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CICRED'S SEMINAR

**Beyond numbers: giving the poor and marginalized a
voice in reproductive health services - A benefit for
all**

Nancy Moss

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a benefit for all**

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Introduction

An example from California

There's something that marginalizes someone like me who lacks experience. Because I am a housewife, I don't go out so I don't realize what's happening, and then you are enclosed in your world with your fears... I'm afraid you'll go into a place and they won't help you or that we'll go to the hospital and they'll say, "Hey, you, go back to Mexico".....That makes one fearful....[1] [Moss, Baumeister, Biewener...Perspectives]

In 1994, the people of California voted for a new law that would deny health services supported by public (state) funds to anyone suspected of being in the United States illegally. The law was directed primarily at the estimated 1.4 million undocumented immigrants of Latino or Hispanic descent in California, an ethnic minority. Because immigration is most likely during young adulthood, many immigrants are young women of reproductive age with pressing health needs. Reproductive health services to this population, of whom 26 % live in poverty [US Census, CPS, 1999], have been provided primarily through public-funded clinics and hospitals.

We begin with this example from our own country, because it illustrates how marginalized women feel when access to reproductive health services is jeopardized by ethnic origin, immigrant status, poverty, and public policy.

Fortunately, legal action in the Federal courts prohibited enactment of the new law, and, while remaining fearful, most Latina women in California were able to access reproductive and primary health care services.

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But what happens when you do go into a public reproductive health clinic? While many are cheerful, sanitary, and efficient, other are not. An African-American woman in California said:

Nobody deserves to go to clinics like that. There's a smell. It's dirty. It feels like a dungeon [prison]...When you walk in, you go up and get a number. And then you just sit. I sat for an hour and a half before I was allowed to tell them who I was. Then I sat for another 3 hours until they put me in a room to wait some more...And the doctor I saw, he was mean. He was really rough when he was examining me....[2] Stevens, P. Marginalized women's access....]

When poverty, marginalization, and reproductive health intersect, it is likely that both clients and clinic workers will walk away unsatisfied and disappointed, and that standards of care may suffer.

In this paper we develop a model for giving poor, marginalized, and vulnerable people a voice in creating and maintaining their own reproductive health services. Our model takes account of multiple actors: multilateral and donor organizations, ministries, administrators and service providers at the local and clinical level, and client populations. It encompasses organizational, technical and political effectiveness. We recommend methodologies that can help to make reproductive health services more participatory and client-friendly while preserving quality of care. But, while recognizing the self-interest of actors at multiple levels of reproductive health care delivery- donors, ministries, and clinic staff, the model is compatible with feminist, ethical and human rights approaches. We hope that a model based upon participatory strategies can also contribute to a reduction in unmet need for services.

Poverty as a context for reproductive health

We regard social and economic conditions as fundamental determinants of men's and women's lives and their health-related behavior [Link BG and Phelan J. (1995). Social conditions as fundamental causes of disease. *Journal of Health and Social Behavior*, extra issue, 80-94; Moss, 2002]. In ways that vary depending upon geopolitical and historical context, social and economic conditions shape decisions about sexual behavior and childbearing, environmental constraints, accessibility and quality of health and social services, and educational aspirations and achievements. [AGI, *Hopes and Realities: Closing the Gap Between Women's Aspirations and Their Reproductive Experiences*, NY 1995.] The addition of racism, gender and sexual discrimination create a potent brew, with adverse consequences for reproductive health.

Poverty and socioeconomic inequalities within and among countries is a major hindrance to reproductive health and to human development [AGI, *ibid.*, World Bank, WDR 2004: Making Services Work for Poor People, Outline, September 24, 2002; UNDP, *Overcoming Human Poverty*. UNDP Poverty Report 1998. NY, 1998]. Widespread recession and state fiscal crises, following upon reductions in state supported sectors (structural adjustment), combined with constant political conflict in some of the world's poorest countries, have slowed progress during the 1990s and the new millennium [*ibid.*].

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According to the UNFPA,

Globalization has clearly increased overall prosperity and stimulated growth. It has also increased income inequality and environmental degradation. Although poverty has declined in percentage terms, the number of people living in poverty has steadily increased, and average incomes in many developing countries have remained low....[UNFPA. The State of World Population, 2001, pa.]

The spread of HIV has lent new urgency to the concerns of the multilateral and donor organizations to reduce poverty and mitigate its impacts on human behavior. The provision of adequate reproductive health services for men and woman, younger and older, urban and rural, mainstream and marginalized people, has become an urgent priority. While the need may be most acute in Sub-Saharan Africa, there are few if any countries where all populations are served equitably with effective, high quality and accessible reproductive health services (Table 1). In many countries, the poor, particularly poor women, have dramatically worse access to reproductive health services.

Table 1
Reproductive health characteristics of eight countries, selected years, 1990s

I ITEM	COUNTRY							
	Bangla- desh	Indi a	Nepa l	Jorda n	Ghan a	Seneg al	Jamaic a	Per u
Per capita GNP (US dollars, 1995)	240	340	200	1,510	390	600	1,510	2,310
Adult literacy rate (1995)								
Female	26	38	14	79	53	23	89	83
Male	49	65	41	93	76	43	81	94
Total fertility rate (1990s)	3.6	3.5	4.6	5.6	5.5	6.0	2.6	3.5
Contraceptive prevalence rate (women of reproductive age in union, 1990-96)								
Total	45	41	29	35	20	7	62	59
Modern	36	36	26	27	10	5	58	33
Maternal deaths/100,000 live births (1990s)	850	570	1,500	150	740	1,200	120	280
Births attended by health staff (in percent, 1990)	7	44	6	86	42	40	88	78

Source: Hardee, K et al. Post-Cairo Reproductive Health Policies and Programs; A comparative study of eight countries. Washington, DC: POLICY Project, The Futures Group, 1998.

A multi-dimensional definition of poverty

While recognizing that disciplines, nations, and advocates differ in their definitions of poverty, conventional measures are the percent of a country's population that falls below a particular income standard or lack items in a breadbasket of material necessities. A multi-dimensional definition of poverty, relevant to reproductive health, takes into account distributional equity, empowerment, security, and infrastructure to support different cultures (Table 2).

Table 2

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**A Multi-Dimensional Definition of Poverty:
Applicability to Reproductive Health¹**

Dimension	Relevance to Reproductive Health Services
<i>Opportunity:</i> Distributional equity in economic resources. Enhanced by stable economic environment, equitable asset distribution, availability of infrastructure	Equitable fees or absence of financial barriers; equitable range and quality of services across districts, communities, and populations; equitable distribution of personnel and equipment.
<i>Empowerment:</i> Individual participation in community decision-making; strengthened by decentralization, transparency, and accountability in all aspects of governance, including management of public health resources	Advocacy groups composed of providers and consumers can and should track flows of resources (including dollar-flow analysis); participation of women's groups, unions, and client populations in governance of services
<i>Security:</i> An individual's protection against economic shocks and personal violence.	Access protected from economic, political, & social barriers; protection for the vulnerable, including women, the young, the aged, and ethnic and sexual minorities Protection from violence and fear of violence across settings, e.g., household, community, refugee camps, from individuals or organizations opposed to unimpeded access to reproductive health services
<i>Capabilities:</i> The substantive freedoms that allow a person to lead the kind of life he or she values.	Accessible, high-quality reproductive health services are part of a multi-sectoral constellation of services that people need to lead healthy lives: adequate sanitation, safe drinking water, transportation, schools, housing, safe agricultural practices.

Our task in this paper is not to propose ways to eradicate or alleviate poverty but to suggest a model for promoting access to and quality of reproductive health services for poor, marginalized or stigmatized population groups. The model is guided by these expanded definitions of poverty.

A reproductive health services model to alleviate the burden of poverty

Because

poverty is embedded in socioeconomic relationships and structural imbalances that have endured for decades, or even centuries [UNDP. Poverty Report, 1998. Overcoming Human Poverty, pa. 18]

¹ Adapted from UNFPA. The State of World Population, 2001.

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a model for reproductive health services must cut across barriers and imbalances. To the extent that accessible, high quality reproductive health services are part of a shared vision, our goal is a model and process that gives all actors a voice. In this loosely-coupled system, actors at all levels, including the bottom level, must have a reasonably high degree of satisfaction in order for the system to function effectively. A high degree of dissatisfaction at any level, including among client populations, results in ineffective service delivery and the consequent waste of human and material resources.

By helping to reduce the adverse effect of poverty on clients' access to high quality reproductive health services, the following two steps may lead to increased satisfaction among all participants.

1) *Improve micro-macro linkages.* UNDP has identified the disconnect between macro-and micro-level activities as a barrier to the eradication of poverty. The same disconnect frequently occurs in the delivery of reproductive health services. Specifically, changes in policy and legislation that take place at the national level may fail to be implemented at the local level because they are disconnected from the every day realities of the poor and marginalized, or because the resources are not available to implement lofty goals. A similar disconnect runs the other way. Even when participatory strategies are available at the local level to give people a voice in services, the lessons learned from local experiences may not be heard by actors at the national or international levels.

2) *Implement participatory strategies.* Top-down design and implementation of policy, programs, and services often results in activities that are disconnected from or unrelated to the lives of clients or end-users [Lerner, S; Szasz I. Research and Policies on Reproductive Health and Sexuality: The Mexican Experience, pp 17-18.] These approaches are particularly useless, or even harmful, when client populations differ culturally, behaviorally, and in perceived needs from policymakers and program planners at national and regional levels. Participatory approaches demand "an active and sustained role in determining how benefits are generated and distributed." The very act of participation is a capacity-building process [UNDP. Poverty Report, 1998. Overcoming Human Poverty, pa. 19.]

Reproductive health services and client populations

Reproductive health encompasses the following services:

- maternal and child health, including prenatal care, normal and problem deliveries, and well-infant care;
- family planning, which includes assessment of need and access to contraception; distribution and delivery via peers, clinic staff, outreach, and other modalities depending upon method choice ;
- gynecology, including cervical and breast cancer screening and referral and services for older women;
- sexually-transmitted disease diagnosis and treatment;
- sexual health services including how the body works, family life programs, re-education for adults

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Ancillary services, to which clients may be referred, or which may be available on-site, include emergency food, housing, child care, services to reduce violence, legal assistance, and complementary/traditional medicine .

As shown in Table 3, the primary objectives and activities for reproductive health services include:

- Reducing unplanned and poorly timed pregnancies and the health risks associated with them
- Improving prenatal and delivery care, particularly effective management of obstetric emergencies
- Screening, testing, counseling and treatment of sexually-transmitted infections
- Increasing the number of skilled providers
- Reducing practices that increase reproductive health risks, including unsafe sex, female genital mutilation, and domestic violence
- Addressing contextual factors such as poverty, education for women and girls, and the unique needs of adolescents and men

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Table 3
Reproductive health objectives, activities, and client populations

Objectives	Activities	Client populations
1. Reduce health risks of unwanted pregnancies		
Reduce unplanned and poorly timed pregnancies	Expand family planning services through community-based workers, social marketing and health facilities	Men and women of reproductive age
Reduce the risk of unsafe abortion	Ensure safety of abortion where not against the law; provide post abortion care & family planning information and services; advocate for legalized abortion	Pregnant women, especially adolescents
2. Reduce health risks of pregnancy and delivery		
Reduce delays in recognizing and managing complications of pregnancy and delivery	Guarantee functioning Emergency Obstetrical Care facilities at the district level; Ensure prompt detection, management and referral of complications; train staff in delivery skills at all levels of health system	Pregnant women and their infants
Improve the capacity of the health system to give quality maternal-newborn care	Ensure early antenatal contact for care, counseling and birth planning; improve postpartum care particularly during first 24 hours after delivery; improve quality of perinatal care through training and supervision; stress lifesaving skills	Pregnant women and their infants
Remove barriers that keep poor women from access to maternity care	Distribute services so they are numerically adequate, not redundant, and geographically accessible to populations in need. Assure that public funds are used to finance transportation and services for the poor.	Poor women
3. Reduce the prevalence of harmful practices that undermine women's health		
Reduce high risk behaviors, especially among youth	Educate youth and adults about family planning and safe sex; provide a variety of methods accessible through a variety of channels	Men and women, particularly youth
Reduce incidence/prevalence of STDS, including HIV/AIDS	Ensure availability of services for STDs; provide appropriate laboratory equipment and drugs	Men and women of reproductive age
Reduce prevalence of FGM	Work with community groups to provide alternative rituals and employment for those who perform FGM	Target national and community leaders where performed; beneficiaries: adolescent women
Reduce violence against women or other marginalized or stigmatized groups	Improve education of men and women about laws and educate about effects of violence on women and society; support involvement of women's groups or other advocates	Target national and community leaders; beneficiaries: all women and other vulnerable, stigmatized, and marginalized populations
4. Improve status of women and marginalized, stigmatized or vulnerable groups in society		
Create an enabling environment for improvements in reproductive health	Improve education and nutrition for girls; provide credit and employment opportunities for women; improve health communications capacity; support involvement of women's groups, men and marginalized groups in reproductive health and rights	Beneficiaries: women, particularly adolescents; vulnerable, stigmatized, marginalized populations

[Adapted from World Bank, Reproductive Health at a Glance. March, 2001. Document # 23180.]

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We expanded upon the World Bank's list of target groups, which we relabeled "client populations", to include stigmatized, marginalized and vulnerable groups in addition to women and adolescents. These client groups may have the highest risk of sexually-transmitted disease, the greatest need for secondary prevention, and the worst access to maternal and child health services. They may be most exposed to social and interpersonal violence. Table 3 includes population groups whose social exclusion places them at particularly high risk of inability to access appropriate reproductive health services in a timely way. Moving beyond women and adolescents, we include all groups for whom stigma, marginalization, and societal discrimination may pose a barrier to receipt of services.

Reproductive health services available to marginalized populations

Within many countries, access to reproductive health services is limited by law, custom, religion, and/or available technology. Restrictions on access can depend upon multiple and sometimes subtle factors. Socioeconomic and geographic inequalities limit the availability of services, and will continue to do so for the foreseeable future. Some reproductive health services, such as abortion, are highly controversial. If abortion is legal, services are simple and inexpensive to provide, and, increasing the availability of legal abortion worldwide would go far to diminish the 20% of maternal deaths that are attributable to illegal abortion [cite]. But when abortion is illegal, it is frequently only urban and wealthier women who are able to obtain safe abortion services [cite]. Similarly, female genital mutilation (FGM) may be legal and customary in some settings, and yet it is highly controversial and politically charged.

Countries vary also in the extent to which marginalized populations have access to quality reproductive health services. Marginalization in India or in Afghanistan is not the same as marginalization in San Francisco. More developed or upper income countries often have a floor for service availability that does not exist in lower income countries. But, across contexts and cultures, being marginalized often equates with worse services. The extent to which this occurs is partly country-driven and partly driven by the nature of marginalization, stigma, or vulnerability. Refugees have questionable legal entitlements when they cross borders; without intervention of multilateral organizations they may have no care at all. Adolescents are often marginalized by their legal status, yet most are likely to be part of the country's majority population. Religious, legal, and cultural conflict over adolescent status and need occurs to the detriment of service availability, and even though, from a human capital perspective, adolescents may be perceived as future working adults and citizens, and thus as a valued resource. The debate over adolescents' access to reproductive health services and technologies has been exacerbated by the conflict between the diminishing age of physical maturation, due to health and nutrition, and normative and cultural changes in the age at which adolescents are considered socially mature. [AGI. Into a New World. 1998].

The situation of marginalized and stigmatized populations with regard to reproductive health care is particularly acute, not only in access to and technical quality of services but in sensitivity of the services to their client populations. A hegemonic approach that does not take account of the needs, preferences, and behaviors of end users may be met with suspicion, avoidance, and/or lack of compliance, behaviors that may result in adverse consequences for users and their networks.

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The influence of multilateral organizations on access to and quality of reproductive health services for the poor and marginalized

For half a century, multilateral organizations and international donors have defined the agenda in population and reproductive health and initiated the steps to carry out their activities (Table 3). While their record over time has been mixed, the donor agencies have become much more adept at responding to and internalizing claimant voices. The former goal of reducing world population, often at heavy social, cultural, and political costs, has been replaced by a much broader approach that situates reproductive health and access to family planning in the context of development, poverty reduction, gender equity, and other health and social goals. This process has been facilitated by the participation of non-governmental organizations and advocacy groups in international meetings, exemplified by the Programme of Action adopted as a result of the 1994 ICPD. [cite] Goals such as efficiency, equity and cultural sensitivity have been adopted by the multilaterals [Pappas G, Moss N. *Health For All in the 21st Century and WHO Renewal: a commentary. International Journal of Health Services 2001; 31(3):647-658.*], but it would be naïve to ignore the mixed motives that donor agencies have in their provision of ideas, technology and financing to lower income countries.

Nonetheless, there are notable successes like Thailand, Tunisia, and Mexico, among the multilateral “graduates,” that have the human and political resources to solve their own problems. Some middle income economies with strong state programming have moved from direct to indirect forms of aid, such as assistance with financing. In countries with very active, model HIV and sexually-transmitted disease control programs, resources can be freed for other health and social sectors.

Other countries do well on some indicators but not on others, often because of political or religious constraints. For example, in the relatively prosperous Southern Cone of Latin America, where abortion is illegal because of pressure from the Catholic Church, there are unduly high rates of maternal mortality [cite]. Multilateral support and financial resources are hypothetically available to conquer maternal mortality, but political will is absent.

The contentiousness of the abortion issue goes beyond the multi-lateral agency-receipient country interface, and affects relations among donor agencies. Nearly two decades of wrangling between the United States and the UNFPA over whether or not US contributions to the UN Agency are or aren't, will be or won't be, used to promote coercive abortions is a classic case in point [Dao J, "US may abandon support of UN population accord," NY Times, November 2, 2002, A8].

On the positive side, besides shaping the big policy picture from a macro perspective, multilaterals can have beneficial effects on reproductive health care. They cajole governments that may be reluctant to move without pressure, and can ensure or augment access to services. WHO establishes standards of care and provides protocols for prevention, diagnosis and disease management as well as laboratory and supply standards. On balance, access to and quality of reproductive health care have probably benefited from multilateral involvement.

On the negative side of the balance sheet, this is a very top down, big picture, government-to-government mode of delivering health services. Policies such as *Health For All*, and strategies to increase equity and to enforce health as a human right, go through cumbersome, often politicized bureaucratic processes before being operationalized at the country level [Pappas and Moss, 2001.] Multilaterals often have weak capacity for external feedback processes and for outside

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information to get in. While draft documents are sometimes posted on websites for external comments (e.g., World Bank), those providing feedback are more likely to be fellow professionals than affected populations. Clients are unlikely to have a meaningful voice.

Lending strategies can have adverse consequences for poor and marginalized users of health services. The World Bank's structural adjustment program, implemented initially during the mid-to-late 1980s, imposed user fees on health, schooling and social services that have had negative consequences for local populations [cite]. For example, the imposition of school fees on cash-strapped families in East Africa has been associated with the rise of the "sugar daddy phenomenon" and associated increases in sexually-transmitted infections among female adolescents [e.g., Silberschmidt M, Rasch V. Adolescent girls, illegal abortions and "sugar-daddies" in Dar es Salaam: vulnerable victims and active social agents. Soc Sci Med 2001;52:1815-1826.].

How multilevel actors can work together for reproductive health services

It is in the public interest to get clients in to services and having them remain long enough for appropriate diagnosis and treatment. But too often, services fail to meet client expectations, resulting in underutilization and a downward spiral of disappointment among both providers and users. Funds are wasted, and clients do not receive the services they need and want. Locals don't come in, or don't cooperate, or are non-compliant with recommendations. Often, clients do not understand the reason for recommended services or drugs. This dismal picture argues for client voices to be taken into account in a systematic way at all levels of the service delivery system. When funders, planners and providers of reproductive health services lack or fail to heed appropriate information from users, efforts are jeopardized at all levels.

Our objective is to encourage and facilitate the design of reproductive health services that are accessible, offer high quality care, respond to the needs of poor and marginalized clients, and meet technical standards of adequacy. This model is not only possible, but is in the material self-interest of all parties responsible for implementation. While some damage, though tragic, may be self-limiting, other services failures have widespread consequences. For example, regardless of the state of obstetric care services, only a certain percentage of pregnant women will experience a life-threatening complication. But in HIV prevention, a failure in the service system will result in an expanded epidemic.

A participatory model for reproductive health services delivery

To meet our objective, we propose a model designed to take account of the needs of actors at different system levels. To inform decision-making, we advocate for participatory strategies that supplement quantitative with qualitative methods and thus give client populations a voice in shaping services.

Participatory strategies for understanding the needs of the poor and marginalized

By strategy, we refer to specific guidelines for action that are designed to bring about a desired goal. Strategies are participatory when those affected by the action share equally in determining their direction. Drawing upon a range of theories, from Freire's conceptualization of

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empowerment and the development of critical consciousness, to constructs of social identity and social capital, participatory strategies assert that there are limits to top-down, provider-directed, health education aimed at changing individual behavior [e.g., Campbell C, MacPhail C. Peer education, gender and the development of critical consciousness: participatory HIV prevention by South African youth. *Soc Sci Med* 2002;(55):331-345.] In response, donors are calling for community-based interventions. Participatory strategies are particularly appropriate for reproductive health, where culture, gender, social roles, and sexuality have a direct influence on use of services.

Specific strategies include:

- *Participatory research*

By participatory research we mean that local participants themselves help to define the important questions relating to reproductive health and that the questions are connected to an action agenda. Participants' own experiences, culture, world views and priorities are sources of evidence AND participants play a crucial role in determining and implementing the study process. Participatory methods "enable both marginal and dominant groups to voice opinions and tell their stories." [Ulin PR, Robinson ET, Tolley EE, McNeill ET. *Qualitative Methods: a field guide for applied research in sexual and reproductive health*. Research Triangle Park:Family Health International, 2002, pa.28; pa107-109] . The key differences in participatory research from conventional methodologies is that participants have power and that they have an activist agenda.

- *A better balance between quantitative and qualitative research*

Population and clinic-based statistical information has been the gold standard in reproductive health research. But actors are turning increasingly to qualitative methods, particularly for understanding poor, marginalized and/or hidden populations, especially in face of seemingly intractable challenges, such as high-risk sexual behavior. According to the UNDP, a priority :

...is to achieve a better balance between quantitative and qualitative information. At present, analysts seem to trust only numeric data, but this paints a partial and potentially distorted picture. A fuller appreciation can only be achieved by bringing in the understanding and insights of poor people themselves—about their conditions, their needs, and their priorities—using forms of assessment that are participatory and that give voice to the aspirations of the poor. [UNDP, *Overcoming Human Poverty*, 1998, pa. 80]

In a clinic setting, this balance can be achieved by coupling statistical and epidemiologic methods which aim to present objective "facts" with narrative methods that more effectively speak for everyday experience.

- *Using new technologies*

Technologies such as the internet, fax machines, mobile phones, and digital and video cameras, while often expensive, have proliferated widely over the past 15 years, and the trend is likely to continue as long as prices fall. When available, they offer people exciting tools for making their voices heard- as long as listeners are ready to hear the words. For example, readers can access

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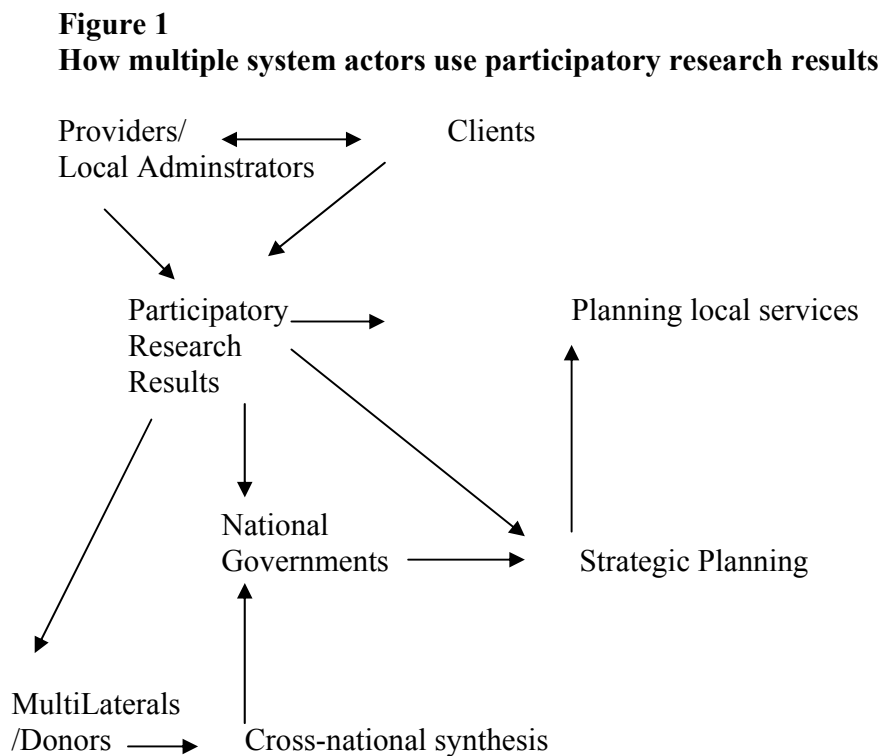
and comment on World Bank documents in draft form via the Internet. Some new technologies can be used very successfully in lower-literacy populations; other are in development. We describe one such tool, photovoice, in detail, below.

- *Encouraging transparency, especially in expenditures*

Simply issuing reports that are only available to a privileged handful of civil servants or professionals is insufficient to guarantee responsiveness to the community. In order for services to be truly accountable to a community, the way in which funding decisions are made and funds expended must be transparent to the community.

Figure 1 shows how a participatory strategy can work across multiple system levels, by building upon participatory research. Poor and marginalized clients groups in partnership with local health providers and district level health administrators generate participatory research results and use results as a basis for negotiating local service delivery.

National governments collect and synthesize national experience based on participatory research results and incorporate lessons learned into strategic planning processes. Both clients and providers participate in synthesis exercises. Multilateral organizations and donors collect national and sub-national participatory research results and synthesize into cross-national lessons learned. The synthesis is used as a basis for negotiating with national governments regarding strategic planning.



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Operationalizing a participatory model for reproductive health services delivery

Our model has 5 key features, starting at the bottom and moving towards the top in the sequence of ownership. It integrates participatory strategies at all levels:

- Recognition of the importance of gaining ownership throughout the system, including *poor and marginalized populations* where the problems services often seek to address tend to cluster; use of participatory strategies and qualitative research methods to understand the needs of the poor and marginalized;
- While improving technical capacity, development of incentives or rewards to empower *medical care providers* to act as links to and advocates for client populations; legitimacy to lobby for resources within the system in response to client needs; advocacy for solutions to client problems;
- Decentralization of decision-making accompanied by transfer of resources and accountability for public funds between *district and central offices*, to local officials;
- Strategic planning at the *national level* to improve ownership at that level and to coordinate donors inputs;
- Facilitation of national planning, capacity building and participatory strategies by *multilaterals*.

Table 4
A participatory model for reproductive health services delivery

Actors	Action at the Interface
Poor and marginalized client populations	Implement participatory strategies <ul style="list-style-type: none">- increase participatory research, especially use of qualitative methods- strengthen community participation links to governance of local health facilities'- Increase use of communication technologies
Providers	Improve technical capacity of service delivery Empower providers to act as links to and advocates for client populations in dealing with the service delivery system.
District/regional administrators	Decentralization of decision-making accompanied by decentralization of funding and requirements for transparency and accountability. Empower administrators to facilitate and respond to local participatory research results
National governments	Recipient countries use strategic planning to increase sense of ownership for programs and to provide coordinating structure for donor inputs Multilaterals and foundations fund and facilitate strategic planning capacity building. Includes funding and technical assistance for implementing participatory strategies
Multilateral agencies	

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By participatory we mean that *client populations* have a voice in determining the problem/s to be addressed, defining affected populations, identifying and analyzing data that will be used to shape services, and disseminating information to the community. Systems should be in place that enable clients to advocate for their own needs.

If clients do not have a voice in services for which they are the intended users, it is quite possible that donors, ministries and local planners will not attain the desired results. Clients may simply fail to access needed services. Those who do access services may refuse to accept care, properly adhere to prescribed treatment, or quit treatment prematurely. While multiple strategies (triangulated methods) are necessary to give full voice to clients, participatory approaches using qualitative methods offer the opportunity for clients to speak outside of a narrow, hegemonic framework developed and imposed by implementing groups with special political, administrative and technical interests.

Stakeholders such as *clinical service providers and outreach workers* can play a crucial linking role. This role needs to be legitimized by encouraging their sense of mission (many service providers are altruistic, at least initially), by giving them an active voice in policies and procedures, and by making sure that resources are sufficient for them to perform their jobs adequately and safely. Health workers have legitimacy that poor and marginalized populations often do not have. Providing a line of communication from clients through health workers to middle and top-level officials will be an empowering process, as long as the context of services is supportive and not punitive. Lynn Freedman has framed this approach from a human rights perspective:

In a human rights analysis, such stakeholder groups are not meant to be public relations arms of the hospital or a conduit for a facility to communicate its views and wishes to the community. Rather the key dynamic must be entitlement and accountability. This does not necessarily imply and adversarial sort of complaint and punishment mechanism. Ideally, by encouraging a community to feel ownership and responsibility for a facility, and by encouraging a facility to view its first line of accountability as being to the community it serves, the result will be sustained high quality, responsive, rights-sensitive services. Moreover, in the community-facility relationship that develops there is ideally a strong alliance that can effectively assert its entitlements and needs to the higher reaches of government where key decisions are made and, when services are in place, can help insure that there is knowledge, information and the means for access within the broader community. [Freedman, L. Using human rights in maternal mortality programs: from analysis to strategy" article (2001) IJGO, 75, pp 51-60].

Local service providers can use participatory strategies to learn about the needs and perceptions of client populations and serve as legitimate communicators of information about client needs to planners and policy makers at the community and district levels. They can identify client needs and expectations; elicit how services are perceived and used by clients; identify problems and achievements in service delivery; and advocate for improved services, needed resources, and client needs

Taking the voices of the poor and marginalized into account in reproductive health service delivery, will strengthen *strategic planning at the national level* to improve ownership by the recipient country and to coordinate donor agendas and inputs. While donors are almost always well-meaning, in practice, their work with in-country agencies can be inappropriate, uncoordinated or conflicting. Donors can help to develop national planning capacity, which has

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worked effectively in Bangladesh and Vietnam. Appropriate national planning and coordination can protect and reinforce a participatory strategy in reproductive health service implementation, guiding donors to the service of local needs.

Engender Health, a US-based NGO has developed COPE, client-oriented, provider-efficient services, to implement the kind of community-facility relationship that we envision. COPE “is designed to help supervisors and staff at service delivery sites to build bridges with community members...[S]taff members learn how community members feel about the services being provided, gather recommendations for improving services or enhancing service strengths, and encourage community members to participate in and take ownership of quality improvement efforts both at the site and community levels. Specific tools include interview and focus group discussion guides, participatory mapping exercises, a site walk-through guide, and tools for analyzing and prioritizing solutions to problems identified, as well as guides for orienting site staff and local leaders to the process.”
[<http://www.engenderhealth.org/news/newsreleases/020516.html>]

COPE has been successfully implemented as part of the Nepal Safer Motherhood Project, where it was used to help identify and solve entrenched problems, particularly related to infection prevention and clinical management of complications in project hospitals, and has been piloted in African settings.

International donor and regulatory organizations can develop and promote agendas that influence service accessibility and appropriateness for local populations. They do this by synthesizing global experiences, allocating investments, creating incentives, and influencing supply chains. Additional donor goals may include topics like poverty reduction, education of women and girls, reduction of violence against women, the promotion of gender equity, and capacity-building. Typically international donors work through ministries of health or through partner organizations (non-governmental organizations) with established presence and authorization to operate in-country .

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St. James Infirmary: A Participatory Clinic for Commercial Sex Workers in San Francisco

The St. James Infirmary, offers “free, confidential, nonjudgmental medical and social services for female, transgendered, and male sex workers... [It is] the first occupational safety and health clinic for sex workers anywhere run by and for sex workers.” There are an estimated 15,000 commercial sex workers in the San Francisco Bay Area, including street and survival sex workers, escorts, and people who work in massage, BDSM, adult film, as nude models, and as exotic dancers.

Typically, sex workers in the San Francisco area use a variety of venues to obtain health care, including private physicians, public health clinics, and emergency rooms. The clinic’s intake data reveal that more than half of clients do not inform their health care providers outside of St. James Infirmary about their occupation, in order to avoid receiving inappropriate or disrespectful care.

There are many factors which affect the working conditions and experiences for sex workers including the political and economic climate, poverty and homelessness, stigmatization, violence, as well as the overwhelming intricacies of the legal, public and social systems. It is the philosophy of The St. James Infirmary to build upon existing skills and strengths in order to allow individuals to determine their own goals while providing culturally competent and non-judgmental services. [<http://www.stjamesinfirmary.org>]

The program goals of St. James Infirmary promote access, collaboration, community-orientation, and comprehensiveness:

Goal 1: To increase access to primary health care and social services for sex workers in San Francisco.

Goal 2: To increase formalized communication, cooperation, coordination, and collaboration among individuals and agencies in San Francisco and the Bay Area who serve sex workers.

Goal 3: To promote community based public health initiatives on behalf of sex workers in San Francisco, which may be used as a *model for improving occupational health and safety standards and developing comprehensive medical and social services for sex workers internationally [italics ours]*. [<http://www.stjamesinfirmary.org>]

The St. James Infirmary was started by COYOTE (Call Off Your Old Tired Ethics), led by Margo St. James, an advocate and commercial sex worker, in partnership with the Exotic Dancers’ Alliance and the San Francisco Department of Public Health (SFDPH). The clinic began offering services one night a week through a memorandum of understanding with SFDPH. For the last 3 years, the clinic has operated one night and one afternoon a week, in space belong to SFDPH’s sexually-transmitted disease clinic, although it is shortly to move into its own location. Its founders consider St. James Infirmary the first occupational safety and health clinic for sex workers and operated by sex workers, anywhere. The 50-person paid and volunteer staff includes current, former, and transitioning sex workers, and the clinic director is an “exotic dancer” by profession. Nearly 700 clients have received more than 2000 units of service since June, 1999 when the clinic opened.

Unlike other health clinics that target sex workers, St. James Infirmary is not limited to treating sexually transmitted diseases which are widely considered to be the only occupational hazards for prostitutes, hustlers, strippers, and exotic dancers. “While these are certainly issues for sex workers, by no means do they represent the full spectrum of occupational hazards they face,” said Priscilla Alexander, the director of COYOTE, whose vision led to the creation of the St. James Infirmary.

Services offered by the clinic are comprehensive, including: primary medical care, STD, HIV, hepatitis B and C, and TB counseling, testing and treatment; and ancillary services such as emergency food and clothing; and referrals and information on child care, mental health, substance use, harm reduction, housing, transportation, legal problems, and financial assistance; Alternative or adjunctive medical care such as acupuncture, chiropractic care, and massage therapy, are available.. In addition, the clinic offers support groups, peer counseling, internships and job apprenticeships for sex workers who wish to leave sex work.

While few communities in the world have the financial resources and liberal political climate of San Francisco, St. James Infirmary can serve as a model and resource for reproductive health services programs serving poor and and/or marginalized populations elsewhere.

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Qualitative methods for participatory research

A problem for policymakers, demographers, researchers and service providers in reproductive health is that until recently, our data came primarily from large-scale surveys that covered multiple topics in an interviewer-administered standardized questionnaire format. While these surveys have been superb at providing comparative, valid data establishing and quantifying targets and outcomes, they have been far less successful at providing the information needed to make services responsive to client preferences and needs [Ulin et al., FHI Qual Methods.].

Using only “objective” data can lead to services that are inappropriate for or underutilized by high-need populations. Worse, the concepts and definitions that emanate from professionals (the etic approach) may not at all be those that represent the client’s perspective (emic). It is particularly important to understand the user’s perspective, and the social, economic, and cultural context, when addressing a marginalized, vulnerable, stigmatized or excluded population whose experience is likely to be vastly different from that of other actors.

The proliferation during the past 20 years of HIV/AIDS, other sexually-transmitted diseases, injection drug use, and homelessness, combined with the permeability of national borders and the displacement, voluntary or involuntary, of large numbers of people from their homelands, has drawn attention to participatory strategies and qualitative methods to understand people’s needs. Behaviors that are the most hidden are often the ones that put people’s reproductive health most at risk. For this reason, qualitative methods that depend on narrative data or participant observation have gained new legitimacy. These methods are far more likely to capture the characteristics and meaning of the political, economic, social and cultural context in which adverse behaviors occur. More specifically, they can capture how risk and need occur in the course of people’s every day lives in families and communities.

Several qualitative data collection methods are available to operationalize participatory research strategies. Focus groups, participant observation, and ethnographic interviews, are more “participatory” than “objective” methods. While some technical assistance may be required initially, in the long run, most of these methods are manageable by locals. Qualitative methods that dovetail with participatory strategies jointly serve the goals of clients and of service providers. Table 5 summarizes these methods and presents case examples of how each may be used to strengthen participatory strategies. We then single out one method, photovoice, which we use as a case example.

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Table 5
Qualitative Methods for Participatory Research

Qualitative Method	Example
<i>Observation</i> : The researcher views and records events and activities; may use key informants; varying degrees of interaction	The community is concerned that family planning outreach workers are doing little more than hand out pills. Observers accompany workers on their rounds to chart and time activities as they occur.
<i>In-depth interviews</i> : A one on one exchange between interviewer and respondent, usually informal, and guided by a few broad topics so as to allow for as much of the respondent's perspective as possible.	It emerges in a community that many women are using contraception without their husbands' knowledge. In-depth interviews lead to understanding of the extent of the barriers to continued contraceptive use among local women.
<i>Focus groups</i> : The use of group interaction to produce data and insights that would be less accessible without the interaction found in a group.	Women in the community are very interested in the female condom but have difficulties with its use. Focus groups are used to explore the attitudes and barriers women face and to allow joint solutions to emerge.
<i>Structured data collection</i> : Individuals and groups may better organize their thoughts with a concrete reference point. Techniques include freelist and pile sort; photovoice; and storytelling.	In order to understand why Latina women have healthy babies, they are given cameras and asked to take pictures of people, places and things that contribute to their health. Women discuss and elaborate on the photos in intensive interviews, leading to new insights among researchers and participants.

(Source: Ulin et al., Qualitative Methods...FHI, 2002)

Photovoice: a participatory and qualitative research method for reproductive health

A recent methodology that has great potential in public health is called "photovoice." We use photovoice as a case example of how the principles of participatory research can facilitate both discovery of the needs and perceptions of end users, as well as the negotiations between end users and their service system. Photovoice is defined as:

a process by which people can identify, represent, and enhance their community through a specific photographic technique. It entrusts cameras to the hands of people to enable them to act as recorders, and potential catalysts for change, in their own communities. It uses the immediacy of visual image to furnish evidence and to promote an effective, participatory means of sharing expertise and knowledge. [Wang C, Burris MA. Photovoice: Concept, methodology, and use for participatory needs assessment. Health Education & Behavior 1997;24(3):369-387, pa. 369]

Photovoice grows out of three sources: the Freirian approach of using visual imagery to enable people to discuss the every day political and social forces that affect their lives (critical consciousness); feminist theory which supports giving accessible yet powerful tools to stigmatized or marginalized groups; and the extensive history, tradition, and experience of photo documentation that encourages people to be their own documentarians [Wang C, Burris MA, 1997; Wang CC. Photovoice: A participatory action research strategy applied to women's health. J Women's Health 1999;8(2):185-192] [Ewald, W; Hubbard J, Shooting Back: A Photographic View of Life by Homeless Children, San Francisco: Chronicle Books, 1999; Franklin, Kristine, McGirr, Nancy: Out of the Dump: Writing and Photographs by Children of Guatemala. New York:Lothrop, Lee &Shepard, 1996.].

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Building upon a Ford Foundation-funded participatory needs assessment in Yunnan, China [ibid] Wang and Burris [1997] outline the advantages of this technique. Photovoice:

- values what people in the community think is important
- provides a powerful descriptive tool for needs assessment, fulfilling its descriptive mandate.
- presumes no special skills, abilities, or literacy, and can be used by the most vulnerable populations.
- facilitates the sampling of a full range of setting and behaviors that may not be accessible to professionals.
- can sustain community involvement in the phase between assessment and implementation, through pride and ownership.
- becomes an interactive tool within the community in the hands of participants, and can focus conversation on health or women's status
- enables participants to bring the explanations, stories, and ideas of other community members into the assessment process
- generates concrete objects (photos) to which everyone can relate, and enhances social appreciation and social ties within the community
- captures a communities strengths, capacities, and resources as well as its needs

The images produced may stimulate social action, to “reach, inform, and organize community members, enabling them to prioritize their concerns and discuss problems and solutions.” [pa. 373] Photography has also been proposed as a method to strengthen family planning research as photos add direct observational evidence that cannot be captured through other means [Donaldson P. Using photographs to strengthen family planning research. *Family Planning Perspectives* 2001;33(4):176-179.]. Even when not used to strengthen participatory processes, photos can illuminate understanding of physical settings, social and behavioral interactions, provide unobtrusive measures on activity or equipment, and other themes and patterns. Photographs can form part of triangulated strategies for data collection.

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Using Photovoice to Explore Neighborhood Effects on Teen Sexual Behavior and Drug Use

In San Francisco we are using photovoice to help us understand the role that neighborhood environment plays in young people's sexual and drug use behavior. In this case, the neighborhood is San Francisco's Mission District, which has the greatest concentration of Latinos in the City. In 2000 there were over 3000 adolescents ages 14-19 in the community; 28 percent of the community's Latino population is less than 20 years old. Area residents experience high rates of unintended pregnancy, sexually-transmitted infections, violent crime, unemployment, and gang affiliation.[Minnis A et al, 2002]

During the first year of a four year study of Latino adolescent sexual networks, the study team conducted four focus groups with Latino teens to generate a list of venues where they spend time, to understand the range of activities that take place in each of the venues, and to describe the social groups likely to be found in each venue. Participants were asked to draw maps of the community and include the places where they spend time and by what routes and mode (such as bus or walking) they move through the neighborhood. They were asked to identify the types of teens who spend time in the venues and the activities they engage in. From this process, the study team learned that teens' perceptions of their community were shaped by violence, and especially by the presence of gangs on the streets. Similar data emerged in intensive interviews.

On the basis of this qualitative work in the study's early phases we were able to obtain supplementary funding for a two year project that includes a photovoice component. Our results will enable us to develop and test community-based interventions that are shaped by neighborhood voices. We will conduct three documentary photography workshop/focus group discussions for some of the boys and girls, ages 14-19, who are participating in our study. Under the guidance of an ethnographer/photographer experienced in working with homeless and other street populations, we will teach participants about documentary photography and give them disposable cameras with which to photograph the neighborhood. To protect their safety, this will be done in small group "field trips." The photographs will serve as the basis for group discussions about the neighborhood. We will record, transcribe and analyse the focus group discussions. Finally, the participants will organize an exhibit of the photography to take place in an accessible community venue. They will receive "certificates of completion" for their workshop participation.

The photo focus group data will be used to help us develop new survey interview questions on perceptions of neighborhoods as risky or safe environments, to better understand the context of drug use and sexual behavior among neighborhood teens, and, in partnership with local adolescents and their community agencies, to develop responsive, community-based interventions.

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Conclusion: How can we put a participatory reproductive health model into action?

- Explore how participatory research priorities can be integrated at national and district levels, much as the Global Forum and the Commission on Research for Health and Education in Development (CORHED) do at the international level. Multilaterals and foundations can support bottom-up research structures whose findings can be integrated into priority-setting. Even where research resources exist at the country-level, they need to be made participatory and responsive to the needs of poor and marginalized people. In this paper we touched upon participatory strategies that best lend themselves to determining goals, methods, and services in reproductive health.
- Build on existing health planning processes to identify where and how the voices of clients can be included, in order to address reproductive health needs and priorities in gender, cultural, economic and social contexts. Foundations can assist with this goal, as they are more nimble and innovative than governmental organizations, and they have the resources to develop and test demonstration projects. US AID could add participatory strategies into its extensive operations research agenda as a “soft,” process activity. Other progressive multilateral donors could demonstrate the utility of this kind of research.
- Put resources into the development of participatory strategies, especially to produce information on client needs. In reproductive health, innovation often follows urgency. While funding has gravitated to HIV vaccine development and clinical trials, condom delivery, anti-retroviral therapies and associated problems of costs and licensing, we have been far less ingenious in reconfiguring reproductive health services to make them responsive and attractive to the populations most in need of them. Failure to incorporate client population perspectives, while extensive resources go to high-cost initiatives like vaccine trials- is a strategy that has high, although not always obvious, opportunity costs.
- Encourage the voices of actors at different levels of the reproductive health system. Empower and enfranchise clinic staff who work in closest proximity to client populations, by training them to use participatory strategies and qualitative as well as quantitative methods to discover client needs. Reinforce technical capacity while developing methods by which staff can advocate for client needs. Reevaluate data collection processes and methods, including training, so that there is a process of continual quality control and feedback to participants. Adapt existing participatory research strategies. Staff at clinic and district levels must feel that they have something to gain by enhanced commitment to participatory strategies. While this local, participatory approach does not solve large infrastructure problems, such as the availability of equipment or approved drugs, it does hold the promise of improving staff involvement, motivation and quality of care.
- Consider multiple strategies for involving poor and marginalized people in reproductive health services. One model can be adapted from Hernando De Soto’s work in Peru’s squatter settlements. In De Soto’s model, indigenous and

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marginalized people who are disenfranchised from state services create their own infrastructure [cite]. While we recognize that this approach, to the extent that it challenges the state, can be dangerous for participants, we encourage adaptations of this community-need-driven locally based, participatory strategy, once appropriate risk/benefit calculations have been performed. Ideally, as in the St. James Infirmary example, when the geopolitical context is not adversarial, a clinic creates collaborative relationships and uses public resources as needed.

- Use women's and indigenous peoples' clubs, groups and societies to inform reproductive health services, promote rights, and broaden agendas. As in the case of St. James Infirmary, groups can lobby for or create their own services. International donors, such as the Global Fund for Women and other NGOs are available to provide small seed money grants and technical assistance for fledgling organizations. Thanks to improved transportation and electronic communications, locally-based groups have opportunities to network and share resources, such as funding opportunities, or lessons-learned, that did not exist a generation ago. This approach takes "participatory" to a more democratic, less professional-dependent, level, although it may introduce other forms of dependence (technology professionals; funders).
- Use multiple channels to reinforce the participatory message. Reproductive health services planners and providers can build on oral tradition, local memory, or even gossip to encourage participation of locals [Ulin, FHI]. The channel selected should match the population needs and practices. For example, in Sri Lanka, notices are commonly posted in hospitals reminding patients and their families of their entitlements within the facility. Certainly well meant, even this overt expression can be ultimately ineffective among a low literacy sub-population. Most important, the participation message should be reinforced throughout the reproductive health delivery system, at every level, so that its importance is understood by all.
- Calculate the tradeoffs between pleasing clients and quality of care, as a mismatch is likely between client and staff priorities. Some conflict and mismatch can be resolved through polite behavior, respectful treatment, listening to patients, and staff communication with village elders and other respected community members. But proactive management is preferable to crisis management. The alienation of clients through discrimination or disdainful treatment can have adverse consequences for disease transmission, maternal mortality, and other outcomes. Likewise, an avoidable maternal death does not create an effective context for problem-solving.

Supporting a participatory approach to reproductive health

In the participatory spirit, we conclude with three voices: client, clinic staff, and multilateral:

My mother said that being poor did not define you as a person. But when you go for health care it is nothing like my mother said. Being poor and not having the money to pay for a doctor means that you get treated like less than a person, period. Anymore, I won't go in, unless what's wrong with me just becomes unbearable. [Rosa, a Latina lesbian in the US, quoted in Stevens PE.

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Marginalized women's access to health care: a feminist narrative analysis. *Adv Nurs Si* 1993;16(2):39-56,

Sex work is very solitary. Isolation keeps people out of services. Then they come in and learn they can be themselves and there is another way. It's a beautiful process. Because everyone is a sex worker here, sex work identity is not such an issue. It's not something stigmatized or focused on. It's not about your sex work. We're all self-empowered. And when you are working with individuals who are empowered for the first time, you are very successful.[Staff member, St. James Infirmary]

...The only real solution is to empower the poor. This will require increased organization and participation of all people in decision-making, and the mobilization of social energy....People's participation means more than simply sharing the benefits of development; it entails an active and sustained role in determining how those benefits are generated and distributed. Participation thus enhances the capacities of individuals or groups to influence and shape the decisions that vitally affect their lives. . [UNDP 1998. *Overcoming Human Poverty*, pa. 19]