

Fransitions

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COMMUNITY PARTICIPATION PARTNERING WITH YOUTH

A Rights, Respect, Responsibility® Paradigm

By Debra Hauser, MPH, Vice President, Advocates for Youth

This *Transitions* focuses on community participation, a movement in the public health field that **respects** the **rights** and **responsibility** of community members—including youth—to diagnose the causes of a community problem and to actively engage in designing, implementing, and evaluating strategies to address the problem. Community participation can be a vital strategy that helps shift the ways in which communities deal with adolescents and their sexual health as community adults partner with young people and with program planners to create appropriate solutions to community problems. For example, when planning a program to prevent sexually transmitted infections (STIs) in adolescents, youth and others in the community partner with program planners to identify the causes and extent of the problem. Together, they design and implement strategies to reduce adolescent STI rates in the community.

Community participation is a *partnership*. The program planner and the community members, including youth, have knowledge and expertise related to the issue. The program planner knows how to facilitate the process and can help community members analyze the problem, such as identifying factors that contribute to high STI rates among young people. The program planner provides the tools and suggests strategies to collect information to help diagnose the cause and extent of the problem. The planner also has professional knowledge of the reproductive and sexual health field, including best practices in teen pregnancy and STI/HIV prevention.

Community adults are important partners in the process, bringing community perspectives to the issue. They are experts in the community's culture and priorities. They understand the community's resources and constraints. During the process of community mobilization, they often become more knowledgeable about adolescent sexual health and more vested in identifying and implementing successful strategies to help young people stay healthy. The process itself helps the community to take ownership of both the problem and the solutions. In so doing, community mobilization also improves program success and sustainability.

Youth's participation as equal partners in this process is essential. Young people should be intimately involved in any community mobilization strategy. Youth have the **right** and the **responsibility** to help diagnose a problem that affects them. Community participation **respects** young people's unique ability to guide the community in understanding how the environment influences youth's reproductive and sexual health behaviors. Youth are also uniquely able to look at the best practices and to identify which strategies might have the strongest impact on their decisions and, consequently, on their health. Youth share responsibility for shaping the programs

Responsibility

We must never merely provide people with programs which have little or nothing to do with their own preoccupations, doubts, hopes, and fears... It is not our role to speak to people about our own view of the world, nor to attempt to impose that view on them, but rather to dialogue with the people about their view and ours.

Paulo Freire, Pedagogy of the Oppressed

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that will affect them. They gain a vital opportunity to learn, to act as leaders, and to earn respect for themselves and their peers. When young people are respected and have a meaningful part in the process, their lives are profoundly affected. Young people who are active in community mobilization often become powerful leaders for adolescent reproductive and sexual health in their communities.

Community Participation—A Strategy for Program Development

Community participation is a strategy that can be used to help program planners appropriately and effectively address issues in adolescent sexual health. The process of community participation **respects** the **rights** and **responsibility** of community members to diagnose causes of a community problem and to actively engage in designing, implementing, and evaluating programs that are intended to improve the problem.

In this edition of *Transitions*, you will read of communities in Burkina Faso, Malawi, Nepal, Peru, and the United States that have successfully employed community participation. Results include:

- Culturally appropriate prevention and intervention strategies
- Increased community understanding of adolescent reproductive and sexual health
- Sustained community investment in adolescent sexual health programming
- Long-lasting partnerships between youth and adults, and
- Young people taking leadership roles.

Resources on Community Participation

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COMMUNITY PARTICIPATION: WHAT IS IT?

By Nicole Cheetham, MHS, Deputy Director, International Division, Advocates for Youth

A community's members are a rich source of knowledge about their community and of energy and commitment to that community. When public health professionals envision a program to address health issues in a particular community, tapping into the community's expertise and enthusiasm is frequently an essential issue. Genuine participation by community members, including youth, is the key. Community members control the project at the same time that professional partners build the community's capacity to make informed decisions and to take collective action.

*Experience has demonstrated that people can devise their own ... alternatives if they are allowed to make their own decisions.*¹

Community participation is a proven approach to addressing health care issues and has been long utilized in HIV prevention in the United States and in development internationally, in projects varying from sanitation to child survival, clean water, and health infrastructure. However, the quality of participation varies from project to project. Moreover, in spite of the failure of many health programs designed *without* the participation of target communities, some professionals continue to question the value of community members' participating in program design, implementation, and evaluation. This article looks at the critical importance of community participation in addressing the reproductive and sexual health of adolescents.

Why Use Community Participation Approaches in Adolescent Reproductive & Sexual Health Programming?

Youth do not live in a vacuum, independent of influences around them. Rather, social, cultural, and economic factors strongly influence young people's ability to access reproductive and sexual health information and services. To improve young people's sexual and reproductive health, therefore, programs must address youth *and* their environment. In order to address youth adequately and appropriately, programs should be designed and implemented with the meaningful involvement of youth.⁺ To address youth's environment, planners must acknowledge that community and families significantly influence youth.

Programs that ignore the influence of community and family in the lives of young people are, in fact, creating a nearly impossible situation—asking young people to change their world on their own. It is unfair to ask youth to change their beliefs and behaviors without also providing community support for these changes. Especially when reproductive and sexual health issues are controversial and/or taboo, it is critical to bring other community members into the process so that they, too, can support healthy change.

If implemented properly, community participation can be effective for a number of reasons.

- Communities have different needs, problems, beliefs, practices, assets, and resources related to sexual health. Getting the community involved in program design and implementation helps ensure that strategies are appropriate for and acceptable to the community and its youth.
- Community participation promotes shared responsibility by service providers, community members, and youth themselves for the sexual health of adolescents in the community.

If youth are powerfully influenced by their communities ... then changes in community attitudes. relationships, opportunities, and environments are needed. ... Successful efforts at changing environments for vouth need to engage more than *youth workers;* instead, whole to be engaged and mobilized. Cornerstone Consulting Group, Communities and Youth Development: Coming Together, 2001

⁺ For more information on forming effective youth-adult partnerships, see *Transitions*, volume 14, no. 1, October 2001, available at www.advocatesforyouth.org/publications/transitions/transitions1401.htm.

- When communities "own" adolescent sexual health programs, they often mobilize resources that may not otherwise be available. They can work together to advocate for better programs, services, and policies for youth.
- Community support can change structures and norms that pose barriers to sexual health information and services for youth and can increase awareness regarding youth's right to information and treatment.
- Community participation can increase the accountability of sexual health programs and service providers.
- Participation can empower youth within the community.

What Is Community?

"Community" is important within a public health context. Research demonstrates that:

- Prevention and intervention take place at the community level.
- Community context is an important determinant of health outcomes.

However, the lack of a commonly accepted definition of community results in different collaborators forming contradictory or incompatible assumptions about community. This often undermines their ability to evaluate the contribution of the community in achieving public health outcomes.

In December 2001, the *American Journal of Public Health* published the results of research to define community within a public health context.² Researchers identified core dimensions of "community," as defined by people from diverse groups. Five core elements emerged: locus, sharing, action, ties, and diversity. A common definition of community emerged:

*A group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings.*²

What Is Community Participation?

Although this may appear to be a simple question, there is no single definition of participation by communities but, rather, a *potpourri* of definitions varying mostly by the degree of participation. The continuum on the next page provides a helpful framework for understanding community participation. In this continuum, "participation" ranges from negligible or "co-opted"—in which community members serve as token representatives with no part in making decisions—to "collective action"—in which local people initiate action, set the agenda, and work towards a commonly defined goal.

Youth from Burkina Faso offer a practical definition of community participation. In an example of collective action (see chart on page 5), these youth work with organizations in their communities to improve adolescent reproductive and sexual health.*

Community participation occurs when a community organizes itself and takes responsibility for managing its problems. Taking responsibility includes identifying the problems, developing actions, putting them into place, and following through.⁴

Who Benefits from a Community Participation Approach?

Community participation has many direct beneficiaries when carried out with a high degree of community input and responsibility. Everyone benefits when participating in the activities. For example, adults and youth might participate in village committees to improve services. Everyone might watch a play or video and learn from presentations about local programs. Youth benefit from improved knowledge about contraception and HIV/AIDS or from increased skill in negotiating condom use, and other community members benefit, too. A truly participatory program involves and benefits the entire community, including youth, young children, parents, teachers and schools, community leaders, health care providers, local government officials, and agency administrators. Programs also

^{*}The project is described briefly on page 7 and stories of participants follow on pages 8 and 9.

Mode of Participation	Type of Participation	Outsider Control	Potential for Sustainability, Local Action & Ownership
Co-opted	Tokenism and/or manipulation; representatives are chosen but have no real power or input.		
Cooperating	Tasks are assigned, with incentives. Outsiders decide agenda and direct the process.		
Consulted	Local opinions are sought. Outsiders analyze data and decide on course of action.		•
Collaborating	Local people work together with outsiders to determine priorities. Responsibility remains with outsiders for directing the process.		
Co-learning	Local people and outsiders share their knowledge to create new understanding and work together to form action plans with outside facilitation.		
Collective Action	Local people set the agenda and mobilize to carry it out, utilizing outsiders, NOT as initiators or facilitators, but as required by local people.		

Community Participation³

benefit because trends in many nations towards decentralization and democratization also require increased decision making at the community level.

What Key Characteristics and Skills Facilitate a Community Participation Approach?

Above all, those promoting community participation need to be able to facilitate a process, rather than to direct it. Facilitators need to have genuine confidence in a community's members and in their knowledge and resources. A facilitator should be willing to seek out local expertise and build on it while bolstering knowledge and skills as needed. Key characteristics and skills important to facilitating community participation include:

- Commitment to community-derived solutions to community-based problems
- Political, cultural, and gender sensitivity
- Ability to apply learning and behavior change principles and theories
- Ability to assess, support, and build capacities in the community
- Confidence in the community's expertise
- Technical knowledge of the health or other issue(s) the project will address
- Ability to communicate well, especially by actively listening
- Ability to facilitate group meetings
- Programmatic and managerial strengths
- Organizational development expertise
- Ability to advocate for and defend community-based solutions and approaches.^{5,6}

What Key Challenges Face Community Participation Programs?

Community participation also poses important challenges. Two are highlighted here.

• Evaluating Participation

One challenge for program planners is how to evaluate community participation. In particular, what should be evaluated—health outcomes, participation levels, improved capacities, or some combination of these and how will they be evaluated? While measuring health outcomes—such as birth rates or sexual health knowledge, attitudes, and behaviors in a particular age group—may be fairly straight forward, it will be important for community participation programs also to identify and measure indicators of *participation*. One of the goals is *to achieve participation*. Whether planners want to measure changes in community self-efficacy or changes in local capacity to identify and solve problems, it is important to define these objectives clearly and to develop appropriate tools for measuring progress toward the objectives. Qualitative tools (or some combination of qualitative and quantitative) may be most appropriate to assess the subjective quality of "participation," but indicators of participation and ways of assessing it should be defined by the community, and community members should decide and carry out the evaluation.

• Scaling Up Participatory Models

Increasingly, funding sources express interest in programs that have potential for "scaling up." Community participation programs present some obstacles to "scaling up" due to their deliberately and intensely local nature. As a program develops and matures, program planners may face the challenge of "scaling down" the intensity of community participation in order to "scale up" the project without compromising its participatory nature and results.

Conclusion

Community participation is a vitally important strategy in efforts to work with youth to improve their sexual and reproductive health. Community participation is a strategy that **respects** the **rights** and ability of youth and other community members to design and implement programs within their community. Community participation opens the way for community members—including youth—to act **responsibly**. Whether a participatory approach is the primary strategy or a complementary one, it will greatly enrich and strengthen programs and help achieve more sustainable, appropriate, and effective programs in the field.

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COMMUNITY PARTICIPATION TO PROMOTE ADOLESCENT REPRODUCTIVE AND SEXUAL HEALTH IN BURKINA FASO: A TEMPLATE FOR PROGRAM DEVELOPMENT

By Nicole Cheetham, MHS, Deputy Director, International Division, Advocates for Youth

In March 1998, Advocates for Youth and the Pacific Institute for Women's Health initiated a four-year project in Burkina Faso to assist rural communities in Kompienga, Boulgu, and Sissili provinces in identifying priorities and designing and implementing strategies related to adolescent reproductive and sexual health. The project also builds capacity among partners in Burkina Faso, including lead partner Mwangaza Action and local youth-serving organizations (YSOs) *Association pour le Développement de la Région de Bittou, Le Reseau des Jeunes de la Sissili et du Ziro*, and *L'Association des Jeunes pour le Développement de Pama.**

Phase I: Identifying Priority Issues—Based on approaches developed by Save the Children and the National Cooperative Business Association, and with assistance from Advocates and Mwangaza, the YSOs developed a methodology to mobilize their communities—including youth—regarding adolescent reproductive and sexual health. Village committees, comprised predominantly of youth, used village assemblies, role-plays, interviews, and folk media to assess adolescent reproductive and sexual health. Committee members interviewed 547 youth ages 11 to 21, 405 parents, and 51 service providers. Youth and adults in the communities identified priorities, including HIV and STIs, contraceptive knowledge and use, female genital mutilation, parent-child communication about sexuality, and adolescents' use of health care services.

Phase II: Identifying Community-Based Interventions to Address Priority Issues—Using the same methodology, Advocates and Mwangaza trained the YSOs' staff on working with their communities to identify *strategies* to address priority issues. Selected strategies included peer education; use of folk and modern media; information, education, and communication (IEC); peer education home visits regarding parent-child communication; and workshops for health care providers on making services friendly to youth.

Phase III: Preparing for Community-Based Interventions—Advocates and Mwangaza trained in each community regarding its selected interventions. The YSOs and village committees then implemented the strategies, with ongoing technical assistance and support from Mwangaza.

Phase IV: Implementing Community-Based Interventions—The YSOs, in collaboration with the village committees, support, implement, and manage the community-based interventions. Currently, about 50 peer educators—25 young women and 25 young men—reach approximately 750 youth per month through group talks, counseling sessions, and home visits. In addition, the YSOs support the peer educators in activities that include theater, role-plays, and video presentations. Advocates, Mwangaza, and the YSOs train health center personnel in providing youth-friendly services.

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Village committees. comprised predominantly of youth, used village assemblies, interviews, role-plays, and folk media to assess adolescent reproductive and sexual health. Youth and adults identified a range of adolescent reproductive health priorities.

^{*}Advocates for Youth provides Mwangaza and the YSOs with technical assistance on program development and implementation while the Pacific Institute is responsible for ongoing evaluation.

COMMUNITY VOICES FROM THE BURKINA FASO PROJECT+

Mélanie—Peer Educator

My name is Mélanie Azagba. I was born in 1979 in Pama, Kompienga Province. This small province borders Togo and Benin. Life is good and many people come here from other countries for hunting or tourism or looking for work. Small businesses spring up—to sell water and other things, including commercial sex, to foreigners.

The attitudes displayed by some foreigners plunge our young people into an entirely different way of life, which is "live your own life, do whatever you want and let your personality blossom." In 1995, at the age of 15, I adopted this philosophy. I began to live as I pleased, without worrying about anything. I smoked, drank all kinds of alcohol, and gave myself easily to any man who seemed to have money. I even turned to commercial sex work.

I made quite a bit of money, which allowed me to buy what I needed. I also had to have abortions because of unwanted pregnancies, and I became tired and weak. My health was no longer very good after two years of fast living and debauchery. I started to ask myself a thousand questions about my condition and my way of life. I had to change, but how? I didn't see how I could do it. I couldn't stop living a life of leisure and selling myself to men who gave me a little money in exchange for sex. What was I to do, especially when people started talking about sexually transmitted infections and AIDS?

This worried me, day in and day out. One day, as I went to visit one of my girlfriends, I saw a huge crowd in the street, listening to two speakers talking about STIs and HIV/AIDS. What a lucky break for me! They talked about the virus, how it is transmitted, and how to stop it. There was also something I had heard lots of talk about—the *opuntuagu* (condom). I spent so much time listening that I decided not to visit my girlfriend after all.

A few days later, I ran into the organization's president, whom I knew well. I talked with him at length about sexual and reproductive health issues, and he convinced me to become a peer educator. After I was trained, I began to sense a significant change in myself. I now feel free and much lighter, as if someone has taken a huge weight off my shoulders that I could no longer bear.

I spend almost all my time, whenever the occasion presents, talking about family planning, STIs, HIV/AIDS, and female circumcision. My friends have nicknamed me "Mélanie Sida" (Sida = AIDS in French). I also organize educational discussions and home visits at least five times a month. I hit almost all social levels—young and old, government employees, ordinary people and people who work on the shady side of the law. Because of how much I do, people often ask me whether I am paid for my work as a peer educator.

Many people who are embarrassed to ask questions in public knock on my door. I always do my best to get to the bottom of their problems. Many of the people who talk with me are youth (girls and boys) who have turned to prostitution and have no one to talk to. Sometimes they want to get out of prostitution. At other times, they come because they are afraid that they might be carrying the HIV virus. To test my role as a peer educator and to see whether my message is getting through, a health services friend lets me know when people, especially women, come to get contraceptive devices. That gives me a great deal of satisfaction, and encourages me to continue to help my community and to promote changes in behavior.

After I was trained, I began to sense a significant change in myself. I now feel free and much lighter, as if someone has taken a huge weight off my shoulders that I could no longer bear.

⁺ Advocates gratefully acknowledges Tom Clark who translated these articles from French into English.

Issoufou—Community Organizer

My name is Issoufou Zampaligré. I was born in 1964, in Bittou, Boulgou Province. I am the President of the *Association des Jeunes pour le Développement de la Region de Bittou* (AJDRB, the Young People's Association for the Development of the Bittou Region). In July 1999, we held the first community participation workshop for the reproductive and sexual health of young people. Mwangaza Action selected Bittou and AJDRB for this opportunity.

This workshop, a first for us, was difficult, because the subjects were new to us. Talking candidly and without embarrassment about sex and male and female genitalia was new for us. It was also the first time we had the opportunity to sit down with people who were very knowledgeable about the subject. We found all of this extremely difficult on the first day of the workshop, but after the ice-breaking exercises, we gradually began to feel at home. Everyone easily found something in his/her own thoughts and experience for preparing our first educational pamphlet.

The program first transformed the organizers who were responsible for its implementation. Because of the social campaigns we are carrying on, my colleagues and I have changed our own behavior such that some people no longer recognize us. We have become trusted sources of information in the city, to the point where even a minor error on our part would be serious. All the young people, the adults, and even old women are encouraging us and asking other young people to follow our example. In our meetings, all the members of the association can express themselves openly and without embarrassment, and these meetings attract real crowds. Before the program, sex among the youth of Bittou was something never publicly discussed.

Now, the community, the government, and outside activists ask the association for advice and assistance. Beyond that, people in the community call us "savior," which is extremely gratifying and increases our enthusiasm to make an even greater effort on behalf of our community. This program is our pride and joy. It has made it possible for us to achieve more than we ever thought we could.

Continued from page 7

Phase V: Final Evaluation—Towards the end of the project, the Pacific Institute for Women's Health will conduct surveys and collect additional data to assess levels of community participation, changes in capacity among local partners, and changes in adolescents' reproductive and sexual health knowledge and behavior.

Conclusion

Although evaluation is not complete, project partners agree that community participation and youth involvement have been valuable and effective in addressing adolescent sexual and reproductive health in these rural, highly traditional communities. Community youth, in partnership with adults, successfully mobilize to address unwanted pregnancy, HIV/STI, female genital mutilation, barriers to reproductive health services, and lack of parent-child communication. In addition, local administrative and religious authorities, involved from the beginning, provide sustained and impressive support.

Nowadays youth come to our as sociation for information on sexual and reproductive health. This did not used to happen before the youth partnership program.

Youth-serving professional

HIV PREVENTION COMMUNITY PLANNING

By Kayla Jackson, MPA, Director, HIV/STD Prevention Programs

Across the United States in 1994, the Centers for Disease Control and Prevention implemented HIV prevention community planning to deal with the changing HIV epidemic and the increasingly diverse communities affected by the epidemic. Community planning enables community members to come together to design local plans that best represent the needs of local populations at risk for or affected by HIV. HIV prevention community planning is mandatory in the 65 state, territorial, and local health departments that receive funds from the federal government for HIV interventions.

Community planning is based on a set of core principles—parity, inclusion, and representation. These principles ensure that all community planning group (CPG) members have an equal voice in voting and making decisions, that the views and needs of all affected groups are involved in the process, and that representatives truly reflect communities' values, norms, and behaviors. Members of CPGs are "persons who reflect the characteristics of the current and projected epidemic in that jurisdiction."¹ HIV prevention community planning has the following core objectives:

- Fostering openness and participation in the community planning process
- Ensuring that the CPG reflects the diversity of the epidemic in the jurisdiction and that the process includes expertise in epidemiology, behavioral science, health planning, and evaluation
- Determining priority HIV prevention needs, based on each jurisdiction's unique, epidemiological profile and on an HIV prevention needs assessment
- Prioritizing interventions, based on explicit considerations of needs, outcome effectiveness, cost effectiveness, theory (from social and behavioral science), and community norms and values
- Fostering strong, logical links between the community planning process and its plans applications for funding and allocation of CDC HIV prevention resources.²

HIV prevention community planning has achieved some real successes since 1994, including:

- Developing planning groups at the local, regional, and state levels
- Opening up the planning process to more people
- Recruiting diverse members that reflect the epidemic
- Improving relationships between health departments and those at risk
- Changing the direction of prevention spending
- Affecting prevention activities (e.g., targeting programs geographically and in recognition of different behaviors and cultures within at-risk populations).²

Despite these successes, youth's representation on CPGs is low. Only about five percent of CPG members are under the age of 24,² even though young people under the age of 25 comprise half of the new HIV infections in the United States.³ Youth, especially youth of color and gay, lesbian, bisexual and transgender youth, are disproportionately affected by HIV.

There are many potential barriers to including youth meaningfully in the community planning process. Many of the attitudes and assumptions of both youth and adults make it difficult for them to work together in partnership. Institutional barriers, such as time constraints, meeting times, financial resources, and transportation, make it difficult for young people to become involved in an adult-oriented process. Commitment to forming effective youth-adult partnerships and willingness to compromise in order to create a more youth-friendly environment are requirements for facilitating true youth involvement.

In order to achieve parity, inclusion, and representation, youth must be actively and meaningfully involved in the community planning process. Bringing youth—especially those at highest risk—to the table is also necessary as an invaluable component of the entire community planning process. Young people provide fresh perspectives and

relevant information about the needs of youth. Youth provide energy and enthusiasm as well as appropriate and pertinent ideas for planning. The most logical way to strengthen and promote HIV prevention among youth in a community is by having young people from that community engaged in the planning of prevention activities.

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A TRUE PEER ADVOCATE*

By Chris Griffey

I have been involved in community planning for three years. I started out on the Missouri Community Planning Group (CPG) in 1998. That was the first place where I could truly be myself and be respected and valued because of who I am. I represented queer youth and, at 18 years old, I was the youngest one of the group. I was appointed cochair of the at-large group. In this group, we did not represent an agency but instead our identities and our communities. I learned how to be a leader in this group. I was on the Missouri CPG for over a year before I moved to Arlington, Virginia, and joined the Virginia Community Planning Committee.

My current expertise has been developed through four years of HIV outreach experience. I represent white, noninjecting drug users (past), youth, queer, and female-to-male transgender communities. When I was a teenager, I engaged in activities that put me at high risk for HIV infection. Now, I am at low risk because I am no longer a substance user and I am aware of how to protect myself.

I have learned how important it is to have my voice heard. It is self-fulfilling to know that I can help change how prevention programs are shaped and run by community-based organizations, AIDS service organizations, and youth service organizations.

While being on the CPGs, I have been able to recognize the barriers to and the successes of youth's participation. Some of the barriers are ageism, transportation issues, and consistency. The successes include gaining knowledge, being heard, affecting change, and taking on leadership roles. I believe that, in order to provide quality services to a target population such as youth, a program needs to come from the grassroots level. If people from the community are not involved, HIV prevention programs will fall short of their goals.

*Adapted and reprinted with permission from the NASTAD HIV Prevention Bulletin, December 2001.

Respect

One cannot expect positive results from an educational or political action program which fails to respect the particular view of the world held by the people. Such a program constitutes cultural invasion, good intentions notwithstanding.

Paulo Freire, Pedagogy of the Oppressed

COMMUNITY PARTICIPATION IN HIV VACCINE TRIALS

By Rose McCullough, Member HVTN Global Community Advisory Board

Scientists and advocates agree that a vaccine is possible to prevent or reduce the risk of infection with HIV. When such a vaccine is developed and available to all at risk for HIV, it could make a major contribution to ending the global HIV/AIDS pandemic. For a vaccine to become a reality, active and broad-based community support and involvement are essential. Involving youth can make a major difference.

The statistics are overwhelming and often repeated. AIDS currently kills more people than any other infectious disease in the world. Twenty-two million people have died from AIDS and 36 million people live with HIV or AIDS. Fifty percent of all new HIV infections are in young people under age 25. To say it another way, worldwide, 7,000 individuals under age 25 become infected with HIV every day—more than 2.5 million youth each year.

Major pharmaceutical companies, government agencies, and academic researchers are conducting HIV/AIDS vaccine research. Some possible vaccines are currently being tested in people. Probably many more clinical trials will be needed before we have a safe, effective, preventive HIV/AIDS vaccine. The HIV Vaccine Trials Network (HVTN) is doing most new HIV/AIDS vaccine trials, and the Adolescent Trials Network (ATN) is responsible for trials for AIDS treatment, prevention, and vaccines in adolescents. The HVTN and the ATN are funded by the National Institutes of Health.

Why is community participation in vaccine trials critical? A vaccine trial *depends* on community participation. No vaccine candidate should move into human trials without the community's approbation. Community members can act as advisors to the trial, helping scientists recruit trial participants, setting trial protocols, and exploring behavioral barriers to a trial's success. Community members also act as trial participants, helping scientists to test the vaccine candidate's acceptability and efficacy.

Why is the participation of adolescents critical? Typically, trials for all sorts of proposed new vaccines, medications, and treatments are conducted first in people over the age of 17. Once an effective vaccine is found, it is then tested in children and adolescents. Imagine a world in which adults could be inoculated against HIV infection but people under age 18 would remain vulnerable to infection for as many as five to seven additional years before the vaccine could be approved for this age group. This horrifying scenario could happen if adolescents are not included in HIV vaccine trials now.

Active participation by young people—such as volunteering for HVTN community advisory boards or helping with community awareness and education—is important to speed-ing HIV/AIDS vaccine development. To be certain that a vaccine is available to youth under age 18 as soon as it's available for people ages 18 and older, youth and advocates need to insist that adolescents have the opportunity to enroll in vaccine trials.

Legal, procedural, perceptual, and scientific barriers pose challenges to participation in vaccine trials by youth under age 18. However, the demographics of the epidemic in the United States and around the world make it essential that young persons and advocates partner to meet this challenge, ensuring that individuals under 18 years of age participate in vaccine trials. The support of youth and of youth-serving professionals can make a difference!

It is irresponsible and, in fact, immoral to continue conducting business as usual--to develop a vaccine tested entirely on adults and then to wait an additional five or more vears before bringing to market a vaccine for youth. Deb Hauser, Vice President, Advocates for Youth, speaking at a press briefing in Washington, DC, November 2000. held in conjunction with the **AIDS Vaccine** Advocacy Coalition

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For information on the HVTN and location of its sites in the United States and developing countries, go to www.HVTN.org. For information on the ATN, contact Dr. Craig Wilson at craig_wilson@geomed.dom.uab.edu. For general information, contact Rose McCullough at AIDSVaccineProject@msn.com.

PARTICIPATING IN AN HIV VACCINE TRIAL

By David Mariner, former staff member at Advocates for Youth

Sometimes I think that future generations will ask "What did you do to end the HIV/AIDS epidemic?" Some people may already have an answer. It could be, "I volunteer at a local clinic." "I participate in an annual fund raising event." "I wrote a letter to my Congressperson." "I am running for the local school board so we can use an effective HIV prevention curriculum in the schools." Some might say, "I participate in a community advisory board, advising and assisting in vaccine trials."

I am proud to be one of thousands who have participated in an HIV vaccine trial. I believe that a safe, cost-effective, HIV vaccine is humanity's best hope for ending the HIV/AIDS epidemic, and I am happy to have played a part in working to reach this goal.

The decision to participate in a trial is a deeply personal one, and it is not made lightly or easily. Most vaccine trials seek participants who are HIV-negative, although some therapeutic trials seek participants who are HIV-positive. Most trials also require participants to be age 18 or over. Thanks, in part, to the work of the AIDS Vaccine Advocacy Coalition and Advocates for Youth, young people under age 18 are being allowed to participate in some trials.

When I considered participating, I was given an informed consent document that outlined everything I needed to know about the trial. It was quite wordy, so I took my time going over it, and I asked questions about things I didn't understand. My questions were similar to those of many prospective participants:

- What is the vaccine made of?
- What are potential side effects and how might they affect me?
- Will the vaccine infect me with HIV? (The answer is, "No.")
- Can I commit to completing the trial? (Many trials last for more than a year, requiring multiple visits.)
- Can I fit these appointments into my school and/or work schedule?

Because I have supportive friends and co-workers and time to make my appointments, I decided that I could make this commitment. It was a fairly easy decision for me, but it isn't an easy decision for everyone.

Future generations *will* ask, "What did you do to end the HIV/AIDS epidemic?" I will be proud to say that I participated in HIV vaccine trials. It is one way I can truly make a difference. What will you say?

I believe that a safe, cost-effective, HIV vaccine is humanity's best hope for ending the HIV/AIDS epidemic, and I am happy to have played a part in working to reach this goal.

PLAIN TALK—COMMUNITIES MOBILIZING TO REDUCE ADOLESCENTS' SEXUAL RISKS¹

Plain Talk is a neighborhood-based initiative, launched by the Annie E. Casey Foundation in 1993, to help adults develop the skills and tools they need to communicate effectively with young people about reducing sexual risk behaviors. Five urban neighborhoods—Mechanicsville in Atlanta, GA; Logan Heights in San Diego, CA; White Center in Seattle, WA; St. Thomas in New Orleans, LA; and Stowe Village in Hartford, CT—received resources and tools to develop and implement a plan adhering to four basic principles:

- Community residents should be central to the decision-making process.
- Residents should come to a consensus about what changes are necessary.
- Communities should have reliable information regarding the problems and practices addressed.
- Adults should not deny the reality that some youth are sexually active.

Each community used "community mapping" to gather critical data regarding beliefs, norms, and practices within that community. This highly collaborative process helped forge community awareness and motivation around the issue of adolescents' sexual risk behaviors. Based on a draft survey instrument, residents developed culturally appropriate surveys and went door-to-door, surveying between 300 and 700 adults in the community. Residents interviewed an equal number of adolescents at "youth-friendly" sites and, with lead agency staff, analyzed the data.

Early on, each community developed a network of supportive, resident, opinion leaders and spokespeople who successfully presented the findings from the community mapping and argued for important community actions. In each neighborhood, the network continued to be a primary means for disseminating information, recruiting residents to participate, and receiving feedback.

The cornerstone of Plain Talk's strategy was adult peer education. In each community, Plain Talk staff worked with interested residents to develop their skills as peer educators. Residents created formal and informal opportunities and used innovative techniques, such as role plays and fables, to give messages cultural relevance and to empower the community's adults. Residents were the primary means of delivering effective and consistent messages to adults and youth. Through work at events around Cinco de Mayo, Kwanza, Valentine's Day, and Father's Day, among others, neighborhood spokespeople gained visibility as knowledgeable "Plain Talkers," approachable by youth and adults alike. Residents also assumed increasing levels of responsibility for planning and carrying out activities. Residents' leadership ensured that messages regarding adolescent sexual health remained culturally appropriate and also empowered residents to tackle other issues of community concern.

Plain Talk succeeded in accomplishing several goals related to adolescent sexual health in the communities of. Plain Talk. Evaluation found that—

- The percentage of young women who experienced pregnancy declined from 54.5 percent in 1994 to 33.6 percent in 1998.
- Sexually active youth who had discussed birth control with an adult were about half as likely, on average, to cause or experience a pregnancy as peers who had no such communication.
- The proportion of sexually experienced youth who had spoken with an adult about birth control, pregnancy, or STI increased from 61 percent in 1994 to 70 percent in 1998.²

Plain Talk successfully mobilized communities to protect young people from the risks associated with pregnancy and HIV and other STIs. It did not attempt to prevent, nor to encourage, teens' having sexual intercourse.

References:

- 1. Adapted and printed with permission from the Annie E. Casey Foundation's Web materials on the Plain Talk initiative, http://www.aecf.org/ publications/plaintalk/
- 2. Grossman JB et al. Adult Communication and Teen Sex: Changing a Community. Philadelphia, PA: Public/Private Ventures, 2001.

MOBILIZING COMMUNITIES FOR CHANGE—THE YOUTH TO YOUTH FOR HEALTHY LIFE PROJECT

By Amy Weissman, Youth Reproductive Health Specialist, Save the Children

In Mangochi District, Malawi, Save the Children recognized that improving the reproductive and sexual health of the district's youth required changing community norms. Young people, in partnership with key adults, needed to participate in planning, implementing, and evaluating activities. First, Save the Children worked with the community to assess the needs of Mangochi youth. Focus group discussions with youth, parents, community leaders, service providers, and other key stakeholders identified concerns and perceptions about youth's reproductive and sexual health. Youth conducted focus groups among their peers, while adults conducted discussions and interviews among adults.

In a workshop, participants used the needs assessment data to identify priority issues, including sexual exploitation and violence, harmful traditional practices, and inadequate reproductive health services. During the workshop, representatives of young people's clubs, organizations working with youth, government officials, and religious leaders designed the *Nchanda ni Nchanda pa umi Wambone* (Youth to Youth for Healthy Life) project, using Save the Children's community mobilization approach. Although youth participated and some of their expressed concerns were among the priority issues, young people lacked the confidence and the authority to make their primary concerns heard. This experience underscored the importance of structuring planning sessions in such a way that those with less power have an equal voice.

Although influencing community norms required engaging key adults in all aspects of the project, Save the Children also believed that youth must "drive" the process. For example, young people exchanged ideas with health providers about issues that need to be addressed to achieve youth-friendly care. Youth and health care providers held dialogues in the seven health centers in the project area. Participants agreed that most health services in Mangochi were not youth-friendly, and the youth identified issues that included long waiting times and lack of confidentiality, such as health providers' reporting to parents when youth sought reproductive health care. The young people's suggestions regarding these issues—for example, maintaining confidentiality, assisting clients quickly, assuring privacy, and refraining from being judgmental—were included in a training course for health services providers. The training course also addressed clients' rights, including the right to information, respect, and confidentiality, and to make informed and responsible choices. As a result, young people began to seek out the trained professionals by name.

Recent evaluation indicated that using a community mobilization approach has been effective. When compared to baseline, male youth demonstrated significant increases in knowledge about STIs and HIV/AIDS as well as significant increases in condom use. Female youth reported increased abstinence. In addition, because the project focused not only on youth, but also on their social environment, the evaluation indicated changes in communication patterns between adults and young people. Significantly more males and females in the project area than in the control site reported talking with their parents about a romantic or sexual relationship. Community participation not only enhanced community ownership of the project but also ensured cultural relevance and increased sustainability. To promote adolescents' adoption of healthy practices, programs need to address youth *and* their social environment. In Mangochi District, community participation has been key to doing so.

Participants agreed that most health services in Mangochi were not youthfriendly, and the youth identified issues that included long waiting times and lack of confidentiality.

THE PARTICIPATORY APPROACH IMPROVES YOUTH'S REPRODUCTIVE HEALTH IN NEPAL

By Sanyukta Mathur, Program Associate, International Center for Research on Women

In Nepal, the International Center for Research on Women and EngenderHealth, along with Nepali partners, currently involves young men and women—married and unmarried, between the ages of 14 and 24 years—in all aspects of research and implementation of a comprehensive reproductive health program. Lessons and obstacles from this project are highlighted below.

1. The project involves the community at all stages and in many ways. Youth and adult advisory groups exchange information between the community and the project team. An adult advisory group supports youth-centered activities. Activities, such as community mapping, body mapping, problem trees, and lifelines, allow youth and adults to discuss health experiences and expectations and to identify youth's needs. To translate the research results into interventions, five youth task forces review youth's reproductive health needs and identify feasible interventions in one of five areas: information and education, counseling, reproductive health services, economic and personal development, and community norms and attitudes.

The project also works with community members—youth and adults—to implement the interventions. For example, trained service providers provide youth with culturally appropriate information and counseling. Workshops enhance communication between youth and their parents. Project partners work with youth to explore restrictive social norms and to provide reproductive health information and education. Finally, project partners involve community members in workshops to discuss and assess the progress of the activities to date.

2. Participation is not easy to achieve. Reproductive health issues are complex and sensitive, and involving the community in planning, implementing, and evaluating a project requires an intensive commitment of time and resources, especially for training field staff. Moreover, questions arise about the extent to which the community "owns" a project that was conceived, funded, designed, and initiated by outsiders. Another issue is maintaining the participation of community sub-groups, which fluctuates between high and low levels and requires special efforts to maintain. A final issue is ensuring participation of community members by age, gender, ethnicity, and social status and ensuring that a particular group does not dominate project activities.

3. Community Participation Yields Rich Rewards. The project yields an in-depth, first person perspective of Nepali youth's reproductive health issues. Involving the community gives a comprehensive understanding of the social, cultural, and economic context of young people's lives. Youth-designed interventions—such as social dramas and adult education programs—are new, interesting, and creative and meet the comprehensive needs of youth. Finally, the participatory approach mobilizes the community, increasing demands for reproductive health information and services.

The project involves communities in many ways and at all stages, but participation is not easily achieved nor maintained. The rewards are rich and exciting although project partners still wait to see if the approach will lead to sustainable change.

Nowadays youth come to our association for information on sexual and reproductive health. This did not used to happen before the program.

Youth-serving professional

REPROSALUD: NATIONWIDE COMMUNITY PARTICIPATION IN PERU

By Cecilia Moya, Clearinghouse Program Associate, International Division,

Advocates for Youth

In 1995, two Peruvian non-governmental organizations, *Movimiento Manuela Ramos* and *Centro de Investigación y Educación Popular Alternativa*, began an innovative, five-year project on reproductive health and rights.^{1,2} The project, *ReproSalud*, focused on social barriers to women's access to reproductive health services, including limited power to negotiate within sexual relationships, social isolation, domestic violence, lack of cash, and low self-esteem. It targeted the poorest, hardest-to-reach, Peruvian women, ages 15 to 49, many of whom begin childbearing by age 15 and live in urban and rural areas where health care services are underused. *RepoSalud* was based on an assumption that, in a more gender equitable setting, women would be more aware of their sexual and reproductive rights and more likely to demand and use quality health care services. Thus, *ReproSalud* aimed to improve women's sexual and reproductive health through individual and community empowerment, using participatory methods to make community education and mobilization the backbone of its efforts.

ReproSalud partnered with women's community-based organizations (CBOs) in eight of Peru's 24 departments. By December 2000, *ReproSalud* established partnerships with 240 CBOs in the Andean highlands and Amazon basin, which, in turn, worked with 2,300 neighboring CBOs. More than 90,000 women and 50,000 men participated in the education and training activities. *ReproSalud* and each partner CBO conducted a self-diagnostic workshop, allowing participants to explore their perceptions, attitudes, and experiences regarding sexual and reproductive health, community gender norms, and available health services. Workshop participants identified the priority reproductive health concerns on which they wanted to take action. Concerns included reproductive tract infections, "too many children," childbirth complications, abortion, teenage pregnancy, domestic violence, and inadequate treatment at health centers.

ReproSalud helped each CBO design and implement a strategy to address the primary reproductive health problem identified in its community, primarily through training a team of health promoters to teach other community members about sexual and reproductive health, emphasizing the selected priority concern. Because women voiced a strong interest in involving their husbands, *ReproSalud* also trained men as health promoters for other men. Involving men helped address important issues, such as alcoholism, violence, forced sex, and communication between partners. The interventions laid the foundation for advocacy by health promoters. In many communities, the health promoters influenced the attitudes of local health care providers and public health authorities.*

Key challenges for ReproSalud include:

- Expanding the base of beneficiaries at a low cost without losing innovative elements
- Conducting an impact evaluation
- Anticipating expenses related to community participation
- Allowing adequate time for training and community mobilization.

Surveys demonstrate significant improvements in reproductive health knowledge and service utilization. Evaluations show dramatic decreases in alcohol consumption, domestic violence, and forced sex and large improvements in contraceptive knowledge and attitudes. Evaluation is incomplete regarding behavior change; yet, interim results support this holistic model and demonstrate the inherent strength of the strategy of community participation.

References:

^{1.} Coe AB. Health, Rights and Realities: An Analysis of the ReproSalud Project in Peru. Takoma Park, MD: Center for Health and Gender Equity, 2001.

^{2.} Rogow D. Alone You Are Nobody, Together We Float: The Manuela Ramos Movement. [Quality/Calidad/Qualité, no.10] New York, NY: Population Council, 2000.

^{*}In 2001, *ReproSalud* received a grant to continue working for five more years. Based on ongoing assessment and evaluation, *ReproSalud* will focus on the Andean highlands and on advocacy, linking community-based advocacy groups to form wider networks.

TIPS FOR PARTNERING WITH YOUTH

By Kayla Jackson, MPA, Director, HIV/STD Prevention Programs, Advocates for Youth

- 1. Treat youth as partners. Ensure that all members of the group, regardless of age, share the decision making power—equal voice and equal vote.
- 2. Welcome, encourage, and affirm contributions and insights from both youth and adults.
- 3. Encourage everyone to recognize the mutual benefits of youth and adults working together in partnership. Ensure that all the adult members "buy into" youth's participating in the process.
- 4. Be selective about the youth and the adults who participate.
- 5. Establish high expectations for everyone involved. Don't patronize youth by lowering expectations regarding them. On the other hand, don't expect more from young people than from adults.
- 6. Provide training and build the capacities of both youth and adults.
- 7. Schedule meetings when youth can attend and in locations accessible to them. Keep young people informed about plans and meeting times.
- 8. Include room for growth and advancement for experienced youth and adults.
- 9. Don't make assumptions about what individuals—of any age—are like.
- 10. Take the time and make the effort to develop a good relationship with youth *before* expecting much. This work is often new to youth; take the time to explain. Youth may interpret adults' being abrupt and hurried as a sign of disinterest in youth's participation; so, go slow and explain what's going on.
- 11. Remember that there are times when youth need to say, "No." Their education, relationships, communities, and extracurricular activities are important, too.

TIPS FOR YOUTH WHEN WORKING WITH ADULTS

Developed by Advocates for Youth's Peer Educators with assistance from the Young Women's Project, Washington, DC

- 1. Most adults have good intentions. Remember that they are seldom accustomed to working in partnership with young people.
- 2. Criticism doesn't necessarily mean condescension or that an adult doesn't value your contribution. It may mean the adult is treating you the same way he/she would an adult colleague. Remember that adults are used to critiquing each other's work and offering constructive ideas to improve a project. Disagreement doesn't mean disrespect.
- 3. Adults may not be aware of the capabilities of young people. You may have to show them.
- 4. Adults often feel responsible for the success or failure of the project. This makes it hard for them to share power. Reassure them that you will share in successes and failures.
- 5. Adults are just as uncertain as youth. Many have just learned to disguise it better.
- 6. Sometimes adults use phrases and expressions, whether consciously or not, that annoy young people and that indicate they aren't treating youth as partners. These phrases and expressions can erode a relationship. Be prepared to call adults on their language.
- 7. Don't be afraid to ask for clarification. Adults often use words, phrases, and acronyms that you might not understand. Adults new to the program may not understand them either. The language of a special issue, like HIV, is riddled with terms that can be wilder any newcomer.
- 8. Don't be afraid to say, "No." Adults will understand that you have other important commitments, like your education, family, friends, hobbies, and sports.

TIPS FOR EFFECTIVELY FACILITATING COMMUNITY PARTICIPATION

By Nicole Cheetham, MHS, Deputy Director, International Division, Advocates for Youth

- 1. Be open and honest from the beginning with regard to what issues the program will and will not be able to address. Unless the program will be able to respond to a wide range of community priorities, it is important to be completely clear from the very beginning regarding what issues the program can and cannot address. If the limits are not very clear, the community may experience disappointment and disillusionment when the participatory process identifies issues that cannot be addressed.
- 2. From the beginning, develop a common understanding of "community participation" among all those involved. If community members understand their participation to mean one thing while program managers hold different views, effective participation may be seriously compromised.
- 3. *Remain flexible*. Communities may identify new priority issues over time or different approaches to resolving previously identified problems. Program managers will need to respond with support and assistance as new needs and approaches arise.
- 4. *Be willing to create and sustain partnerships.* A community's needs may vary widely and may go well beyond the expertise of the persons or agency providing assistance. Establishing and sustaining partnerships may be critical to responding effectively to the community's diverse needs.
- 5. *Build capacity for informed decision-making*. Communities may lack adequate information and skills to make informed decisions about community-wide health issues. Programs may need to build local capacity so community members can make informed decisions about the best strategies to meet their needs.
- 6. *Recognize that participation takes time*. Community participation absolutely requires time for community members to engage local stakeholders, ensure consensus, and shape the program. Planners need repeatedly to recognize and acknowledge this time constraint.

FILMS BY TEENS FOR TEENS

Scenarios USA is a program to get teens thinking about their choices and decisions around important issues that affect their lives, such as HIV/AIDS, unwanted pregnancy and violence. Teens, ages 12 to 22, address these issues by writing stories for the Scenarios contest, *What's the Real Deal*.

Winners get to make their stories into short films in their hometown, working with a professional filmmaker and crew. The finished products are high-quality short films that educators can use to spark discussion on important issues. The films have been shown on MTV, PBS and NBC affiliates, Oxygen, at film festivals and on the Internet as well as on ABC's *World News Tonight* and NPR's *On the Media*.

Teenagers in New York City and Laredo, Texas, wrote the two most recent films released by *Scenarios USA*. The New York film, *From an Objective Point of View*, tells the story of two best friends who make a pact not to have sex without consulting the other and whose pact verges on being broken. The result is an honest look at teenage desire. Written by 16-year-old Janet Aponte, the film was directed by Jim McKay (*Our Song*) and Hannah Weyer (*La Boda*) and shot in Brooklyn.

The Laredo Story is adapted from an essay written by a 14-year-old girl who feels pressure regarding "drugs, alcohol, and doing what it takes to fit in." She decides to maintain her individuality and to remain abstinent. The film was written by Samantha Hernandez, directed by Griffin Dunne (*Practical Magic* and *Lisa Picard Is Famous*) and shot in the Texas-Mexico border town of Laredo.

To order, contact Scenarios USA, 110 West 18th Street, 6th Floor, New York, NY 10011 or phone 646.230.7677.

GET INVOLVED!

Fight for Your Rights: Protect Yourself Support Honest, Realistic Sex Education!

In April, Advocates for Youth announced its partnership with the media giant MTV in a yearlong campaign, *Fight for Your Rights: Protect Yourself*, the first-ever mass mobilization of young people in the United States to fight for their right to responsible, medically accurate sexual health information.

Through this campaign, youth will finally have a way to make their voices heard.

To learn more, to become an activist, to fight for your rights, visit www.advocatesforyouth.org/ffyr/intro.htm or phone Advocates for Youth's Youth Empowerment Initiatives at 202.419.3420.



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