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Evidence for the importance of community involvement: Implications for initiatives to prevent mother-to-child transmission of HIV

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The Population Council is an international, nonprofit, nongovernmental institution that seeks to improve the well-being and reproductive health of current and future generations around the world and to help achieve a humane, equitable, and sustainable balance between people and resources. The Council conducts biomedical, social science, and public health research and helps build research capacities in developing countries. Established in 1952, the Council is governed by an international board of trustees. Its New York headquarters supports a global network of regional and country offices.

The International Center for Research on Women (ICRW), founded in 1976, is a private, nonprofit organization dedicated to improving the lives of women in poverty, advancing women's equality and human rights, and contributing to broader economic and social well-being. ICRW does this, in partnership with others, through research, capacity building, and advocacy on issues affecting women's economic, health, and social status in low- and middle-income countries. The Center's international, multi-disciplinary staff works from its headquarters in Washington, DC, and its office in New Delhi, India.

Foreword

Mother-to-child transmission is the primary route of HIV infection in children under 15 years of age. Since the beginning of the HIV epidemic, more than 5 million children worldwide have been infected with HIV. Clinical trials in several countries have shown that mother-to-child transmission of HIV can be greatly reduced through administering a short, affordable course of antiretroviral therapy to pregnant women. These trials culminated in a recommendation by UNAIDS and its partners in the Interagency Task Team for the Prevention of Mother-to-Child Transmission that prevention of perinatal transmission should be a part of the standard package of care for HIV-positive women and their children. Moreover, it is quickly becoming clear that mother-to-child transmission prevention programs can enhance communities' understanding of and response to HIV. As a result, governments in Africa, Asia, and Latin America in collaboration with international and nongovernmental organizations have moved rapidly to improve antenatal care and incorporate interventions to prevent mother-to-child transmission of HIV into clinical and community-based care.

The acceptability, operational concerns, costs, and impact of this package of services on preventing mother-to-child transmission of HIV and on child morbidity and mortality are being addressed through a number of monitoring and evaluation activities. Advocates for issues concerning women's and children's health have raised equally important questions about how such interventions will be understood and received in the various communities in which they are becoming available, and how the interventions themselves can benefit from community input and involvement. In response the Population Council and the International Center for Research on Women (ICRW) initiated several activities to identify effective mechanisms for enhancing community involvement in efforts to prevent mother-to-child transmission. With support from Glaxo Wellcome's Positive Action Program and UNAIDS, the Population Council and ICRW analyzed the literature on community involvement in the introduction of health and other technologies at the local level and assessed community views on preventing mother-to-child transmission in Botswana and Zambia.

This paper offers lessons learned from the literature review of community involvement in earlier introductions of biomedical and other technologies. These lessons can guide appropriate and effective community involvement in the introduction of services for the prevention of mother-to-child transmission of HIV. A second companion paper, available on our website, discusses research in Botswana and Zambia that showed gaps in community knowledge about HIV transmission, particularly from mother to child, and yielded insights into community perspectives about the barriers to using voluntary counseling and testing services; the stigma and fear associated with HIV; traditional norms on breastfeeding; and the role of family and community members in women's decisions to participate in programs to prevent mother-to-child transmission of HIV. A separate publication ("Community involvement in the prevention of mother-to-child transmission of HIV: Insights and recommendations"), also available on the Population Council website, offers our recommendations for strategies for community involvement, which we hope will encourage program planners to include community participation, education, and mobilization as critical program elements.

An intervention that addresses mother-to-child transmission of HIV is complex, yet it is one of the few biomedical interventions currently available for reducing the transmission of HIV that is feasible and affordable in resource-constrained settings. Placed within the framework of community involvement, it offers an enormous opportunity to improve HIV prevention and care. Successful interventions can influence how AIDS is perceived by the community, reduce stigma, and have an effect beyond the immediate prevention of perinatal transmission. Without community involvement, however, the opportunity to effect positive change may be squandered.

<div align="right">Naomi Rutenberg, Mary Lyn Field-Nguer, and Laura Nyblade</div>

Evidence for the Importance of Community Involvement:
Implications for Initiatives to Prevent Mother-to-Child Transmission of HIV

Ann Leonard, Purnima Mane, and Naomi Rutenberg, Population Council

Mother-to-child transmission is the primary cause of HIV infection in children under 15 years of age. Since the beginning of the HIV epidemic, an estimated 5.1 million children worldwide have been infected with HIV (UNAIDS 2000c). Several recent clinical trials have documented the efficacy of a short course of antiretroviral drugs, potentially affordable in low-income countries, for the prevention of transmission of HIV from mother to child. In October 2000, a technical consultation held on behalf of the UNAIDS/UNICEF/UNFPA/WHO InterAgency Task Team on the Prevention of Mother-to-Child Transmission of HIV recommended that such prevention services be included in the minimum standard package of care for HIV-positive women and their children (UNAIDS 2000c). Multilateral and bilateral aid agencies and private foundations are currently collaborating with governments in Africa, Asia, and Latin America to improve antenatal care and incorporate a package of prevention interventions into clinical and community-based care.

The recommended standard package of care includes voluntary HIV counseling and testing, provision of antiretroviral drugs (zidovudine alone, zidovudine and lamivudine, or nevirapine), and counseling on infant feeding options (UNAIDS 2000c). The UNICEF/UNAIDS/WHO policy and guidelines on infant feeding (1998) state that counseling for an HIV-infected woman should include information about the risks and benefits of different infant feeding options, as well as specific guidance to help her select the option most suitable for her situation. The final decision about infant feeding should be the woman's, and she should be supported by health workers with information and counseling to implement her choice. For HIV-positive women who choose to breastfeed, exclusive breastfeeding is recommended for the first 4–6 months of her infant's life. UNICEF is also working with governments and suppliers of breastmilk substitutes to identify practical ways to provide infant feeding alternatives such as home-prepared or commercial infant formula with generic labels to mothers participating in pilot projects (UNICEF 2000).

Initiatives to prevent mother-to-child transmission of HIV launched by governments, intergovernmental agencies, and international organizations are faced with tremendous challenges in assisting women to make multiple decisions about how to protect their baby, addressing the stigma surrounding HIV testing and disclosure, coping with the lack of women's autonomy in many settings, and recommending strategies for safe infant feeding. Despite these challenges, an increasing number of such initiatives are being put into place not only because of the moral imperative to make this prevention option available to people around the world, but also because there is growing evidence that these initiatives may have substantial positive demographic and epidemiological effects (Wood et al. 2000).

The acceptability, operational concerns, costs, and impact of this package of services on prevention of mother-to-child transmission of HIV and child morbidity and mortality are currently being addressed through a number of monitoring and evaluation activities (for example, see Horizons/Population Council 2000). Equally important research questions, yet to be comprehensively addressed, are how such interventions will be understood and received in the various communities in which they become available, and how the interventions can be strengthened by community inputs and involvement.

The purpose of this paper and of related research at the community level in Botswana and Zambia conducted by the International Center for Research on Women (Nyblade and Field-Nguer 2001) is to underscore the importance of involving the community in the prevention of mother-to-child transmission of HIV, and to highlight the need to understand community attitudes and garner community support so that successful outcomes are achieved. This work is supported in part by Glaxo Wellcome, which has donated zidovudine to UNICEF for use at pilot project sites and is committed to helping establish community-led counseling and information support through its Positive Action Program.

This paper draws from experiences of and approaches to community involvement that have been carried out in the development and health fields over the last 40 years. While we place particular emphasis on examining interventions related to the delivery of new health care technology related to HIV/AIDS prevention and care, we also draw upon the wide spectrum of development

experience. We do not purport to include all the work done on this subject, which is enormous in scope; rather, our goal is to identify what has been learned from related experiences that can be useful in the design, implementation, monitoring, and evaluation of interventions to prevent mother-to-child transmission.

We present examples of community involvement that demonstrate how interventions that involve community members in the development, implementation, and monitoring of activities are more likely to have more effective outcomes and be supported and sustained beyond the life of the intervention. These examples show that when community involvement is an integral part of an intervention, there is a greater likelihood that the intervention will be more acceptable and more effective in meeting its objectives and that it can more easily enhance appropriate practices. This is true in part because community involvement can positively affect the norms and contextual factors that bolster acceptance and use of new interventions. After presenting the evidence for community involvement, we underscore some of the challenges unique to programs that address prevention of mother-to-child transmission. We conclude with a set of guidelines that can be used to expand community involvement in interventions to prevent mother-to-child transmission of HIV.

WHY COMMUNITY INVOLVEMENT?

UNAIDS defines a community as: "a group of people with something in common, whether they live together, come from the same area (village or town), gender, or ethnic background. Communities are also people who work together . . . or share common behaviour. . . ." Within these groupings, "there are common interests and understanding that bring people together and unite them around a common purpose" (UNAIDS 1996). Viewed in the framework of human rights, it is clearly the right of communities to participate in the design, implementation, and evaluation of interventions designed to affect their own well-being. Communities are not only the main beneficiaries of health and development programs; in the case of HIV/AIDS, they are the frontline in prevention, care, and support efforts.

Community involvement can take many forms: community members can be informants in formative and evaluative research relevant to the delivery of services; they can design or shape

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interventions; they can deliver services; they can be advocates; and so forth. Community participation is both a process toward an end and an outcome in itself. This is particularly true when it comes to marginalized and underprivileged groups, who often do not have any voice in matters that affect their lives.

The process of involving the community often facilitates community mobilization toward a given end. In the context of HIV/AIDS, UNAIDS describes a mobilized community as one whose members "are aware in a detailed and realistic way of their individual and collective vulnerability to HIV/AIDS and who are motivated to do something about their vulnerability" (UNAIDS 1997). Community members are often willing to invest their own resources—including money, labor, time, and materials—in activities they see as benefiting themselves and their community. Evidence based on case studies in Australia, Canada, Thailand, and Uganda (UNAIDS 1998b) clearly shows that communities are prepared to take leadership roles, take responsibility, and devise ways of sustaining the activities they initiate, and that they are able to work in partnership with national governments.

From a Transfer-of-Technology to a Participatory Approach

From the 1960s through the 1980s, a transfer-of-technology approach was central to many development efforts (Chambers 1997). This approach reproduces a standardized technology that has been used successfully in one sociocultural, environmental, or technological setting within a significantly different context. Such an approach is based on the view that the technology itself is widely applicable; and, indeed, a standardized approach can be successful in certain conditions.

Numerous examples in the development literature, however, document the shortcomings of a pure technology-transfer approach. Particularly noteworthy are cases where the construction of irrigation systems and dams, which had been successful elsewhere in reducing drought and increasing food production, has had serious negative and completely unexpected consequences when transferred to other settings. Examples include increased outbreaks of malaria in Ethiopia (Ghebreyesus et al. 1999) and Sri Lanka (Ramasamy et al. 1992) and elephantiasis and schistosomiasis in Ghana (Hunter 1997). In these cases, planners and implementers paid inadequate attention to the local

conditions, social relations, and indigenous knowledge that could have been used to help achieve program goals. As a consequence, they undermined the success of what could have been valuable innovations in local communities.

In the 1970s and 1980s, assessments of the outcome of hundreds of rural development technology-transfer projects identified the serious limitations of this approach (Chambers 1983; Cernea 1985). Schumacher's (1973) widely acclaimed *Small Is Beautiful* underlined the importance of development interventions that reflect the availability and limitations of local resources and capacity. He emphasized that communities must be made part of the evolutionary process of development, not merely recipients of Western-style initiatives that destroy the possibility of self-reliance and self-help.

The result, consequently, has been a new emphasis on participatory approaches to learning and action. A participatory approach enables development practitioners to appreciate the knowledge and insights of local community members. Such an approach to health and development emphasizes that those proposing an intervention (often referred to as "external change agents") need to take their lead from community members. Many initial applications of participatory research in health were centered around involvement of communities and health professionals in needs assessment, planning, and evaluation of programs (de Koning and Martin 1996).

Projects that build upon this kind of community involvement are often more likely to be supported and sustained beyond the life of the intervention. One example of the positive effects garnered through use of a participatory approach is the Bangladesh Rural Advancement Committee (BRAC). Established in 1972, BRAC is built upon a firm belief in people's ability to manage the process of development. It uses a community-driven development process that fosters empowerment and self-reliance. Initially formed as a program designed to control diarrheal disease by the introduction of home-based oral rehydration therapy, BRAC developed into a dynamic project that addresses a full range of health issues and the needs of the most marginalized and poor within each community (Lovell and Abed 1993).

Community Involvement Works

Strict transfer-of-technology approaches and completely community-driven approaches are two ends of a spectrum in development work. In reality, there are a range of approaches to and levels of community involvement. However, intervention research on a number of health promotion efforts documents that projects with substantial community participation are more likely to succeed than those that focus on reproducing external technologies and practices. For example, Manikutty (1997) initiated and compared two water supply and sanitation projects within the same water authority in Kerala, India—one promoted community participation and the other did not. People within the project that involved the community benefited from an improved water supply and were more likely to improve their sanitary habits, claim satisfaction with the project, and continue their involvement.

Similarly, a study of urinary schistosomiasis interventions in Ghana explored varying health education and community participation approaches in different communities (Arteetey et al. 1999). The study demonstrated that greater community involvement in the education process led to more self-help health initiatives. A study in Uganda explored the key factors leading to the success of initiatives to prevent river blindness (human onchocerciasis) (Katabarwa, Mutabazi, and Richards 2000). Where community members felt they were involved in the planning and execution of the project, prevention targets were significantly more likely to be exceeded.

Founded and initially operated by a small and dedicated group of women volunteers in northern Tanzania, KIWAKKUKI (the Kiswahili acronym for Kilimanjaro Women's Group in the Fight Against AIDS) expanded rapidly and experienced "growing pains" that threatened its future development. KIWAKKUKI initiated an intervention research project in which an interactive process helped the group to define its structural and management needs, outline the necessary steps to bring about change, analyze the results, and modify its goals and strategies. The participatory nature of the workshops permitted group members to voice their concerns and difficulties, with the result that positive steps could be taken toward developing a more open and decentralized organization. The participatory approach has now been adopted as integral to the organization's operation (Leonard and Muia 1998).

In Peru, an unusual collaboration between the Manuela Ramos Movement, a women's health organization, and USAID has resulted in an expansion of the *Manuelas' autodiagnóstico* (self-evaluation) style of community involvement to improve the quality of reproductive health services in rural areas. Originally the program was designed to work exclusively with local women. However, the women argued early on that if change was to occur, their husbands also needed to be involved. Like many women's organizations, the *Manuelas* were reluctant to use funds designated for improving women's health on workshops for men; however, in keeping with the program's approach of listening to community perspectives, the *Manuelas* heeded the advice of the local women. Now the *Manuelas* view this parallel work with men as an element critical to the program's success. As one of the male participants reported: "I went to the training to learn. I learned that the men should not hit the women, and to not drink and hurt them . . . We have been together for 28 years; we have 11 children. Now I don't drink and I don't hit her. We have changed—completely." And, according to one 49-year-old woman, "The training opened the subject of how to have relations, to have . . . pleasure. He learned about the clitoris [she smiles]. It is a big change" (Rogow 2000).

In Uganda the Stepping Stones program develops community support through the use of participatory techniques to promote open, dynamic, and innovative reflection on HIV/AIDS and, ultimately, to devise a plan of action that fosters community support. Stepping Stones was successfully used to educate and mobilize entire communities on how to minimize their risk of becoming infected with HIV (Welbourn 1998). Involvement of affected persons in services, for example the involvement of people living with HIV/AIDS in HIV/AIDS services, is another means of community involvement. In Ecuador a study of the involvement of people living with HIV/AIDS in HIV/AIDS service organizations found that when service beneficiaries were cared for by people living with HIV/AIDS, the organization provided better-quality care that responded more appropriately to the needs and expectations of the beneficiaries (Horizons/Population Council and International HIV/AIDS Alliance 2000).

In a review of the effectiveness of community participation in the control of vector-borne diseases in Latin America—especially through control of *Aedes aegypti*—the authors conclude: "There is no alternative to increased [community] participation . . . as strategies that do not involve the

community to any appreciable degree . . . do not appear to be an adequate alternative" (Winch, Kendall, and Gubler 1992).

GUIDELINES FOR COMMUNITY INVOLVEMENT IN THE PREVENTION OF MOTHER-TO-CHILD TRANSMISSION OF HIV

We have organized the lessons learned from our literature review into a set of guidelines. We illustrate the potential benefits of each of the guidelines with further examples from published research. We believe that these guidelines provide useful directions for involving program planners, policymakers, and community leaders in the prevention of mother-to-child transmission.

Explore Community Norms and Values

An inherent problem with the transfer-of-technology approach, or with approaches that neglect to involve communities, is that the resulting intervention does not reflect community norms and values. This shortcoming can create significant barriers to a program's success.

For example, in the 1960s a comparatively high prevalence of leprosy existed among the Hausa of northern Nigeria. Culturally, the Hausa were not known to fear or stigmatize individuals with the disease. People affected by leprosy lived with their families in compounds and were integrated into the society; when their disease became advanced, they became beggars and obtained alms from the community. Christian missionaries, however, brought with them a fear of leprosy and of the people infected, whom they soon isolated in hospitals. For the Hausa, the results were tragic. The missionaries' attitudes and culturally inappropriate public health interventions not only stigmatized leprosy but also increased the Hausa's suspicions and fears about missionaries and their motives (Shiloh 1965).

Research in the Gambia and Tanzania on the acceptability of using bed nets impregnated with an insecticide for the control of malaria revealed that a number of cultural patterns and beliefs affected communities' reception to their use. In the Gambia, 99 percent of the Mandinka used bed nets, as opposed to 58 percent of the Fula. Researchers explored community perspectives to understand why

this was so and learned that the Mandinka appreciate privacy and that it is traditional for Mandinka husbands to give bed linen as part of the marriage exchange. The Fula, on the other hand, prefer to be unencumbered because of their nomadic lifestyle and, as such, resisted bed nets (MacCormack and Snow 1986). In some coastal areas of Tanzania, people felt that bed nets were similar to shrouds used to cover corpses and therefore refused to use them (Winch 1990).

In some societies, culturally specific norms inhibit the discussion of particular issues, such as sexual behavior. In the case of HIV, community norms about gender roles have often made it difficult to promote messages that insist on mutual fidelity, abstinence, or condom use. Some interventions, such as those used in the Women and AIDS Research Program of the International Center for Research on Women (Weiss, Whelan, and Gupta 1996), have focused on learning from community members how these norms can be challenged or shaped to encourage prevention. Others have helped to identify how community norms, such as the strong taboos against oral sex (Mane and Aggleton 2000) or the emphasis on men's responsibility to protect their families from infection (UNAIDS 2000b), can be incorporated into efforts to promote prevention. In Zimbabwe, Voices and Choices, a participatory research program that involves women living with HIV, has created a network through which communities have begun to discuss the taboos surrounding sex (Sayagues 2000), including the use of powdered herbs for dry sex (which is associated with increased transmission of HIV) and the extent of sexual coercion. This research has led to a greater involvement of men in discussion and debate and the establishment of links between the organization and mainstream health services.

Assess and Utilize Sources of Social Influence

It is important to identify local sources of social influence that can facilitate community involvement and ensure cooperation from influential members. The challenge is to make use of social influence without reinforcing harmful power dynamics or hierarchies.

Several projects have demonstrated how community leaders can be involved in efforts that ultimately empower women. In India Bhende (1995) described the necessity of reaching out to community leaders and parents before starting an intervention that educated girls about HIV and

involved them in educating others. Also in India, the Women's Development Programme built a coalition of women to put pressure on local institutions about such issues as alcoholism among men, which led to widespread domestic violence. United around a common cause, the women were introduced to the local officials who had the power to address their concerns. Through community consensus, the women succeeded in instituting policies to stop the public consumption of alcohol. When the police failed to uphold the new policy, the women then sought the support of a number of influential male village elders. With encouragement from the elders, the police finally agreed to prosecute drunken husbands who beat their wives (Jain et al. 1986).

In work on AIDS, there is much discussion about the role of religious leaders, including those at the community level, in HIV prevention and support. As early as 1992, an assessment of the potential for integrating HIV/AIDS into family planning activities in Uganda revealed that religious organizations were already responding to the HIV/AIDS information needs of their immediate communities. The Islamic Medical Association was able to convince religious leaders that condoms should be promoted for HIV/AIDS prevention because they were already being used for family planning (UNAIDS 1998a). While a Catholic hospital could not promote condom use, it made sure that its clients were aware of the effectiveness of condoms in preventing the transmission of HIV (Bair et al. 1993). As sources of social influence, local religious leaders can play a persuasive role in influencing their communities. The multiple implications of their influence—positive and negative—need to be considered when designing interventions.

Those who rank high in the community hierarchy, however, do not always hold the key to successful interventions. Often the community members who are most affected by an issue are a powerful resource that, when organized, can help to advocate for needed changes and garner support for planned interventions. In the United States, outraged mothers of various racial and socioeconomic groups have banded together to speak out on drunk driving; in 2000 women also converged on Washington, DC in a Million Moms March to advocate for more effective gun control—two areas where the power structure has been slow if not reluctant to intervene. In many industrialized countries, when AIDS struck their communities gay advocates mobilized to lobby for broader support in the fight against the epidemic and develop effective responses to issues of prevention and care at the community level (UNAIDS 1998b).

Work Through Social Networks

Individuals belong to social networks that contain friends, relatives, and others whose actions, communication, or perceived traits help them to address challenges and innovations in their own lives. Research on social networks suggests that social networks within communities can identify issues specific to their members and influence the degree to which their constituents are willing to change behaviors (Working Group on Factors Affecting Contraceptive Use et al. 1993; Gujit and Shah 1998; Bond, Valente, and Kendall 1999). Examples of formal and informal social networks include local women's groups, marketing associations, local political associations, mutual aid and rotating credit groups, traditional birth attendants, church groups, and youth organizations. Social networks transmit and distill information in terms that are meaningful to an individual's ability to make decisions and take action. The function of social networks in evaluating the social cost and benefits of the behavior promoted by an intervention, such as requesting an HIV test during pregnancy, is likely to be most important in environments of uncertainty where these costs and benefits are poorly understood. In such environments it is natural for people to seek guidance from others before acting (Montgomery and Casterline 1998).

Working through social networks is all the more important when discussing such sensitive and potentially volatile issues as sexual abuse, domestic violence, reproductive rights, and HIV/AIDS or when trying to reach groups that are difficult to find. For example, in Namibia the Okatumbatumba Hawkers (street sellers) Association successfully integrated an HIV participatory education initiative into existing social networks within the informal urban economy. This initiative provided HIV prevention messages and addressed issues of social stigma and discrimination surrounding HIV and AIDS (UNAIDS 2000a).

Peer groups are a type of social network, and peer counseling and peer education capitalize on this network and its influence. According to behavioral theories, peers can serve as persuasive role models for change, and interventions research has proven this to be true. There is abundant evidence from work on HIV prevention to illustrate that peer-group networks may be the most effective means of reaching adolescents and other groups that are marginalized or difficult to reach, such as sex workers, street children, drug users, gay and lesbian groups, and socially

underprivileged communities such as inner-city African-American women in United States (Horizons/Population Council et al. 2000). For example, young male and female peer educators in Sri Lanka facilitated discussions with other adolescents about such normally taboo subjects as virginity, sexual behavior, and decisionmaking. Findings showed that single-sex sessions helped young women develop public voices that enabled them to participate in subsequent group discussions with young men (Silva et al. 1997).

Social networks themselves can be consulted in order to identify appropriate peer educators. A peer education program in the United States for injecting drug users selected peer educators on the basis of nominations from the community of drug users. The educators were then trained in needle hygiene and reducing sexual risk. The program subsequently documented a significant increase in safe injecting practices among members of the peer educators' networks (Latkin, Vlahov, and Knowlton 1996).

In India, the Child in Need Institute (CINI) learned through focus-group discussions that men in West Bengal were generally ignorant of their wives' reproductive health. In response, CINI initiated an awareness campaign spearheaded by 20 trained male peer educators who organized meetings and disseminated reproductive health information. The intervention's success has been evident in the increasing numbers of both men and women who are accessing CINI's services. In addition, the peer educators have begun to question nonegalitarian gender relationships within their own families (Raju and Leonard 2000).

Because people often place great faith in the knowledge of others who have firsthand experience with a disease or treatment, peer counselors are a frequent means of educating women about treatment options and helping to develop community and support groups. The Tanzania AIDS Support Organization, the Kenya AIDS Society, and similar groups elsewhere have worked closely with people living with HIV/AIDS to involve them in promoting risk reduction and in sensitizing both their peers and community members to the need to reduce stigmatization (Leonard and Khan 1995; Nakawunde and Ekawu 1998).

Foster Family and Social Support

Experience has also shown that it is critical to foster social support from partners and families both before and during interventions in order to facilitate program goals of behavior change. The Centre for Health Education, Training, and Nutrition Awareness (CHETNA), based in Ahmedabad, India, has been working to improve pregnancy outcomes in Gujarat State. To that end, CHETNA introduced activities to educate village women about the need for a healthy diet during pregnancy. The typical response from women, however, was, "Why don't you give this advice about what I should eat to my family members? If I start eating what you suggest, my husband and mother-in-law will beat me." When they saw that women lacked control over their own food intake, CHETNA staff realized they needed to involve men in their reproductive health programs (Raju and Leonard 2000).

Social Action for Rural and Tribal Inhabitants of India (SARTHI) had a similar experience when, in an effort to address the high frequency of sexually transmitted infections among its female constituency, it organized meetings at two mobile clinics and urged village women to participate. Despite indications from the women that they would attend, attendance rates were very low. Upon investigation, SARTHI staff discovered that many women backed out when they were unable to obtain their husbands' permission to attend. From this experience, SARTHI realized that access to health care for women is not simply a matter of physical access; it is also a matter of social access (Raju and Leonard 2000).

A study in Egypt evaluated the effects of husbands' involvement in their wives' postabortion recovery and use of contraception. Researchers concluded that when husbands received counseling by senior or well-trained staff, they were more likely to support their wives. Support from husbands was in turn associated with improved postabortion outcomes (i.e., faster emotional and physical recovery) (Abdel-Tawab et al. 1999). A review of experience in Africa found that the effect of voluntary HIV counseling and testing on individual behavior change was mixed, but that condom use increased among serodiscordant couples when they were counseled and tested together (Brown et al. 2000).

It is important here to caution that the involvement of a partner in decisions that influence a woman's life should *always* be the choice of the woman. In addition, a woman's right to make decisions without the involvement of her male partner must be respected. In some instances women may derive greater empowerment when they are given opportunities to receive support from other women. In a study based in São Paulo, Brazil (Kalckmann et al. 1998), women volunteers were introduced to the female condom and participated in women's support groups where they shared their experiences over a period of time. At the end of the study 75 percent of the participants were using the female condom and spoke highly of it.

Husbands are not the only family gatekeepers when it comes to women's reproductive health. Workers in the CINI program, noted above, also learned from their peer educators that newly married young men were, in fact, willing to listen to discussions of new and gender-sensitive ways of approaching women's health. However, the young men continued to be unable to act on their intentions because of immense social pressure from their elders, particularly older women in the family. This led CINI to emphasize that intervention programs for women's health must involve all family members, not just husbands and wives (Raju and Leonard 2000).

Harness the Collective Power of Women As Agents of Change

In many communities, women have become powerful advocates for change through participation in groups where they discuss problems and aspirations and forge a strong collective identity. Examples described earlier show how women are not only amenable to adapting to innovations but often act as gatekeepers and even leaders in the process of social change. To involve women, interventions must meet women's needs, be sensitive to the realities of their lives, and offer the potential of bringing them needed resources and opportunities.

The STD/HIV Intervention Program in Sonagachi District in Calcutta, India, began as a project to train sex workers as peer educators. However, the women were not content merely to educate other sex workers about HIV/AIDS and distribute condoms; they also mobilized internal and external resources to address many other needs within their community. The program has resulted in improvements in a range of outcomes desired by the community, including sexual health;

immunization programs; developmental programs for children; formal education for sex workers; an increased sense of social identity, self-respect, and dignity among sex workers; and an increased acceptance of sex workers by the community (Bandyopadhyay 2000).

After failed attempts to involve men in wasteland rehabilitation in tribal areas of western India, SARTHI began to work successfully with groups of women. The women have been able to work together to clear and plant land and have proven to be capable of standing up for themselves. In one case, several goats belonging to the local mayor were found grazing on a group's plantation. Eighteen women caught the animals and had them locked up in the local stockyard, a facility operated by the mayor himself. He was unable to reclaim his own goats until he paid a fine of 700 rupees to the group. This is an extraordinary development, given that only a short time before, this group of women would not uncover their faces in the presence of a man (Sarin 1993).

In the Dominican Republic, *Promoción de la mujer del sur* (Advancement of Women of the South) demonstrated the collective power of women to bring about social and economic change (Hilsum 1986). The project evolved from a nutrition program into a strong women's movement that challenged the government's policy on retaining land for the production of cash crops for export to the United States. The consequent imbalances in land tenure and access to new technologies left subsistence farmers either landless or with poor-quality land that gave very low yields. The women's project rejected food aid programs as detrimental to health in the long term and fought to maintain ownership of local food production through successfully campaigning for technological assistance.

Link Clinic and Community-based Sources of Information and Services

In the case of health-related interventions, even when well-trained health providers are available to offer clients accurate information, drugs, supplies, and medical care, widespread (and often valid) distrust of clinic-based assistance limits its impact. Negative attitudes among providers and lack of empathy for clients, well documented in the family planning literature, can be even more pronounced in the area of HIV/AIDS. Women are further disadvantaged in their relations with providers because of their low social status. It is not surprising that women often supplement

information given to them by providers with the experiences of women they trust—women like themselves. A study of family planning adoption in western Kenya found that women wish to consult family planning nurses in order to get proper instruction on method use and tests to ensure that a particular method "rhymes" with their bodies. However, they supplement providers' instructions with conversations with friends and neighbors—women whose physical and social circumstances they regard as being like their own (Rutenberg and Watkins 1997).

Frequently, community-based health and social workers bridge the gap between community members and formal clinic services. For example, another study in western Kenya cites volunteer community-based distribution workers as an important source of contraceptive supply when they live close to their clients. This proximity enables them to address women's needs for reassurance about contraceptive side effects more successfully than clinic-based staff (Chege and Askew 1997). In New York City, Families in Transition, an outreach project that targets women affected by HIV in poor areas of the city, recruits neighborhood women (known as *compañeras* or companions) to act as the first point of contact for HIV-infected mothers, who are often cautious and fearful of formal health delivery services. The *compañeras* inform women of the range of health and social support services that are available and how best to access them (Ireland and Krauss 1997).

In an intervention with traditional midwives to improve postabortion care services in Morelos, Mexico, it became evident that the influence of indigenous workers can be eroded if the hospital structure does not recognize their legitimacy. In this case midwives accompanying a woman to the hospital were being ignored and badly treated by hospital staff. Hospital-based providers, therefore, needed to be educated about the importance of developing respect and trust for the midwives. Support from higher levels in the health care system was also required to reduce the risk that midwives would be the target of punitive and legal actions when they stabilized a woman with severe bleeding, accompanied her to the health center or hospital, or otherwise assisted her with lifesaving care (Billings et al. 1999).

Traditional healers often take a more holistic approach to illness and health as compared to the more narrowly focused biomedical perspective of Western-style medical practitioners (Green 1994; Farmer 1997). For these reasons, traditional healers are often thought to be an appropriate bridge

between the community and medical clinicians and formal health care facilities. For instance, the Zimbabwe National Traditional Healers Association (ZINATHA) developed and carried out an HIV/AIDS project in coordination with the Ministry of Health and the National AIDS Control Program. The association also worked closely with chiefs and other opinion leaders to encourage the modification of traditional practices that contribute to the spread of AIDS and the adoption of alternative rites and rituals that do not put people at risk of contracting HIV (Leonard and Khan 1995). A similar program, carried out by the AIDS Foundation of South Africa in KwaZulu Natal, integrated traditional healers into the district health system. This has enabled traditional healers to play a central role in the struggle against HIV/AIDS (Msezane 2000).

Analyze the Political and Socioeconomic Context

No matter how obvious the benefits of a proposed intervention may appear to those initiating it, the political and socioeconomic context may influence whether community involvement is facilitated or hindered (Zakus and Lysack 1998). In Nicaragua a successful malaria control program that was based on local epidemiological assessments and community participation began to fail following implementation of the country's macroeconomic structural adjustment program, which resulted in less willingness on the part of community members to work "for the public good" (Garfield 1999). On the other hand, where there is a climate of political change based on mass participation for the general good, there is potential for positive community involvement. In Honduras the nongovernmental organization MOPAWI (*Mosquita Pawisa*) has been instrumental in changing government policy through a high level of community participation in lobbying and advocacy. This has enabled the communities of eastern Honduras to obtain environmental protection, government recognition of ethnic diversity, and greater recognition of their rights as indigenous peoples (Brehm 2000). Similarly, a field trial in West Timor, Indonesia, highlights the potential of community-controlled political groups to support health initiatives. Health service posts run by village committees are offering a range of health services and were in large part responsible for implementation of a highly successful community-based malaria control program (Mantra 1992).

COMPLEXITY OF INTERVENTIONS TO PREVENT
MOTHER-TO-CHILD TRANSMISSION OF HIV

Engaging communities in preventing mother-to-child transmission is particularly challenging because of the complexity of decisions surrounding HIV testing, issues concerning women's autonomy, stigma associated with HIV/AIDS, and infant feeding practices. In countries where antenatal facilities offer interventions, pregnant women will need to make a series of difficult decisions:

- Whether or not to seek antenatal services;
- Whether or not to take an HIV test;
- Whether or not, and with whom, to discuss the results of the HIV test;
- If the test is positive, whether or not to use antiretroviral drugs to reduce the risk of perinatal transmission of HIV; and
- If the test is positive, how to feed the infant in order to maximize his or her health in view of the benefits and risks of different feeding options.

Women in traditional societies have low social status within their families and communities; hence, their ability to make their own decisions about sexual and reproductive health is severely circumscribed. Matters related to pregnancy are often decided upon by husbands, in-laws, and elders (Raju and Leonard 2000).

Stigma associated with HIV is often the biggest barrier to effective prevention and care initiatives (Malcolm et al. 1998). Offering mother-to-child transmission prevention services as part of antenatal care may actually deter women from seeking antenatal care out of fear of the consequences of testing for HIV. Women may be further discouraged if they doubt the facility's ability to keep such information confidential. Ideally, once diagnosed as HIV-positive, a woman should be able to share the results with and seek support from family members. Yet revealing her HIV status can potentially subject a woman to stigmatization, ostracism, divorce, loss of family ties and economic support, and physical abuse. Not revealing her status to her family, on the other hand, can compromise her ability to participate in and benefit from interventions that address mother-to-child transmission. While such interventions should assist women in accessing care and emotional

support, dealing with potential side effects from medication, and preparing for their future decline in health, presently they have little to offer.

In resource-poor settings, choosing how to feed their infants safely and properly is a particular dilemma for HIV-infected women (White 1999). The risk of transmitting HIV to a breastfeeding child must be weighed against the benefits of breastfeeding to nourish the child and protect him or her against illness. Formula feeding can prevent HIV transmission, but unless it is safe and affordable it can put an infant at risk of other life-threatening infections. In addition, significant problems are associated with finding a culturally appropriate, nutritionally adequate, easy-to-use, hygienic, and affordable substitute for breastmilk.

A woman must make decisions about infant feeding based on knowledge of benefits and risk not only to her infant but also to herself. In many cultures, breastfeeding is considered a sign of being a good mother and is almost universally practiced. In addition, it has been widely promoted as "best" in the same countries where we now may be telling some women not to breastfeed, a situation that contributes to the stigmatization of not breastfeeding. In addition, a decision not to breastfeed may mean a rapid return to fecundity that can put a woman at increased risk of unplanned pregnancy. Finally, decisions regarding how to feed her infant are rarely made by the mother alone.

COMMUNITIES AS PARTNERS IN PREVENTING MOTHER-TO-CHILD TRANSMISSION

Research conducted by the International Center for Research on Women (Nyblade and Field-Nguer 2001) in Botswana and Zambia found that the benefits of technologies that may prevent HIV infection (e.g., serostatus testing, antiretroviral drugs, and breastmilk substitutes) can be overshadowed by prevailing community norms, values, and beliefs regarding HIV/AIDS. Overcoming negative community perceptions about people living with HIV/AIDS and educating community members about HIV transmission are necessary to increase women's willingness to be tested for HIV, which is a prerequisite for participating in interventions to prevent mother-to-child transmission.

The findings from Botswana and Zambia also indicate that women trying to decide whether or not to participate in a prevention program are strongly influenced by the opinions of their spouses and partners, as well as those of family and community members. Parents, in-laws, and other relatives have varying degrees of influence on decisions about testing, disclosure, and drug treatment, and often have significant authority over infant feeding. The research findings demonstrate that, in order to succeed, programs to prevent mother-to-child transmission must be able to provide information, education, services, and support to these significant others in women's lives.

These observations underscore the critical need for community involvement in the introduction of programs to prevent mother-to-child transmission of HIV. In Ndola, Zambia, a pilot project to integrate HIV voluntary counseling and testing and improved infant feeding into existing clinic services and community-based activities exemplifies community involvement in identifying alternative infant feeding options. To develop feeding recommendations appropriate for women in the Ndola community, the National Food and Nutrition Commission conducted research on the relationship between HIV and infant feeding, which included an assessment of household food preparation as well as locally available replacement foods and breastmilk alternatives. The research documented the stigma faced by nonbreastfeeding women and identified positive infant feeding concepts and practices in these communities that could be reinforced as part of the project. Additionally, the researchers surveyed the market and noted the availability and prices of milk, formula, and replacement foods such as pulses, fruits, and vegetables. The research resulted in a practical set of recommendations for infant feeding that are both acceptable to and achievable in the community (National Food and Nutrition Commission et al. 1999).

Community members have important roles to play throughout the process of preventing mother-to-child transmission. These include encouraging women (and men) to seek voluntary counseling and testing, providing support within the community to women (and men) diagnosed with HIV, and providing women with needed support and assistance throughout pregnancy and after childbirth. For example, community input can shape services for voluntary counseling and testing so that they provide information to women on prevention options in the context of women's prescribed roles and address fears about the problems women are likely to face if they reveal their HIV status to family and community members. In turn, services for voluntary counseling and testing should make

use of community-based organizations to provide support and services to women and their families. Health services will need to work with social service organizations to ensure that the needs of HIV-positive women (including self-care; treatment; and support before, during, and after childbirth) are met, rather than focusing only on mother-to-child transmission.

There is ample evidence that community-based organizations are coming forward to meet the challenges of HIV. The Kenya AIDS Society (KAS) is one example. Its primary goal is to reduce the stigma associated with HIV. KAS mobilizes people living with HIV to respond to their own health problems in a positive way and informs the wider community about HIV prevention and the care of those infected. KAS has established counseling outlets in a number of dispensaries and hospitals to provide health education and counseling to people living with the disease and their families, and to deal with fears related to care. An underlying principle of KAS's work is the importance of community involvement in HIV prevention and care and reducing the stigma associated with HIV (Leonard and Khan 1995). The AIDS Service Organization of Uganda has conducted pioneering work in similar areas, focusing on families and communities as sources of support.

Therefore, if involved and appropriately educated, community groups can offer specific support for efforts to prevent mother-to-child transmission of HIV. For instance, they can help spread the message that while breastfeeding continues to remain important, a decision by HIV-positive women not to breastfeed deserves the community's support rather than its condemnation. Communities are also well placed to offer long-term support to women beyond prevention initiatives. To this end, interventions can help by building ties between community leaders, women's groups, networks of HIV-positive people, and organizations that work for HIV-positive people and their families, so that a supportive environment is created in which HIV-positive people can live and exercise the choices they make. Community members and organizations can also influence national policy, as has recently been shown in South Africa where advocacy by community groups for greater access to nevirapine for pregnant women is finally resulting in action by the government (Brown 2000).

CONCLUSION

A review of some four decades of development experience underscores the need for active involvement of community members when new interventions affecting their well-being are being contemplated. Greater involvement of the community is most clearly mandated when an intervention is complex, addresses sensitive issues, and demands changes in community norms and values. It is important that communities be seen as partners in any such undertaking, and thus as a source of expertise in developing and sustaining such interventions. Community-driven programs must recognize that local groups may have conflicting interests or differing access to power and may resist changes they do not understand or that they perceive as threats to their interests. In addition, particular attention needs to be paid to marginalized, less vocal, and less powerful members of the community to ensure that their needs are addressed.

Some key principles of community involvement that emerge from our discussion may be summarized as follows:

- Community groups can effectively assess problems, propose solutions, and implement change, but need ongoing and appropriate support from health and development systems and professionals.
- Community members' perceptions of their needs and of the contextual factors that impinge on their lives may be quite different from those of program planners and implementers; the key is learning to listen and give credence to the community's point of view.
- Failure to involve the community may not only result in an unsuccessful intervention, but may also produce unforeseen and possibly adverse effects.
- Interventions aimed at the "general good" may also inadvertently leave out marginalized members within communities.
- Community participation need not be resource-intensive but must engage communities throughout an intervention and plan for how communities will be involved beyond the specific project.

There is a need to understand community norms and engage in meaningful dialogue with community members prior to and during interventions, to design culturally appropriate and varied

interventions that meet the needs of beneficiaries living in diverse situations, and to involve communities in all phases of any project. Such community involvement is more likely to ensure the success of interventions to prevent mother-to-child transmission of HIV. While dedicating more time and resources to build, sustain, and support such community involvement, program planners also need to ensure that formal-sector services are sensitive to women's needs and that they back community efforts even after a specific initiative has been accomplished. The potential benefits for women, their infants, and families, as well as for the community at large, justify such a comprehensive approach.

Care should be taken, however, that community involvement is not seen as a solution for all problems. Governments and international organizations should not expect communities to take full responsibility for interventions. Rather they must work in partnership with communities to ensure successful outcomes. Support must be provided through policies and programs that meet the range of needs of infected women and their families both during interventions to prevent mother-to-child transmission and beyond. In view of the extent of the AIDS epidemic, communities clearly cannot be expected to assume responsibilities for services only governments can provide, and they will need assistance to provide the services only they are best placed to organize.

Acknowledgments

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