection is preventable. I will extend compassionate support to anyone infected with HIV that I encounter because of the research project. I understand the importance and urgency surrounding every transmission of the virus.

I understand that the nature of the study is to share ideas openly, and honestly with the participants. Because of the open sharing, and participation in a round table discussion that culminates the project, I understand that strict confidentiality is not possible. I also understand that outside of the sharing of
ideas and collaboration with others in the study every attempt will be made to maintain my confidentiality.

I know that I am expected to share my ideas in a group, and I will not try to impose my ideas on others, but contribute to a common understanding by remaining honest, and open minded. I can expect that equal weighting will be given to my own, as well as, others points of view, and opinions. I will receive calls to verify what I have said, and to clarify what I mean. If needed I may get a written request to check that what the researcher heard from me was the meaning that I was trying to convey. I will respond to any such request. I understand that the research has been approved by the univercitie's Institutional Review Board. If I have further questions about the research I may contact Dr. Hunt in the Department of Social Work at California State University San Bernardino. The phone number is (909) 880-5501.

________________________________________
Michael Black, Researcher / Date

________________________________________
Name of Participant (Print) / Date Signature of Participant / Date
APPENDIX III

Debriefing Statement:

You have been a very important participant in a research process that has explored the best fit for intervention and education with youth concerning HIV/AIDS in an oppressed neighborhood. You have been exposed to frank discussions of high risk behaviors. Because HIV/AIDS is an emotional and compelling problem your role as a participant could have exposed you to both stigma and stress that may effect you negatively.

If you feel that you are in need of any services that may help you cope with the stress and stigma of the research please feel free to contact me (Michael Black) at (909) 824-5003 or Dr. Hunt at (909) 880-5496. We will make every effort to link you with any services that are available to you that might help you. Even if you currently feel that you have not been effected by the research, and some issue arises at a later date please call because your well being is important to us. Thank you for your cooperation and support of the research project.

_________________
Michael Black, Researcher / Date
References:


Lurie, P., and Reingold, A. et. al. (1993) The Public Health Impact of Needle Exchange Programs In The United States And Abroad; School of Public Health University of California Berkley/Institute For Health Policy Studies University of California, San Francisco, October 1993.


