

**YOUTH AND COMMUNITY BASED PARTICIPATORY RESEARCH:  
SUGGESTIONS FOR FUTURE DIRECTIONS**

by

Cara Nikolajski

BA, John Carroll University, 2005

Submitted to the Graduate Faculty of  
Behavioral and Community Health Sciences  
Graduate School of Public Health in partial fulfillment  
of the requirements for the degree of  
Master of Public Health

University of Pittsburgh

2007

UNIVERSITY OF PITTSBURGH  
GRADUATE SCHOOL OF PUBLIC HEALTH

This thesis was presented

by

Cara Nikolajski

It was defended on

July 31, 2007

and approved by

Thesis Advisor:

Jessica Griffin Burke, PhD, MHS

Assistant Professor

Department of Behavioral and Community Health Sciences

Graduate School of Public Health

University of Pittsburgh

Committee Member:

Diane Abatemarco, PhD

Assistant Professor

Department of Behavioral and Community Health Sciences

Graduate School of Public Health

University of Pittsburgh

Committee Member:

Emilia Lombardi, PhD

Assistant Professor

Department of Infectious Diseases and Microbiology

Graduate School of Public Health

University of Pittsburgh

Copyright © by Cara Nikolajski

2007

**YOUTH AND COMMUNITY BASED PARTICIPATORY RESEARCH:  
SUGGESTIONS FOR FUTURE DIRECTIONS**

Cara Nikolajski, MPH

University of Pittsburgh, 2007

Community Based Participatory Research (CBPR) is becoming popular in the field of public health. While many studies focus on including adults in the CBPR process, far fewer have utilized the input and expertise of children and adolescents. Successful CBPR projects are important to the field of public health due to their ability to open the doorway to the health needs and experiences of youth. This review paper first provides relevant background information regarding the health of youth living in the United States, the importance of adopting a life course approach to public health interventions, and the field of Community Based Participatory Research. It then explains the review methodology utilized and presents the results of the literature review. Specific attention is paid to summarizing CBPR work conducted with youth and the key issues related to such work. This review concludes by providing suggestions for future successful applications of CBPR with youth populations, and discusses the benefits and challenges of conducting this type of research. Results from this review contribute to a better understanding of the importance of utilizing ideas and insights of young people in order to create programming and policy changes that effectively address their needs.

## TABLE OF CONTENTS

<b>1.0</b>	<b>INTRODUCTION.....</b>	<b>1</b>
<b>2.0</b>	<b>BACKGROUND .....</b>	<b>3</b>
<b>2.1</b>	<b>HEALTH ISSUES CHALLENGING TODAY'S YOUTH.....</b>	<b>3</b>
2.1.1	Overall Health Status .....	4
2.1.2	Mental Health.....	4
2.1.3	Child Maltreatment .....	5
2.1.4	Obesity .....	5
2.1.5	Teenage Pregnancy and Sexual Intercourse.....	6
2.1.6	Sexually Transmitted Infections (STIs) and HIV/AIDS.....	6
2.1.7	Smoking .....	7
2.1.8	Bullying, Fighting, and Carrying a Weapon .....	7
<b>2.2</b>	<b>THE LIFE COURSE APPROACH TO HEALTH: WHY FOCUS ON CHILD AND ADOLESCENT HEALTH?.....</b>	<b>8</b>
<b>2.3</b>	<b>GUIDELINES AND COMMON METHODOLOGIES USED IN CBPR ...</b>	<b>10</b>
<b>3.0</b>	<b>METHODS .....</b>	<b>13</b>
<b>4.0</b>	<b>RESULTS .....</b>	<b>15</b>
<b>4.1</b>	<b>CBPR AND YOUTH PARTICIPATION.....</b>	<b>15</b>
4.1.1	Stress .....	17

4.1.2	HIV/AIDS .....	17
4.1.3	Substance use and HIV/AIDS .....	18
4.1.4	Rural health.....	19
4.1.5	Immigration Experiences .....	19
4.2	<b>KEY ISSUES IN CONDUCTING CBPR WITH YOUTH.....</b>	<b>20</b>
4.2.1	Community Entrée and Participant Recruitment .....	21
4.2.2	Issue Identification.....	22
4.2.3	Human Subject Concerns.....	22
4.2.3.1	Consent .....	23
4.2.3.2	Confidentiality.....	25
4.2.3.3	Issues of Child Maltreatment .....	26
4.2.4	Methods and Implementation.....	27
4.2.5	Dissemination and Translation of Findings.....	29
5.0	<b>DISCUSSION .....</b>	<b>30</b>
5.1	<b>SUGGESTIONS FOR CONDUCTING CBPR WITH YOUTH.....</b>	<b>30</b>
5.1.1	Community Entrée and Participant Recruitment: Working with After-School Programs and Other Existing Community Services .....	30
5.1.2	Issue Identification.....	31
5.1.3	Human Subject Concerns: Parental Involvement .....	32
5.1.4	Methods and Implementation: Creative and Artistic Approaches .....	34
5.1.5	Dissemination and Translation of Findings: Creative Exhibits .....	36
5.2	<b>POTENTIAL BARRIERS OF YOUTH FOCUSED CBPR.....</b>	<b>36</b>
5.3	<b>POTENTIAL BENEFITS OF YOUTH FOCUSED CBPR.....</b>	<b>38</b>

<b>5.4</b>	<b>LIMITATIONS AND STRENGTHS OF THIS LITERATURE REVIEW</b>	<b>39</b>
<b>5.4.1</b>	<b>Limitations.....</b>	<b>39</b>
<b>5.4.2</b>	<b>Strengths .....</b>	<b>40</b>
<b>6.0</b>	<b>CONCLUSIONS .....</b>	<b>41</b>
	<b>BIBLIOGRAPHY.....</b>	<b>42</b>

## LIST OF TABLES

Table 1. Summary of select health problems experienced by youth in the United States.....	3
Table 2. Summary of methods used to identify relevant literature.....	14
Table 3. Overview of youth CBPR projects .....	16



## **1.0 INTRODUCTION**

Children and adolescents today are faced with numerous health issues including obesity, poor mental health, and abuse (CDC, 2004; CDC, 2005; US HHS, 2005). According a 2005 US Department of Health and Human Services report, over 15% of individuals under the age of 17 are in less than excellent or very good health.

This thesis will examine literature addressing Community Based Participatory Research (CBPR) with youth. The specific aims of this paper are to 1. Summarize and provide an overview of the research conducted to date, and 2. Describe key issues researchers face when conducting CBPR with youth.

This review first provides relevant background information regarding the health of youth living in the United States, the importance of adopting a life course approach to public health interventions, and the field of Community Based Participatory Research. It then presents the review methodology utilized and the results of the literature review. Specific attention is paid to summarizing CBPR work conducted with youth and the key issues related to such work. This review concludes by providing suggestions for future successful applications of CBPR with youth populations, and discusses the benefits and challenges of conducting this type of research. Results from this review contribute to a better understanding of the importance of utilizing ideas and insights of young people in order to create programming and policy changes that effectively address their needs.

While the terms “child”, “adolescent”, and “youth” are often used interchangeably, this review uses the word “youth” to refer to anyone under the age of 18 years old. Instead of independently addressing “early childhood” (ages 1-5), “middle childhood” (ages 5-10) and “adolescence or late childhood” (ages 10-21) as defined by the *American Academy of Pediatrics* (Green & Palfrey eds., 2001), this review adopts a more inclusive approach similar to that employed by United Way. Within this organization, “youth” are defined as all school-aged children 6-18 years old (United Way, 2007). The fact that it is only around age six years old that children begin to think critically about their experiences and the world around them (Green & Palfrey eds., 2001) suggests that children below age six may not be capable of understanding and articulating the types of information and feedback required by CBPR. Thus, a CBPR approach may not be beneficial for children younger than six years of age.

## 2.0 BACKGROUND

### 2.1 HEALTH ISSUES CHALLENGING TODAY'S YOUTH

Youth in the United States experience a number of health problems which increase their chances of living with health difficulties or dying from disease. Table 1 provides an overview of the scope of select health issues among youth.

**Table 1. Summary of select health problems experienced by youth in the United States**

<b>HEALTH ISSUE</b>	<b>POPULATION AGE</b>	<b>PERCENT</b>	<b>SOURCE</b>
<b>Mental Health Issues</b>	6-11 years old	9.6%	US Dept. of Health and Human Services: Child Health, 2005
<b>Abuse</b>	< 18 years old	1.24%	Childhelp, 2006
<b>Obesity</b>	6-11 years old	30.3% overweight 15.3% obese	American Obesity Association
"	12-19 years old	30.4% overweight 15.3% obese	
<b>Teenage Pregnancy</b>	< 20 years old	7.7%	Guttmacher, 2000
<b>Sexual Intercourse</b>	High School Students	33.9%	CDC Youth Risk Behavior Surveillance, 2006
<b>HIV/AIDS</b>	< 25 years old	20,000 new cases per year	Schaalma et al., 2004
<b>Smoking</b>	Middle School students	11.7%	CDC Youth Risk Behav. Surveillance, 2006
"	High School students	22%	
<b>Bullying/Fighting</b>	High School students	33%	CDC Youth Risk Behav. Surveillance, 2006
<b>Carrying a Weapon</b>	High School students	17%	CDC Youth Risk Behav. Surveillance, 2006

### **2.1.1 Overall Health Status**

The US Department of Health and Human Services (US DHHS) asserts that, "84.1% of individuals under the age of 18 years old were in excellent or very good health", according to parent reports (US DHHS, 2005). This percentage varied by racial/ethnic background, and parental income. Nearly 91% of white parents reported that their children were in good health, while only about 65% of Hispanic families stated the same. Familial income greatly affected the health status of youth in that only 67% living below the poverty level were considered very healthy by their parent(s). This percentage increased substantially as family income increased with nearly a 94% excellent health rating in youth whose parents made an annual income four times greater than the federal poverty level (US DHHS, 2005).

### **2.1.2 Mental Health**

According to the US Department of Health and Human Services (2005), nearly ten percent of American children were reported to have a mental health issue in 2003. The statistics show that socio-emotional problems are more pervasive in non-Hispanic blacks and are more evident in young males. These issues become more apparent as children increase in age. Family income and lack of insurance also attribute to a greater number of youth suffering from mental health problems (US DHHS, 2005).

### **2.1.3 Child Maltreatment**

Child maltreatment can cause a number of mental health problems such as depression and negative behavioral manifestations; however, the physical pain that is inflicted upon children each year is a particularly staggering statistic. Over 12 per every 1,000 youth under the age of eighteen are maltreated each year. The types of child maltreatment range from neglect and medical mistreatment to sexual abuse and rape. Nearly 1,500 children die per year as a result of maltreatment and those who do not die are more likely to abuse substances such as drugs and alcohol. Nearly one-third of maltreatment victims will go on to mistreat their own children (Childhelp, 2006).

### **2.1.4 Obesity**

Obesity has become one of the largest health issues among children in the United States. According to the American Obesity Association (2005), 30% of children ages 6-11 are considered overweight, and 15% are obese. While the scope of the obesity epidemic is particularly notable among African American, Hispanic, and Native American children, Caucasians also have a higher prevalence of obesity than ever before. Obesity causes a number of adverse health issues both in children and adults. The risk for asthma increases greatly as body mass rises in children. Obesity increases the risk for Type II diabetes to 12.4%, and hypertension is also more noticeable in those who are overweight. In younger children, being overweight can also lead to malformations in bone growth due to the excess weight being placed on bones, joints, and growth plates in the body (American Obesity Association, 2005).

### **2.1.5 Teenage Pregnancy and Sexual Intercourse**

Adolescent sexual activity has been a topic of much discussion over the years with high rates of teenage pregnancy, STI's, and the abstinence movement. Despite the improvements in teenage pregnancy levels in the last fifteen years, the United States still has among the highest rates of teenage pregnancy in the industrialized nations (Perrin & DeJoy, 2004). The Guttmacher Institute (2006) projected a teenage pregnancy rate of 7.7% in women under the age of twenty in 2002. The 2005 Center for Disease Control and Prevention Youth Risk Behavior Survey noted that nearly 40% of high school students were taking part in sexual intercourse. Of these 40%, 63% used condoms during their last intercourse, and 18% used birth control pills. Unfortunately, there are still many high school students who are not using any method of birth control and many of those who use contraceptives do not use them properly or during every intercourse. Of this same percentage of students taking part in sexual intercourse, nearly 25% reported using drugs or alcohol prior, further decreasing the ability to use proper contraception (CDC, 2006).

### **2.1.6 Sexually Transmitted Infections (STIs) and HIV/AIDS**

Sexually Transmitted Infections (STIs) and HIV/AIDS are becoming a growing issue among adolescents within the United States. Each year, about 25% of sexually active teenagers will acquire an STI. Chlamydia is the most common with over 1,500 cases per 100,000 adolescents (Schaalma et al., 2004; US DHHS, 2005). People under the age of 25 represent over half, or nearly 20,000 new cases of HIV per year (Schaalma et al., 2004). In 2002, teen girls represented 51% of new cases in 13-19 year olds. African Americans and Hispanics represented 65% and 20% respectively of all new infections (Kates, 2005).

### **2.1.7 Smoking**

By age fourteen, the majority of smokers have had their first cigarette and 90% of smokers will begin before turning twenty-one (Mowery, Brick, & Farrelly, 2000). There has been a sharp decline in the number of adolescent smokers; however, as of 2004 nearly 22% of high school students and 11.7% of middle school students reportedly smoked (CDC, 2004; CDC 2005). According to the Substance Abuse and Mental Health Services Administration (2003), every year almost 760,000 youth under the age of eighteen become addicted to cigarettes. If unchanged, this will inevitably lead to a slew of health problems and an increased likelihood of premature death as a result of smoking related illnesses (American Lung Association, 2006).

### **2.1.8 Bullying, Fighting, and Carrying a Weapon**

Youth are more likely to take part in violent behavior than any other age group. This violence can spawn from a number of factors such as violence in the home, association with negative peer groups, poor community environment, stress and anxiety, depression, and other mental health issues (US Public Health Service, 2001). The recent influx of school shootings is only one of the startling examples of adolescent violence that is on the rise today. According to the CDC (2006), nearly 750,000 young people were treated in the emergency room for violence related injuries in 2004 (Anderson et al., 2001; CDC 2006). Bullying is an every day occurrence in US schools and in a CDC survey, nearly 33% of students stated that they had taken part in a physical fight, and 17% admitted to carrying a weapon only weeks prior to the survey (CDC, 2004). Sadly, murder is the leading cause of death for African Americans between the ages of 10-24, and the majority

of these homicides are attributed to gun use (CDC, 2006). Gender differences, such as males taking part in drug activity and female gossip issues, show the need to explore, with public health research, the manifestations of youth violence (Yonas, O'Campo, Burke, Gielen, & Peak, 2005).

## **2.2 THE LIFE COURSE APPROACH TO HEALTH: WHY FOCUS ON CHILD AND ADOLESCENT HEALTH?**

An individual's health choices made during childhood and adolescence contribute to their health status in adulthood. According to the World Health Organization (2004), the "Life Course Approach" to health can be beneficial in that it focuses on healthy growth and development in children and adolescents through education and other interventions. According to Ben-Schlomo and Kuh (2002), such an approach, "examines the long-term effects on health and disease of physical and social exposures during gestation, childhood, adolescence, young adulthood, and later adult life." Chittleborough et al. (2007) explains further by stating that, "it [the Life Course Approach] includes the study of biological, behavioral and psychosocial pathways that operate across a person's life course, as well as across generations, to influence health status."

Chronic disease is an area in which the Life Course Approach has become especially popular. Until recently studies primarily focused on the chronic disease process from adulthood to later life; however, these studies neglected to look at how health behaviors and nutrition habits that are formed in childhood can affect future ailments such as cardiovascular disease and cancer. Life Course studies have been beneficial in recognizing some of the youth risk factors that lead to disease in later life. By identifying these risk factors, researchers can create public



health initiatives to enhance the current and future health of youth (Ben-Shlomo & Kuh, 2002; Lynch & Smith, 2005).

The Life Course Approach has been used to measure a number of health problems that start in childhood and are continued into adulthood. The literature survey of the Life Course Approach conducted by Chittleborough, Baum, Taylor, and Hiller (2007) determined the socioeconomic indicators that influence disease trends from childhood into older adulthood. The results found that social structures such as income, education, and family structure are some of the aspects that should be monitored to enhance health over time. Lynch and Smith (2005) determined that number of siblings and socioeconomic standing led to a greater incidence of hemorrhagic stroke. Diet in young adulthood plays a role in cancer risk later in life. In addition, lower birth weight can lead to a slew of possible health problems along the life course. Each of these health indicators opens the doorway for creating positive health interventions for youth.

Smoking, alcohol and drug use, eating habits, and sexual behavior during childhood and adolescence are only few of the factors that can greatly influence today's youth future health. Smoking has been proven to lead to lung cancer as cell damage occurs throughout the years (Mowery, Brick, & Farrelly, 2000). STI's such as HPV can lead to cervical cancer if untreated (Schaalma et al., 2004; UDS DHHS, 2005; Kates, 2005). Drug and alcohol abuse distorts the way in which people think and behave and may pose great risks such as unprotected sexual behavior, driving under the influence, and liver damage (CDC, 2006). The United States is leading the world in obesity, especially in young people, which attributes to higher rates of cardiovascular disease (American Obesity Association, 2005). Creating interventions that target young people are crucial in order to promote a healthier environment that decreases risks for poor health in the future.

### **2.3 GUIDELINES AND COMMON METHODOLOGIES USED IN CBPR**

The field of Community Based Participatory Research (CBPR) is a growing discipline in the field of public health (Gebbie, Rosenstock, & Hernandez, 2002; O'Fallon, Dearrl, 2002), and increasingly researchers are seeking to conduct such work with youth. CBPR is an approach that involves the community of focus in many components of the research process. This includes participant recruitment all the way to the dissemination of results and the creation of community programs. The collaboration between researchers and the community in the CBPR process is unique in that it does not purely rely on the "expert" knowledge of researchers. Rather, the community members and project participants are the experts and they teach researchers about the issues that they are facing within the community in order to create positive changes (Minkler & Wallerstein, 2003).

CBPR has been used in a number of projects and has been tailored to work with a variety of populations. One study was conducted to determine barriers to cervical cancer screenings among Apsaalooke women. Female participants aided in the creation of a culturally competent and effective training manual to explore these barriers. Another study used CBPR approaches to determine HIV issues faced by the Latino community in Durham, NC. With this information, participants and study staff developed a survey and community members were trained to conduct interviews, observe participants, and take fields notes. Members of the community helped to disseminate the findings by co-authoring a book chapter, presenting the results of study, and creating further plans for action (Israel et al., 2002). These examples exhibit two very different approaches to CBPR; however, both effectively demonstrated key principles of this type of research.

Israel et al. (2002) created a list of nine guiding principles of CPBR that can be used to facilitate community-based research. The principles are listed as follows:

1. Acknowledge the community as the unit of identity.
2. Build on strengths and resources within the community.
3. Facilitate a collaborative, equitable partnership in all phases of research, involving an empowering and power sharing process that attends to social inequalities.
4. Foster co-learning and capacity building among all partners.
5. Integrate and achieves a balance between knowledge generation and intervention for the mutual benefit for all partners.
6. Focus on local relevance of public health problems and on ecological perspectives that attend to multiple determinants of health.
7. Involve systems development using cyclical and iterative process.
8. Disseminates results to all partners and involves them in the dissemination of results.
9. Involve long-term process and commitment to sustainability (Israel, 2002).

These guidelines suggest that the involvement of all community members and stakeholders in the research process is critical in creating effective programming and initiating social and political change.

There are a number of research methods utilized in the CBPR process, each offering a way of obtaining key information from community members and stakeholders. These methods may be used individually or in combination to provide a holistic view of a given health issue

from the perspectives of participants. Focus groups, interviews, surveys, forums, nominal group process, pile sorts, and community mapping are only a few of the methods that can be used to involve community members in the CBPR process (Israel et al., 2005).

Individuals are members of families, communities, and social groups, making them crucial components in the social ecological process. Each of the above methods engages participants to better explain and understand the parts they play as members of various communities. According to Thompson and Kinne (1990), "the increasing focus on 'community' in health promotion is due, at least in part, to growing recognition that behavior is greatly influenced by the environment in which people live." CBPR can aid in the exploration of the attitudes, norms, cultures, and behaviors of youth in order to better understand how young people fit into the social ecological model.

### 3.0 METHODS

A multi-pronged approach was used to identify relevant literature for inclusion in this review. First, select databases were searched to find articles related to child and adolescent health, CBPR with youth, and key issues pertaining to CBPR and young people. PubMed, OVID, and Google Scholar all revealed a number of useful resources. Search terms and phrases included "CBPR and children", "research with children/adolescents", "child health issues", and "ethical issues of research with youth". The titles of the search results were first reviewed for relevance, and if they appeared promising, the abstracts were read for specific subject matter. If the abstracts contained useful information the full text articles were reviewed and used for this paper. When searching the particular journals containing these articles, other relevant articles were also identified. For instance, after locating an article in *Children and Society*, other issues of the same journal were reviewed to find additional sources for this paper.

An online search of credible public health resources was also conducted to gather specific information, such as statistics, on given health issues. Some of these resources included the *Centers for Disease Control and Prevention*, *World Health Organization*, *American Lung Association*, *American Obesity Association*, and the *Guttmacher Institute*. Each site provided well researched and up-to-date information pertaining to the introductory section of this review.

Speaking with professionals who have conducted research in related fields yielded a better understanding of where to find articles, what to search for, and which books would be

useful. For example, the recently published books *Ethical Issues in Community-Based Research with Children and Youth* (Leadbeater et al., 2006) and *Methods in Community-Based Participatory Research for Health* (Israel et al., 2005) were suggested by one professional.

Finally, a bibliography search was conducted by looking at the resources used in the various books, websites, and articles that were obtained during the information gathering process. The bibliographies were scanned to determine any useful articles or books. If the sources seemed beneficial to this paper, a search was performed and the articles and books were reviewed. Table 2 describes the number and percentage of sources found via each data collection method.

**Table 2. Summary of methods used to identify relevant literature**

<b>METHOD OF COLLECTION</b>	Database Search	Basic Internet Search	Journal Scan	Professional Recommendations	Bibliography Search
<b>NUMBER OF SOURCES</b>	18	18	2	11	8
<b>PERCENTAGE OF TOTAL</b>	31.6%	31.6%	3.5 %	19.3%	14.0 %

## **4.0 RESULTS**

According to Baker, Metzler, and Galea (2005) the best way to initiate positive social change and improve upon social inequalities is to engage those who are directly affected by given health issues. Emphasis is placed upon considering different genders, races, and ethnicities to obtain more culturally competent information and ideas. However, the other component that must be added to this equation is to involve populations of varying ages in CBPR. Youth experience health concerns much differently than do adults and elderly populations. When research is conducted on a given health issue, youth are often the voice that is left unheard due to difficult issues that arise when conducting research with this vulnerable population (Alderson, 2001). CBPR is not employed as readily with youth as it is with adult populations; however, there are a number of studies that have overcome the challenges of working with young people to involve them in the research process.

### **4.1 CBPR AND YOUTH PARTICIPATION**

The scope of Community-Based Participatory Research with youth is relatively limited. Results from this literature review uncovered only five published studies which explicitly employed CBPR to address health issues among youth. Table 3 provides an overview of these five studies by describing the focus area of the work, the demographics of study participants, the types of

methods employed, and the consent obtainment procedures. Each study is described in greater detail below.

**Table 3. Overview of youth CBPR projects**

AUTHOR AND YEAR	FOCAL AREA	SAMPLE CHARACTERISTICS				METHODS	CONSENT PROCESS
		N	AGE	RACE	GENDER		
Chandra, A., & Batada, A. (2006)	Exploring coping mechanisms and social supports that adolescents use to deal with stress.	N=26	Average 14.5 years old	100% African American	73% Female	-Questionnaire -Audio Journal -Pile-sort activity -Personal Network Map	"Several consent forms completed"
Veinot, T. et al. (2006)	Study HIV-positive youth's perceptions of, and experiences with, anti-retroviral treatment.	N=34	12-24 years old	-56 % White, European -32% African American -6% Aboriginal -6% Unknown	38% Female	-Interviews -Demographic Survey	"Standard procedures" for obtaining informed consent
Marcus, T. et al. (2004)	Preventing substance abuse and HIV/AIDS in adolescents via Project BRIDGE.	N=61	13-14 years old	97% African American	54% Female	-Focus Groups -Media creation, playwriting, and musical composition. -Life Histories -Interviews	Parental consent and child assent obtained
Groft, J. et al. (2005)	Understanding health problems that rural youth face in order to create positive programming to promote a healthier life.	N=288	Average 15.5 years old	*	46% Female	-Survey	1st page read aloud to students and consent and confidentiality explained. Participation implied consent
Streng, M. et al. (2004)	Studying the immigration experiences of adolescent Latino immigrants.	N=8	Average age 17.5 years old	100% Latino	-25% Female	-Photovoice	Students under 18 years of age given parental consent and assent forms. Those over 18 could self-consent

\* Represents information not given in article



### **4.1.1 Stress**

Chandra and Batada's (2006) work in Baltimore, Maryland focused on stress issues with twenty-six African American adolescents and utilized a multi-method approach to include youth in the study process. Participants took part in pile sorts, questionnaires, audio journaling, and the creation of personalized maps of support services. These activities led to the creation of a video that helped facilitate conversation about stress and related issues. Clear distinctions between genders became evident in regard to what contributed to feelings of stress. Romantic relationships, neighborhood issues, and peers were a larger source of stress for females; whereas, school was listed as a major stressor by the majority of male participants. Also, males were more likely to avoid coping with stress or distract themselves from the cause of the stress. Females were more apt to actively seek support during stressful situations (Chandra & Batada, 2006).

### **4.1.2 HIV/AIDS**

HIV and youth is a topic for which researchers may hesitate to utilize CBPR methods due to the stigma and secrecy that often comes with having the virus. However, such concerns can be overcome as illustrated by Veinot et al's (2006) work utilizing CBPR with thirty-four multi-ethnic youth to address HIV issues. Veinot et al's study employed mixed methods (e.g. interviews and surveys) and focused on experiences with anti-retroviral treatments. Participants were obtained via various HIV/AIDS community organizations in Ontario, Canada and snowball recruitment aided study personnel in finding several other youth participants. The HIV positive youth, community program coordinators, researchers, and health care professionals helped with

each aspect from designing the program to disseminating the findings. Interviews with participants allowed those affected by the disease to voice their feelings, goals in life, and treatment issues. Although the article did not state that further programming was created for HIV positive youth as a result of this study, many implications for future programs were listed. Outreach programs for youth dealing with HIV treatment and support for managing medications are some of the ideas that this collaborative study elicited, thanks to the input of the involved youth community (Veinot et al., 2006).

#### **4.1.3 Substance use and HIV/AIDS**

CBPR activities can also be used to engage young people by teaching them about various health topics. The study conducted by Marcus et al. (2004) about *Project BRIDGE* discussed building life skills to help prevent the spread of HIV by teaching adolescents the importance of positive decision making. The *Project BRIDGE* curriculum consisted of life skills training, faith activities, and abstinence promotion exercises, all of which were utilized to promote healthy decision making. After taking part in the curriculum, students provided input on improvements during focus group discussions. Participants became so interested in the curriculum information that they wanted to become activity leaders and peer educators. They wanted to teach what they were learning to other youth, making them key players in the dissemination of information. The findings suggested that those who took part in *Project BRIDGE* were less likely to use marijuana, were more afraid of contracting HIV, and were more apt to feel compassion for those stricken with HIV/AIDS than those in the comparison group (Marcus et al., 2004).

#### **4.1.4 Rural health**

Inner city youth are not the only young people taking part in CBPR to better their lives and the lives of those within their communities. Although there are far fewer research endeavors that have focused on rural youth, a shift is taking place to include these remote populations. Jean Groft and colleagues (2005) published an article addressing their CBPR study conducted in Canada. The goal of their work was to identify adolescent perceptions of various health issues, both physical and mental, that they were being exposed to. Two hundred and eighty-eight students took part in the study and helped researchers and school administrators identify positive programming to reverse the negative health trends that begin in adolescence. The goal was to stop these adverse behaviors early before they led to problems in adulthood. The collaboration with the researchers, school personnel, parents, and students created an environment in which multiple stakeholders could work together for the best interests of the participating youth. The involvement of students in the program creation process provided them with a voice and a level of empowerment to create more effective and interesting school-based activities (Groft et al., 2005).

#### **4.1.5 Immigration Experiences**

CBPR recognizes a wide range of viewpoints and can be especially useful in creating culturally competent interventions with varying ethnic groups. *Realidad Latina*, a study conducted by Streng et al. (2004), focused on eight Latino youth and their experiences immigrating into the United States. The Photovoice method was used to address experiences of what it was like being a Latino and high school student in North Carolina, the social activities in which participants

took part, and solutions that could be applied to the issues that were revealed during the photo discussion sessions. The results from the study determined that many of the youth felt as though they had a limited future due to the stereotype associating cheap labor with Latino immigrants. Many felt rejected and as though their limited knowledge of the English language created large barriers to finding jobs and going to school. Many others believed that schools were racist toward them by providing very little support. These themes and photographs were displayed during a community exhibition. Although many community members and school personnel acted defensively towards the exhibit, action was taken via school administration and researchers to determine how to create a more positive environment for Latino students (Streng et al., 2004).

These examples show just how valuable community-based participatory research can be on a multitude of levels. Both private topics and issues of public concern can be explored with this approach. All ages, races, and ethnicities can gain positive outcomes from taking part. Also, CBPR creates a venue for more culturally competent and effective public health interventions.

#### **4.2 KEY ISSUES IN CONDUCTING CBPR WITH YOUTH**

Conducting CBPR with today's youth can be incredibly beneficial to the field of public health; however, there are a number of key issues that researchers need to address when working in this field. Gaining entrée into youth communities, participant recruitment, issue identification, potential human subject concerns, method selection and dissemination of findings must all be addressed in order to contribute to the success of CBPR work with youth. While many of these

matters may also be applied to research with adults, there are extra considerations that must take place when vulnerable youth participants are involved.

#### **4.2.1 Community Entrée and Participant Recruitment**

Gaining entrée into a community is a critical first step in the CBPR process. It is this step that allows researchers to gain the trust of community members in order to facilitate a CBPR project. Simply walking into a community and expecting youth to talk about issues pertaining to health will most likely yield less than useful results. Researchers must become acquainted with their youth participants if they want them to feel comfortable talking about the health issues of their communities. Taking part in community social events, attending school functions, or just walking around the neighborhood can provide insight into the every day activities of participants. Key informants can also be utilized to shed light into the experiences of community participants and to gain entrance into facilities or information that is not always accessible to outsiders (Goodman et al., 1991; Kahn, 1970).

Within the five youth CBPR articles discussed in this review, the entrée and participant recruitment process was not described in great detail. Chandra and Batada (2006) relied on recruiting participants that were known personally by one of the project facilitators. Within this context, a bond already existed between youth participants and the research staff. Veinot et al. (2006) recruited participants through a number of community facilities such as hospitals, youth organizations, and clinics. Marcus et al. (2004) focused their intervention on youth belonging to a popular African American community church. Although it is not explicitly stated, each of these studies relied upon common CBPR entrée gaining social organizations to gather participants.

### **4.2.2 Issue Identification**

A pure CBPR approach would utilize participant input to identify issues of relevance and prioritize which issues to address during the project. This process can be accomplished in a number of ways such as speaking with key community informants. More structured methods including the nominal group technique, pile sorts, and community forums (Israel et al., 2005) can provide insight into topics of interest. By using these techniques, stakeholders can brainstorm about health topics of concern and determine which would be most beneficial to tackle.

Chandra's *Shifting Lens* study (2006) used techniques such as pile sorts, questionnaires, and network mapping to determine topics of interest to the youth participants. In some cases, researchers must focus on topics that are already created by funding sources. The *Project BRIDGE* study conducted by Marcus et al. (2004) was tailored around the initiatives of the Substance Abuse and Mental Health Services Administration's Center for Substance Abuse and Prevention. The other mentioned studies did not state exactly how topics were chosen; however, it seems as though the majority were determined by university researchers prior to participant recruitment.

### **4.2.3 Human Subject Concerns**

There are a number of human subject concerns that researchers must take into account when conducting a CBPR project. Some of these include consent procedures, confidentiality, and issues with reporting abuse. By understanding these concerns, researchers can assure that their participants remain unharmed during the CBPR process.

#### **4.2.3.1 Consent**

There are issues of great importance that may arise when dealing with human subjects concerns in research. This is especially true if participants are below the age limit required for legal consent in the jurisdiction in which the research is taking place. Not only are the parents or legal guardian(s) of the youth usually required to give consent for participation; often, children are also required to provide their own assent.

Creating assent forms at a reading level that allows youth to adequately understand the research project and its components can prove difficult for some researchers. This is especially true if the assent form must be created for elementary school children with a very low reading level. It may be difficult or nearly impossible to convey the project's components in a language that gives all the necessary information (Thomas & O'Kane, 1998; Cree, Kay, & Tisdall, 2002). However, even though the vocabulary of youth participants may not be as developed as adults, researchers must not assume "non-competency" in young participants. Rather, assent forms should be amended in ways that engage various age groups with the use of language adjustment or pictures to assure understanding (Punch, 2002). Marcus et al. (2004) and Streng et al. (2004) both conducted studies in which child assent was obtained before the start of the CBPR project. The study conducted by Groft et al. (2005) discussed the project procedures out loud to participants to assure understanding and obtain assent.

Informed consent is always required when working with youth that have yet to enter their teenage years. This issue becomes more complex when dealing with adolescents. It can be difficult to determine the age that a participant must be to make informed decisions for him/herself without involving parents or guardians in the process. Many youth may not want their parents or guardians to know that they are taking part in a research project, especially if the

information is private or sensitive in nature (Leadbeater et al., 2006). According to the World Health Organization, parents may not have the right to deny mature youth participation in a research study that can enhance the sexual health of their child. If the study has no other means to understand the health issue than to work with dependent youth, and if the study will create positive changes towards the health of youth participants, they may be able to participate without parental consent (WHO, 2004). However, if laws in the jurisdiction in which the research is taking place state that even mature adolescents cannot make their own decisions about taking part in sexual health studies, researchers must abide by them (WHO, 2004).

The competency of youth participants to give informed consent is a multi-faceted topic of much debate. Maturity levels vary for youth, some mature at a young age, while others may take a few more years to reach an age in which they can make their own informed decisions. When working with developmentally delayed youth, a consent form may be necessary from parents or guardians well into the youth's teen or even adult years. In any youth research projects, the competence of the research subjects must be assessed to determine the level of consent necessary (Leadbeater et al., 2006). This can raise other questions such as: Should developmentally delayed youth be considered for the study? Should these youth be given different consent procedures than those who are considered mature enough to make decisions for themselves? Should parental consent be required of all youth participants, no matter their maturity level, even if youth will refuse because they do not want their parents to know the study's topic?

Difficulties with obtaining consent may also lead to difficulty in recruiting enough participants from target populations. According to Leadbeater et al. (2006) nearly 80% of youth will agree to take part in a project if they give their own consent. Many times the parents or guardians are contacted and asked to call if they do not wish to allow their child to participate. If



students are asked to have their parents sign a consent form, the number of participating youth drops to nearly 60%. If a youth is given a parental permission form, he/she may not return the form due to parental unwillingness to sign or reluctance to ask permission due to the nature of topic of study. High-risk youth are often underrepresented due to high familial stress and unwillingness to disclose private information. In addition, forgetting to return the form or the length and complexity of the form may cause a lack of representation of youth participants (Leadbeater et al., 2006; Morrow & Richards, 1996).

It is sometimes difficult to obtain parental consent. In the case of child abuse, the parents may be the perpetrators and may refuse to allow their child to disclose information to researchers. This is especially true since researchers are often obliged, upon discovery, to report incidences of child abuse. The best interests of the child should be the main focus in any research endeavor involving youth. Youth advocates or court appointed guardians may give consent in some cases; however, they too may pose a threat in that they may not be familiar with the child on a more personal level. Personal or political interests and agendas may also affect the ability of a non-parent to make informed decisions that relate to the youth participant's best interests (Kinard, 1985; Leadbeater et al., 2006).

#### **4.2.3.2 Confidentiality**

Confidentiality is another subject that must be addressed to assure that none of the youth's personal information will be disclosed to people who are not involved in the research project. In conducting any type of research with youth, private information may be revealed that even the child's parents or guardians do not know about. Issues may arise if the consenting adult thinks he/she has access to disclosed information. He/she may believe that it is his/her right as a parent

to have these private thoughts revealed, not realizing that this would jeopardize the confidentiality of the youth participant (Thomas & O'Kane, 1998).

With research projects that focus on particularly private information such as HIV or sexual abuse, confidentiality protocols may take on a whole different dimension. In such cases, youth may be asked to expose information about themselves or family members that they have previously kept secret. The stigma attached to such topics forces researchers to take extra precautions when contacting participants and their family members about the research project (Cree, Kay, & Tisdall, 2002).

#### **4.2.3.3 Issues of Child Maltreatment**

Sensitive topics, such as issues of child maltreatment, are often overlooked when it comes to conducting research with youth. Although much can be gained by talking to children and adolescents about their experiences with maltreatment, many researchers do not wish to take on the responsibility of dealing with the ethical complexity of such studies (Editorial, 2003). Retrospective studies may be useful; however, the responses given by adults with past histories of maltreatment may not be similar to the responses of youth that are currently experiencing the abuse. This makes it even more important to initiate discussion on how to overcome some of the ethical road blocks in order to gain a better understanding of the implications of this complex problem (Leadbeater et al., 2006).

When maltreatment is disclosed during a study, it is the responsibility of the research team to report it to Child and Protective Services. This may be considered a breach of confidentiality; however, if properly outlined in the consent and assent forms this breach can be avoided. One question to address is how much should be explained in the consent form regarding the reporting of abuse and neglect. In many cases, only a small statement regarding

the reporting of disclosed maltreatment is added to the consent form. However, this does not include what further actions will be taken if Child and Protective Services are involved. Arrests, intervention by social workers, foster care, all of which are possible outcomes of reported maltreatment, may have a variety of impacts on the involved youth. Children and adolescents may feel that they are at fault for compromising the stability of their family. This may lead to emotional manifestations such as depression and anger. On the other hand, reporting the abuse helps to release the youth participant from the cycle of violence and will, hopefully, allow them to lead normal lives free from harm (Putnam et. al, 1996; Leadbeater et al., 2006).

Another question that must be considered when child or adolescent maltreatment is revealed is the capability of the researcher to determine whether or not it should be reported. Many researchers may not be clinically trained to determine whether actions such a slap or spank are to be considered child abuse. The fine line between a punishment and abuse may cause a researcher to falsely report or under report such actions to Child and Protective Services. Some may believe that it is better to be safe than sorry; however, this can cause severe damage to the parent's reputation if the youth is found not to be a true victim (Fisher, 1994; Leadbeater et al., 2006).

#### **4.2.4 Methods and Implementation**

The selection and implementation of the research methods employed is important because it can contribute to the effectiveness of the CBPR project. Choosing methods that can adequately engage youth is a critical component to the CBPR process.

In conducting CBPR with youth, it is important for the researcher to build a rapport with participants to create an environment in which young people can feel comfortable and at ease.

The methods that are utilized should find ways of engaging youth in a manner that is most effective for their age group. Using adult research methods may allow youth to feel that they are on an equal plain and have the same level of competency as their adult counterparts. However, a face to face, purely conversational interview may prove less effective than an interview that uses drawings or photographs. Some children may lack the attention span or communicating ability of adults and may require alternative research methods. Thought must be placed into which methods would be most useful in getting the desired information from youth participants while assuring their comfort and confidentiality (Punch, 2002). Examples utilized in the five mentioned projects consisted of questionnaires, piles sorts, and audio journaling (Chandra & Batada, 2006), interviews (Veinot, 2006), focus groups, playwriting (Marcus et al., (2004), and Photovoice (Streng et al., 2004). Each of these methods provided data collection procedures that catered to the topic of focus in these CBPR projects

Researchers need to make concerted efforts to limit potential power differentials between themselves and participants. This is particularly important for CBPR work because perceptions regarding power dynamics can negatively affect the development of trust and the resulting data. In some cases, young participants may view the researcher as an authority figure and may formulate their responses to questions in a way that they think is appropriate for such an audience. No matter how much knowledge a child has about the topic of study, he/she may feel forced to disclose information that he/she does not feel comfortable talking about. Or, the participant may not feel comfortable talking with someone that is seen as a power figure, thereby, limiting the amount of information collected during the study and possibly making the findings less reliable (Mahon, Clarke, & Craig, 1996; Punch, 2002).

#### 4.2.5 Dissemination and Translation of Findings

Dissemination of findings and a commitment to action are both key aspects of the CBPR approach. After the research project is completed, the next step is often to create a program or intervention that addresses the findings and takes steps to create change within the community. With CBPR, participants play a central role in the dissemination and action taking process.

The dissemination processes differ greatly among the five highlighted CBPR youth studies. *Realidad Latina* conducted by Streng et al., (2004) used the photographs taken during the Photovoice sessions to create an exhibition and facilitate a community forum. Policy makers, teachers, community groups, parents, and students were all invited to participate and talk about action plans. Chandra and Batada's (2006) study of urban African American youth stress dispersed findings with the use of a participant created teen health promotion video. Participants and other community members also helped with the creation of a guide for adults to use to aid teens in coping with stress. Each of these examples involved young participants in the critical CBPR principles of disseminating findings and taking action.

The opinions and plans of the different stakeholders, specifically the researchers and community members, involved in research projects may lead to conflict regarding the dissemination of the research findings. The youth community may believe that the data belongs to them and should be distributed and used in a certain manner. Often times, when universities are facilitating the research process, they may collect the data, write the findings for publication, and may have their own ideas for the best ways to initiate change. Involving youth in the research process may help to create a more cohesive bond between youth participants and researchers (Leadbeater et al., 2006).

## **5.0 DISCUSSION**

CBPR is a particularly valuable approach because it provides researchers with the opportunity to learn from and empower participants to taking positive steps towards bettering their health and the health of their communities. The following discussion section offers specific suggestions regarding key issues including gaining entrée into youth communities, participant recruitment, issue identification, potential human subject concerns, method selection and dissemination of findings that must all be addressed in order to contribute to the success of CBPR work with youth. It then highlights potential barriers and benefits associated with youth focused CBPR, and acknowledges the limitations and strengths of the literature review.

### **5.1 SUGGESTIONS FOR CONDUCTING CBPR WITH YOUTH**

#### **5.1.1 Community Entrée and Participant Recruitment: Working with After-School Programs and Other Existing Community Services**

After school programs and community groups provide access to a number of possible youth participants for community-based research ventures. One of the main goals of CBPR is to use the facilities and resources already in existence within the community in order to utilize social capital (Altman & Goodman, 2001). Schools are an excellent resource for conducting

community-based research with young people because they provide trusted venues in which researchers and school staff can work together to promote a research endeavors. Even if students are not engaged in attending school, CBPR projects may provide interesting and beneficial lessons and learning opportunities to further enhance their knowledge and desire to attend classes (Becker, Randels, Theodore, 2005).

Existing community facilities, such as non-profit organizations and community centers also may provide a level of youth participation that would otherwise be more difficult to obtain. The staff in these facilities often has access to personal information regarding the youth and can offer connections and information as to which youth have the ability or desire to take part in a CBPR project. It would be more difficult to find participants without the connections that community centers and schools provide.

Utilizing these facilities also allows peers to learn from one another and create valuable connections between teachers, community leaders, and students (Becker, Randels, Theodore, 2005). The above locations provide an environment for group work to take place. When working with groups, youth are able to learn from one another and come up with ideas that may be more difficult to produce on an individual basis. Activities involving groups of children or adolescents create a venue in which children can feel more comfortable around and supported by their peers (Thomas & O'Kane, 1998; Yonas, 2006).

### **5.1.2 Issue Identification**

There is a wide range of relevant youth health issues such as obesity, abuse, smoking, teenage pregnancy, and HIV. Current methods for topic identification may in fact work; however, the five articles of focus did not touch upon this process in great detail. What is clear is that the

CBPR work conducted to date is limited in that it does not address the scope of issues faced by young populations. For example, community based studies focusing on teenage pregnancy, smoking, or weapon carrying were not topics covered by any of the addressed studies or found during the reference search.

Even if constricted by funding sources, there are ways to involve youth participants in the creation of subtopics of importance. Once an umbrella topic is chosen research methods can be utilized to explore these issues in greater detail. For example, if the overall topic is neighborhood safety, researchers can ask participants what subtopics they feel contribute to issues of safety. These brainstorming sessions can allow youth participants to provide insight into the focus of the study and determine what topic will be the most modifiable.

### **5.1.3 Human Subject Concerns: Parental Involvement**

CBPR provides community members with the opportunity to voice their concerns and suggestions to create healthier lives for themselves and their neighborhoods. Involving children and adolescents is an important component to this process, even with the challenges that come with involving young people in research. With some health concerns it may be possible to involve both youth and parents, creating an environment in which both groups can work side by side. For example, a Photovoice project involving children and their thoughts of community health may be supplemented with their parents answering the same questions through their own lens. Not only does this give varying perspectives of a similar health topic, it also aids in combating difficult consent issues. Parents that are actually taking part in the project may be less skeptical about allowing their children to also participate..



With studies that are more private in nature, parental involvement may not be possible. This is especially true if the parents are the perpetrators of abuse, or if information about sex or drug use will be disclosed by the youth participants. These issues, although more challenging, are still possible to overcome by looking into the laws of the areas in which the research is taking place. As stated earlier, if a given jurisdiction does not have a law stating otherwise, adolescents may take part in research studies about sexual health without parental consent if the study will improve their health or prevent negative health behaviors (WHO, 2004).

In studies that involve private information, passive consent may be more beneficial in obtaining a more random sampling of participants. Passive consent involves notifying parents about the study by sending a letter to their homes and allowing them to respond only if they refuse to allow their child to participate. This differs from active consent in that there does not have to be signed permission by the legal parent or guardian. With passive consent, it is very important to create an environment in which youth participants are fully protected, especially due to the lack of parental involvement (Leadbeater et al., 2006).

Some youth may feel that they will be punished in some way if they do not take part in a research project. Coercing a child or adolescent to take part in any research project is an obvious breach of personal rights and should be avoided at all costs. The *Youth Mood Project* discussed by Leadbeater et al. (2006) overcame these issues by involving case workers to help determine which youth were physically and emotionally able to take part in such research. After this was determined a letter was sent to the parent/guardian's house with an attachment that could be returned if they refused to allow the child to participate. Finally, if participation was not denied, a member of the study team went directly to the youth's home to gain signed consent and assent (Leadbeater, et al., 2006).

Each study will contain information that varies in regard to privacy and difficulty in obtaining consent. It is important to consider these differences and recognize that a procedure that works with one study may not work with another. Some may even be considered unethical if applied to another research venture. Overall, the protection of the youth involved is the first and foremost important aspect of any research being conducted. However, by avoiding this type of research because of its associated challenges, researchers would be denying people of critical data that could greatly improve the lives of children and adolescents both now and in the future.

#### **5.1.4 Methods and Implementation: Creative and Artistic Approaches**

Many youth are able to take part in research that uses methods such as focus groups, interviews, and surveys; however, sometimes a more art-based approach may be useful to peak the interest of young participants. Artistic research methods for use in CPBR endeavors are increasing in popularity. Art such as painting, drawing, and photography can create emotional reactions to issues that may not be as accessible via other methods (Ponto et al., 2003). These types of methods generate an innovative and creative venue for young people to express themselves and learn from one another (Yonas, 2006).

Photovoice is one artistic method that encourages participants to take photographs of aspects of their lives that pertain to certain public health topics. Photovoice, literally places cameras in the hands of the community members and enables them to reflect on the photographs they take (Wang & Burris, 1994). This approach can be applied to young people by allowing them to come up with the topics they want to photograph, talk about, and apply to create public health interventions. Photovoice can be used with various ethnic backgrounds and ages. All

children, regardless of their educational level, can take part in this public health approach (Wang & Pies, 2004; Streng et al.).

Visual Voices is a research method that has received increased attention from researchers interested in generating conversation about health issues through the use of painting, drawing, and writing. In relation to CBPR, participants may be asked which health topics are important to them. After discussing their creations, a final exhibit is constructed that can be displayed in neighborhood centers, parks, or schools to enhance awareness and facilitate learning within the community. This can be especially beneficial when conducting research with youth because it is creative and fun, yet structured (Yonas, 2006).

Much like Visual Voices, the "draw-and-write" technique is an artistic method that can be used to engage young people in the CBPR process. With this method, children are asked to draw pictures or write about health topics of interest to researchers. This can be used with children of all ages, including very young children. The themes that come out of the drawings can be applied to the enhancement of community public health programs, especially those that focus on children (Pridmore, & Bendelow, 1995).

Community mapping is a method that offers useful visual information about which community changes are necessary to enhance the health of neighborhoods. This is a research technique that can be conducted with youth to determine their beliefs about what makes a healthy community (Pridmore & Bendelow, 1995). According to Hancock and Minkler (1997), a healthy community is made up of several factors including safe housing, good public transportation, cultural and social supports, all of the basic needs, and many other components that enhance daily living. Community mapping activities with youth allow them to draw their ideal neighborhood and explore the changes that could be made and the possibilities that exist to

better their lives. Not only is this activity fun, but it can be conducted with limited necessity for strict parental consent due to its lack of private disclosure.

### **5.1.5 Dissemination and Translation of Findings: Creative Exhibits**

Disseminating the findings revealed by participants can be an innovative process especially if artistic methods are utilized. The writings, drawings, paintings, and photographs from Visual Voices projects aid in the creation of a mural display. Photovoice photographs can be used as exhibits in community facilities. Community maps can be displayed in classrooms to create awareness among students. Each of these examples builds upon the artistic creations of youth that can be developed during the CBPR process.

Once displayed, key community members such as policy makers, school staff, organizations, parents, and students can all be invited to view the murals, photographs, and displays. Such creations have the ability to foster learning among people of all ages in hopes that they will gain awareness and insight into important health topics. This will allow further steps to be taken towards the development of interventions that combat negative health issues and promote positive health outcomes.

## **5.2 POTENTIAL BARRIERS OF YOUTH FOCUSED CBPR**

CBPR is an approach that suffers from potential barriers worth addressing. Ideally, conducting CBPR with youth would permit all participants to equally take part in each step of the process to benefit from what is learned. While this is possible in some situations, most projects will take a

large degree of consideration as to the level of engagement that young people should have, how structured the project should be, and to what degree researchers can explore certain issues. When working with young children who have not reached a high level of cognitive development, CBPR activities should be more structured to keep participants successfully involved. Adolescents also have varying degrees of attention and maturity levels, making it crucial to consider exactly what level of freedom these youth should have while participating in a project. Young children may not have the ability to aid in the creation of research topics, the dissemination of findings, or the creation of further programming (Israel et al., 2005). While they can offer valuable information in regard to their own experiences, different CBPR endeavors will require varying levels of youth engagement dependent upon age, maturity level, and cognitive ability.

Cost is a factor that must be considered with any type of research endeavor; however, extensive CBPR projects may require much funding, especially for more artistic approaches. The materials for a Visual Voices or Photovoice project may cost a great degree more than what is needed to conduct drawing exercises or interviews. When determining which types of methods to use while conducting CBPR with youth, it is also necessary to consider the level of funding that the researcher is willing to spend on project materials.

It is important to recognize that youth can be highly influenced by their peers, a factor that can greatly affect how a child participates in a project. For example, one child may notice another drawing or writing about a certain topic and may feel that he or she should mimic those same ideas. While working in groups is beneficial in many cases, it is important to attempt to prevent participants from copying from one another in order to gain a better understanding of individual viewpoints (Pridmore & Bendlow, 1995).

When conducting research in any community facility it is important to recognize that no one should ever be coerced into taking part in a research project. In a school setting, it may be more difficult for a child to refuse participation. In a case such as this, it is crucial that the possible participants be reassured that they will not be negatively impacted should they choose not to participate. It is also important that rewards for participating be limited in order to engage youth who actually want to take part, rather than those that feel they have to or will be rewarded if they do so (Pridmore & Bendlow, 1995).

### **5.3 POTENTIAL BENEFITS OF YOUTH FOCUSED CBPR**

Despite the above noted potential barriers, CBPR is a unique research approach with several strengths and potential benefits to public health research and practice. By conducting CBPR with youth, researchers can gain a better understanding of childhood factors that contribute to disease later in life. CBPR projects can open up the doorway to research that looks directly at the problems youth are facing by placing their own thoughts, feelings, and voices within the data. This will decrease the need for retrospective studies that may be flawed due to recall bias, and will focus on what is presently happening with children and adolescents.

Multitudes of positive outcomes could occur by allowing young people to talk about their experiences. Non-profits, schools, child health programs, and adolescent health organizations can use this approach to create better programming. By allowing children and adolescents to voice their "expert" thoughts in regard to a health topic, a wealth of knowledge can be gained and applied in a more effective and useful manner.

CBPR can be adapted to work with people of almost any age provided they are cognitively able to participate. It not only provides useful data, it can also be utilized to empower young people to have a voice in their health, provide community displays via artistic creations, and foster an environment in which young people can learn from one another about their experiences. CBPR also has the ability to enhance teamwork and social skills through projects that require interaction between youth.

This approach is not limited to use by researchers. It can also be beneficial to community leaders and program facilitators by allowing them to learn more about the needs of their community members. Many of the CBPR methods discussed in this review can be taught with the use of train-the-trainer workshops. Community members can learn about activities that can engage young people and to help facilitate discussion of changes that need to be made to make their neighborhoods and lives better.

## **5.4 LIMITATIONS AND STRENGTHS OF THIS LITERATURE REVIEW**

### **5.4.1 Limitations**

While this review contributes insight into CBPR and youth participation, it suffers limitations worth noting. Many articles were reviewed to provide valuable resources for this paper; however, it is possible that a number of works were overlooked during the search. Articles may have been omitted from the search as a result of the search terms used. Not all journals were scanned in their entirety and only select professionals were asked about their feedback regarding

other valuable books and articles. CBPR with youth is conducted world-wide; therefore, articles regarding projects in other countries may not have been accessible due to translation issues.

This literature review was written to provide an overview of the issues that coincide with conducting CBPR with youth. Each of the sections was written to provide general information so readers can gain a better understanding of these topics. The health statistics gathered regarding children and adolescents is also not a complete listing of all the issues youth are facing today. While each of the mentioned problems is important, there are many others that contribute to the health and development of youth.

#### **5.4.2 Strengths**

To date, no overarching examination of CBPR and youth participation has been conducted. This review takes into account what other articles only look at in pieces. Overviews of health status, current applications of CBPR and youth, identification of key issues, and suggestions for future work make up this comprehensive review. This information can be used to successfully involve youth in future CBPR projects, further allowing them to express their thoughts and feelings regarding public health topics. By taking these ideas into account, researchers can mix and match methods and project designs to best suit their needs and the needs of the youth participants.



## **6.0 CONCLUSIONS**

Involving youth in CBPR provides insight into their place in the social ecological model of society. Young people are affected by public policy, family life, schools, peers, and their own personal struggles. While it may be challenging, CBPR with youth provides a lens into a world that cannot often be accessed as an adult. Researchers must overcome the issues that result from working with young people in order to gain a better understanding of how youth view important health topics. Involving young people in the CBPR process allows them to take part in the betterment of their current and future health and the health of their communities. Gaining entrée into communities, allowing youth to partake in topic generation, addressing issues related to human subject research, utilizing engaging methods, and effectively disseminating results are all components that researchers must account for when conducting CBPR with youth. Recognizing these principles will allow researchers to create effective, youth driven, public health projects and interventions.

## BIBLIOGRAPHY

- Alderson, P. (2001). Research by children. *Social Research Methodology*, 4(2): 139-153.
- Altman, D., & Goodman, R. (2001). Community intervention. In A. Baum, T. Revenson, & J. Singer (Eds.), *Handbook of Health Psychology*, Mahwah, New Jersey: Lawrence Erlbaum Associates, Publishers, 591-612.
- American Academy of Pediatrics (2001). Bright futures family tip sheets. *Families and Communities: Tools and Resources* online at: <http://www.brightfutures.org>.
- American Lung Association (2006). Smoking and teens fact sheet. *American Lung Association* online at: [http://www.lungusa.org/site/pp.asp?c=dv\\_LUK9O0E&b=39871](http://www.lungusa.org/site/pp.asp?c=dv_LUK9O0E&b=39871)
- American Obesity Association (2005). Fact sheets: Obesity in youth. *American Obesity Association* online at: [http://obesityusa.org/subs/fastfacts/obesity\\_youth.shtml](http://obesityusa.org/subs/fastfacts/obesity_youth.shtml).
- Anderson M., Kaufman J., Simon T., Barrios L., Paulozzi L., Ryan G., et al. (2001) School-associated violent deaths in the United States, 1994–1999. *Journal of the American Medical Association*; 286:2695–702.
- Baker, E., Metzler, M., & Galea, S. (2005). Addressing social determinants of health inequities: Learning from doing. *American Journal of Public Health*, 95(4): 553-555.
- Becker, A., Randels, J., Theodore, D. (2005). Project BRAVE: engaging youth and agents of change in a youth violence prevention project. *Community Youth Development Journal* online at: [http://www.cydjournal.org/2005Fall/pdf/Becker\\_Article.pdf](http://www.cydjournal.org/2005Fall/pdf/Becker_Article.pdf).
- Ben-Shlomo, Y., & Kuh, D. (2002). A life course approach to chronic disease epidemiology: conceptual models, empirical challenges and interdisciplinary perspectives. *International Journal of Epidemiology*, 31: 285-293.
- Centers for Disease Control and Prevention (2004). Cigarette use among high school students - United States, 1991-2003. *Morbidity and Mortality Weekly Report*; 53(23): 499-502.
- Centers for Disease Control and Prevention (2004). Youth risk behavior surveillance: United States, 2003. *Morbidity and Mortality Weekly Report*; 53(SS02):1–96.

- Centers for Disease Control and Prevention (2005). Tobacco use, access & exposure to tobacco among middle & high school students, US 2004. *Morbidity and Mortality Weekly Report*. Vol. 54(12).
- Centers for Disease Control and Prevention, National Center for Injury Prevention and Control (2006). *Web-based Injury Statistics Query and Reporting System (WISQARS)* online at: [www.cdc.gov/ncipc/wisqars](http://www.cdc.gov/ncipc/wisqars).
- Centers for Disease Control and Prevention (2006). Alcohol: frequently asked questions. CDC online at: <http://www.cdc.gov/alcohol/faqs.htm>.
- Centers for Disease Control and Prevention (2006). Youth risk behavior surveillance- United States 2005. *Morbidity and Mortality Weekly Report* online at: <http://www.cdc.gov/mmwr/PDF/SS/SS5505.pdf>.
- Chandra, A., & Batada, A. (2006). Exploring stress and coping among urban African American adolescents: the Shifting the Lens study. *Preventing Chronic Disease* online at: [http://www.cdc.gov/pcd/issues/2006/apr/05\\_0174.htm](http://www.cdc.gov/pcd/issues/2006/apr/05_0174.htm).
- Childhelp (2006). National child abuse statistics: Child abuse in America. *Childhelp* online at: <http://www.childhelp.org/resources/learning-center/statistics>.
- Chittleborough, C., Baum, F., Taylor, A., & Hiller, J. (2007). A life-course approach to measuring socioeconomic position in population health surveillance systems. *Journal Epidemiol Community Health*, 60: 981-992.
- Cree, V., Kay, H., Tisdall, K. (2002). Research with children: sharing the dilemmas. *Child and Family Social Work*, 7: 47-56.
- Denzin, N., & Lincoln, Y. (2000). The discipline and practice of qualitative research. In N. Denzin & Y. Lincoln (Eds.), *The handbook of qualitative research*. Thousand Oaks, CA: Sage.
- Editorial (2003). The neglect of child neglect *The Lancet*, 361(9356), 443.
- Fisher, C. (1994). Reporting and referring research participants: Ethical challenges for investigators studying children and youth. *Ethics & Behaviour*, 4(2), 87-95.
- Gebbie, K. Rosenstock, L., Hernandez, L., eds. (2002). *Who will keep the public healthy: educating public health professionals for the 21st century*. Washington, DC: National Academies Press.
- Goodman, R., Smith, D., Dawson, L., Steckler, A. (1991). Recruiting school districts into a dissemination study. *Health Education Research*, 6(3), 373-385.

- Green, M., & Palfrey, J. Eds. (2001). Bright futures family tip sheets. *American Academy of Pediatrics: National Center for Education in Maternal and Child Health* online at: <http://www.brightfutures.org>
- Groft, J., Hagen, B., Miller, N., Cooper, N., Brown, S. (2005). Adolescent health: a rural community's approach. *Rural and Remote Health* 5 online at: <http://www.rrh.org>.
- Guttmacher Institute (2006). U.S. teenage pregnancy statistics, national and state trends and trends by race and ethnicity. *Guttmacher Institute* online at: <http://www.guttmacher.org/pubs/2006/09/12/USTPstats.pdf>.
- Hancock, T., & Minkler, M. (1997). Chapter 9. Community health assessment or healthy community assessment: Whose community?, Whose health?, Whose assessment? In Minkler, M. (Ed.). *Community Organizing and Community Building for Health*. New Brunswick, NJ: Rutgers University Press.
- Israel, B., Eng, E., Schultz, A., Parker, E. (2005). *Methods in community-based participatory research for health*. San Francisco, CA: Jossey-Bass.
- Kahn, S. (1970). *How People Get Power*. New York: McGraw-Hill.
- Kates, J. Leggoe, A. (2005, September). HIV/AIDS policy fact sheet: The HIV/AIDS epidemic in the United States. *Kaiser Family Foundation* online at: <http://www.kff.org>.
- Kinard, M. (1985). Ethical issues in research with abused children. *Child Abuse and Neglect*, 9: 301-311.
- Leadbeater, B., Banister, E., Benoit, C., Jansson, M, Marshall, A., & Riecken, T. (2006). *Ethical issues in community-based research with children and youth*. Toronto, Canada: University of Toronto Press Incorporated.
- Lynch, J., Smith, G. (2005). A life course approach to chronic disease epidemiology. *Annual Review of Public Health*, 26: 1-35.
- Mahon, A., Glendinning, C., Clarke, K., Craig, G. (1996). Researching children: methods and ethics. *Children and Society*, 10: 145-154.
- Marcus, M. (2004). Community-based participatory research to prevent substance abuse and HIV/AIDS in African-American adolescents. *Journal of Interprofessional Care*, 18(4): 347-359.
- Minkler, M., & Wallerstein, N. (eds.) (2003). *Community based participatory research for health*. San Francisco, CA: Jossey-Bass.

- Morrow, V., Richards, M. (1996). The ethics of social research with children: an overview. *Children and Society*, 10: 90-105.
- Mowery P., Brick P., Farrelly M. (2000). Legacy First Look Report 3. *Pathways to Established Smoking: Results from the 1999 National Youth Tobacco Survey*. Washington DC: American Legacy Foundation.
- O'Fallon, L., & Dearry, A. (2002). Community-based participatory research as a tool to advance environmental health sciences. *Environmental Health Perspectives*, 110: 155-159.
- Perrin, K., & DeJoy, S. (2004). Abstinence-only education: How we got here and where we're going. *Journal of Public Health Policy*. 24 (3), 445-459.
- Ponto, J., Frost, M., Thompson, R., Allers, T., Will, T., Zahasky, K., Thiemann, K., Chelf, J., Johnson, M., Sterioff, S., Rubin, J., Hartmann, L. (2003). Stories of breast cancer through art. *Oncology Nursing Forum*, 30(6): 1007-1013.
- Pridmore, P., and Bendelow, G. (1995). Images of health: exploring beliefs of children using the 'draw-and-write' technique. *Health Education Journal*, 54: 473-488.
- Punch, S. (2002). Research with children: the same or different from research with adults? *Childhood*, 9(3): 321-341.
- Putnam, F., Liss, M., & Landsverk, J. (1996). Ethical issues in maltreatment research with children and adolescents. In K. Hoagwood, P. Jensen, & C. Fisher (Eds.), *Ethical issues in mental health research with children and adolescents* (pp. 113- 32). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Schaalma, H., Abraham, C., Gillmore, M., Kok, G. (2004). Sex education as health promotion: what does it take? *Archives of Sexual Behavior*, 33(3): 259-269.
- Streng, M., Rhodes, S., Ayala, G., Eng, E., Arceo, R., Phipps, S. (2004). *Realidad Latina: Latino adolescents, their school, and a university use Photovoice to examine and address the influence of immigration*. *Journal of Interprofessional Care*, 18(4): 403-415.
- Thomas, N., O'Kane, C. (1998). The ethics of participatory research with children. *Children and Society*, 12: 336-348.
- United Way (2007). Online at [www.unitedway.org](http://www.unitedway.org).
- US Department of Health and Human Services, Health Resources and Services, Maternal and Child Health Bureau (2005). *Child health USA 2005*. Rockville, MD: US Department of Health and Human Services.

- US Public Health Service (2001). Youth violence: a report of the surgeon general. Information from Chapter 4: Risk Factors for Youth Violence. *US Public Health Service* online at: <http://www.surgeongeneral.gov/library/youthviolence/chapter4/sec3.html>.
- Veinot, T., Flicker, S., Skinner, H., McClelland, A., Sauliner, P., Read, S., Goldberg, E. (2006). "Supposed to make you better but it doesn't really": HIV-positive youth' perceptions of HIV treatment. *Journal of Adolescent Health*. 38, 261-267.
- Wang, C., Pies, C. (2004). Family, maternal, and child health through Photovoice. *Maternal and Child Health Journal*, 8(2): 95-102.
- World Health Organization (2004). A Life Course approach to child and adolescent health and development. *WHO* online: [http://www.who.int/child-adolescent-health/OVERVIEW/Supporting\\_Life.htm](http://www.who.int/child-adolescent-health/OVERVIEW/Supporting_Life.htm).
- World Health Organization (2004). Guidelines for research on reproductive health involving adolescents. *Scientific and Ethical Review Group* online at: [http://www.who.int/reproductive-health/hrp/guidelines\\_adolescent.html](http://www.who.int/reproductive-health/hrp/guidelines_adolescent.html).
- Yonas, M. (2006). Visual Voices: "Bringing children and a nation together through art". Accessed online at: <http://www.visualvoices.org/index.html>.
- Yonas, M., O'Campo, P., Burke, J., Peak, G., Gielen, A. (2005). Urban youth violence: do definitions and reasons for violence vary by gender? *Journal of Urban Health*, 82(4): 543-551.