

8

Participation in sexual and reproductive well-being and rights

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One of the most fundamental values in participatory work is that of supporting people to gain the confidence and capacity to recognise, analyse and act to change their realities. Reading through back copies of *Participatory Learning and Action*, we were struck by the continuing relevance of the editorials and lessons learnt from work on sexual and reproductive well-being and rights. If the programmes described in them continue to be developed and spread; if they actively involve those most affected and are integrated with services; and if the creation of enabling environments allows people to enjoy sexual intimacy without fear of pregnancy or disease and be supported in their reproductive and sexual choices, much would change. Much has been gained with the use of participatory approaches in sexual and reproductive well-being and rights work. But an enormous amount still needs to be done.

In this piece, we pick up a series of key issues in participation in sexual and reproductive well-being and rights, looking at lessons learnt and exploring ways in which practitioners are addressing the new challenges thrown up by the changing environment. The key issues we will focus on are:

- participatory HIV prevention and care work in a time of crisis;

- sexuality, poverty and development;
- participation, sexuality and gender; and
- whose agenda counts in participatory planning?

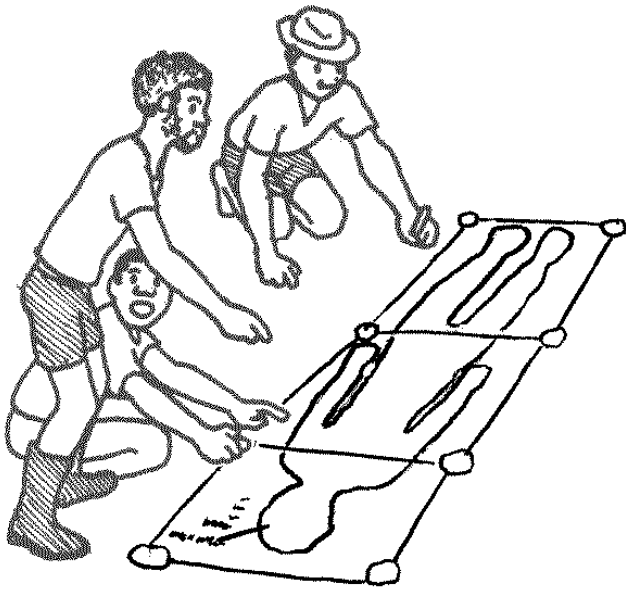
Participatory community-based HIV prevention and care work

Since *RRA Notes* 16 on health (July, 1992), *PLA Notes* 23 (June, 1995) on participatory approaches to HIV/AIDS programmes and *PLA Notes* 37 (February, 2000) on sexual and reproductive well-being were published, we have seen the scale of the HIV epidemic increase beyond our worst fears with devastating impact (see Welbourn, section 9, this issue). In some countries, this has shifted the focus from long-term sustainable development to crisis interventions. Donors, development organisations and communities are more impatient with lengthy participatory mobilisation and planning processes and want to see interventions and results rolled out to achieve maximum coverage as rapidly as possible.

In *PLA Notes* 37, Edstrom, Cristobal, de Soyza and Sellers (2000) point out that

...scaling up capacity-building and participatory processes may be more important than scaling up 'intervention packages'. It is a common mistake to assume that it is the resulting strategies which need scaling up to achieve an impact,

Illustration from cover of
PLA Notes 37: Sexual and
reproductive health



Cartoon: adapted by Paul Mincher with acknowledgement to Regina Faul-Doyle

Box 1: Schools as risky spaces

The International HIV/AIDS Alliance, Planned Parenthood Association of Zambia (PPAZ) and the Ministry of Education are working with teachers and pupils in basic schools in Zambia to analyse why schools are high-risk places for HIV transmission and unwanted pregnancy and what they can do to prevent it. The teachers are engaged in a participatory process to explore their own HIV, reproductive, gender and sexuality issues and role in sexual risk and prevention in the school. They used mapping to show risky places, drama and role-play to explore how teachers contribute to HIV transmission and pregnancy, hot-seating to understand their motivations and the Margolis wheel to find ways to address the causes. Teachers acknowledged the problem of sexual abuse and made plans to address it. They then facilitated a participatory assessment with pupils, using many of the same tools to analyse the situation with them and get their ideas on how to respond. For example, they expressed their hopes and fears about sexuality and life-skill lessons and gave suggestions on how it could be taught safely. Pupils wrote anonymous questions, stories and problem letters and put them in a box in the classroom. This produced a wealth of questions and stories, which showed high levels of sexual activity and sexual abuse and fed into the development of an initial set of lessons aimed at creating a safe environment for teaching sexuality.

when successful strategies usually derive their success from the process adopted.

Rolling out participatory community assessments in a cascade training model using a fixed set of PLA tools can easily lead to token participation and planning based on the opinions of the powerful. Vulnerable people may be pressured to speak courageously in public about contested issues and left to face the consequences without follow-up support.

What's needed is an approach in which insiders and outsiders share their different knowledge, with the outsider bringing to the table new ideas and perspectives from other sites and cultures. Participation then becomes working with local people to select interventions known to work and creatively find the best approach to implementing them. Part of this is understanding better how particular environments – schools are one example, see Box 1 – might be seen as risky spaces, and working with people to explore ways to reduce risk that take account of the complexity of factors that only those who know these spaces well are able to identify.

Poverty, sexual and reproductive health and development

The Primary Health Care Declaration of Alma Ata in 1978 named structural, economic and political inequalities as determinants of poverty and health status. Poverty and inequality have deepened since 1995 in most African countries. But poverty limits the impact of interventions that

ignore the very real effects that a lack of economic and personal power might have on women's and men's abilities to exercise control over their lives. All too often interventions proposed by communities to address poverty are ignored by agencies working on sexual and reproductive health.

Even where communities call for sexual and reproductive health (SRH) interventions, poverty continues to be a major barrier to access. In the Eastern province of Zambia, for example, communities demand condoms, sex education, voluntary counselling and HIV testing (VCT) and sexually transmitted infection (STI) treatment as key interventions. But free condoms are often not available and rural farming communities do not have the cash to buy them every time they have sex. The health services are severely weakened by structural adjustment policies. The community workers and peer educators who are trained to teach skills-based safer sex, distribute condoms and refer to health services do not have the bicycles and incentives to reach the remote villages in their districts. They are poor and need money to pay others to weed their maize.

Poverty affects opportunities for using participatory approaches, which require long-term adequate levels of funding for community-level work. The most vulnerable people need some material assistance to attend PLA sessions or skills-based learning activities or they stay away to survive. Young people are at risk of HIV because of their poverty. Many have to consider using their sexual assets to meet their

Box 2: Responding to poverty

In 1998 Care Zambia conducted a participatory study with young people in peri-urban Lusaka to explore issues around their sexual and reproductive health and generate a community response, which was reported in *PLA Notes 37*. The range of participatory methods used, and the richness of the learning they generated inspired others working with young people. Local adults reading the report were shocked at, for instance, the extent to which girls bartered their bodies to meet their most basic needs. Young people were trained to counsel and sell condoms to their peers. In a participatory evaluation, some years later, peer counsellors reported on their distress when poorer young people did not have cash to buy condoms and they were obliged to send them away empty-handed, or when they could not afford effective STI treatment. The evaluation resulted in peer educators exploring the nature of commercial sexual activity in the compounds and condom and STI treatment accessibility further, and developing proposals to continue the project further in their own compounds. (Source: Flyer on Participatory Ethnographic Evaluation and Research (PEER), Options and CDS, Swansea.)

most basic needs. Jill Lewis, whose contribution to *PLA Notes 37* showed an inspiring example of work with young people that is sensitive to issues of identity and difference, argues,

The limitations of the living conditions of people inhibit ongoing, sustained outreach. I dream of work that, with blocks of five years' funding, resources the local trained people to initiate and mount in turn their direct work with people...

Barriers to addressing poverty effectively include:

- funding focused on short-term HIV interventions;
- lack of expertise in economic intervention and credit;
- difficulties in achieving multi-sector collaboration;
- small projects that generate too little income to make a difference; and
- no linking up of local issues to advocacy for national and global level changes.

As well as action at a local level, those involved in sexual and reproductive well-being need to ally with movements for social and economic justice. They need to advocate for action at the national and macro level to release the wealth needed by poor people to be capable of meeting their basic needs and planning their own action to manage their sexual lives safely.

Participation, sexuality and gender

Globalisation and the commoditisation of sexuality in advertising and media have contributed to a culture which pressures young people to achieve the norm of attractiveness through buying clothes, shoes, cosmetics, mobile phones and the like: 'I shop, therefore I am'. Sexual activity has come to

Box 3: Mapping bodies

Body maps, described in *PLA Notes 16*, have been used in a wide range of creative ways by people working in sexual and reproductive health to explore bodily processes, risks and pleasures. Annie George (personal communication) used them with women in Bombay to open up discussions about sex and sexuality. Kim Batchelor describes in *PLA Notes 37* how HIV prevention workers at a workshop in Dallas and New Mexico mapped erogenous zones, organs associated with the birth process, and those affected by sexually transmitted infections (STIs), and used them to discuss the effects of body image on vulnerability to STIs. In a powerful example of how body maps can be used to enable people to reclaim their own knowledge about their bodies, Jonathan Morgan worked with South African HIV positive women using body maps to explore and share their experiences of using anti-retrovirals (see http://web.uct.ac.za/depts/cssr/body_maps.html). Ann Sturley (2000) shares her experiences of using body mapping with men to explore their anxieties about vasectomy, in *PLA Notes 37*.

be de-linked from relationships, caring and compassion. In rich countries, this contributes to low self-esteem and self-harming behaviour. In poor countries, some have sex to acquire the material goods that identify them as attractive, modern and successful. Take, for example, the advertisements for a hair product that are to be seen in rural districts in various African countries. They show an African woman with straight shiny hair, and the slogan is along the lines of 'be yourself'.

Think, though, of the other ways this slogan could be used to give young women (and men) a stronger sense of their potential and capacities. 'Be yourself' is a good way of thinking about what empowering sexual and reproductive well-being and rights work can do. Rather than tell people what they ought to do – whether encouraging them to do what others do and follow norms, or set themselves apart from the crowd by doing things that others don't do – 'be yourself' could be about enabling people to become more fully the person they are. It is about the freedom to be, the freedom to have the kind of relationships that bring happiness and the kind of sex that brings pleasure.

Working with participation in addressing sexuality and gender is not the same as participation in work with natural resources or water supplies and the like. Sexuality and gender are intimate, private and emotionally loaded. They link into deeply held beliefs and feelings. For many societies, talking about sexuality is restricted to very specific and private situations and going outside these boundaries willy-nilly can lead to harm in ways that outsiders may be unable to anticipate. Public participation in discussions on intimate aspects of sexu-

ality may be dangerous for participants and the facilitator if it is not carefully planned with the groups concerned and safe ways found to talk.

Sexuality, gender and HIV affect all of us very directly in a way that other areas of life may not. Our values around these areas are very strongly held and that makes it difficult to listen and respond in a respectful and enabling way. Time, trust and caring are needed for continuing conversations in which people's stories and discourses change over time as they feel able to speak about their reality. Processes which do not rely too much on diagramming and public groups are needed. Participatory narrative and performing arts activities may be more helpful for reflection than linear diagramming tools which may bring out stereotypes and norms. A small group relaxed conversation with a facilitator who is committed to helping people reflect and find ways to protect themselves from HIV might create a more intimate space for sharing than the use of diagramming tools. These can serve to open up tricky issues but can result in the tyranny of consensus, leaving little space for individuals to express their difference and explore their own personal feelings.

Discussions of sexuality in public groups often generate normative pictures rather than the reality and complexity of desire, sexual preference, relationships and practice. Some things are unmentionable and deeply stigmatised. This means that there is a limit to the value of democracy and consensus in community discussions even if groups are carefully set up for safety. Men who are attracted to other men, for example, will keep quiet when homosexuality is vilified in a group of men. In such settings, the facilitator has a key role in enabling people to get through layers of normative assumptions that we may not ever question or challenge, to reflect and begin to challenge each other, 'peeling the onion' until they reach a more nuanced, complex and authentic picture of how sexuality and gender influence sexual safety. He or she needs to provide new knowledge, challenge harmful beliefs and talk about what has been done elsewhere and succeeded.

What we're taught to think about sexuality and gender and what we hear from society, the church, our parents, the media and popular culture, create a set of stereotypes and norms. If we're asked what a 'typical man' thinks or does, it is easy enough to find a stereotype to fit. But when we're asked about the men in our own lives and whether they fit that picture, we soon realise that it doesn't really capture our own experience. Information provided by trainers or found in guides on participatory approaches to gender and sexuality may offer information which limits the discussion to stereotypes or known categories outside the stereotype,

Box 4: Innovative methods to explore sexuality

Participatory tools are often used to explore the reasons why people don't use condoms. Groups of men often agree that condoms feel cold, sex is less enjoyable, women want to feel their ejaculation and so on. Many of these men have not personally used a condom, they are expressing group norms. In such a discussion with men in Rwanda, Jill Lewis asked 'Has anyone ever spoken with you about how condoms enhanced their sexual pleasure?' The men were amazed at this idea and engaged in quite a different way about the possibility of using condoms (personal communication). In Porto Alegre in Brazil, de Nazareth, Hassen and colleagues worked with groups of young women to find out what kind of information they thought would be most interesting and useful to their peers, and the medium that they thought would make it most appealing and accessible. One group produced a photo novella, which they scripted and featured in themselves, another created a rap song, others still chose other ways of communicating that had a better chance of reaching people than conventional leaflets or posters (Hassen, 2002).

Box 5: The importance of sexual pleasure

Participatory work with rural communities and in schools in Zambia shows that women and girls are interested in sexual pleasure and able to ask for it in their own ways. Local puberty teachers traditionally teach girls how to masturbate in rural Zambia. Girls go to 'blue movies' as much as boys and five middle-aged women laughed that they had all reached orgasm through just watching a blue movie. Safer sex erotic movies could do more than all the leaflets being distributed. Many men and women are keen to talk about how to be a good lover and how to satisfy their partners. The right to pleasure and the opening up of new possibilities for pleasure with freedom to experiment are important areas for participation.

Men and women teachers in Zambia thought about all the questions that they had always wanted to ask the opposite sex about sexuality. They exchanged questions and discussed their answers alone and then formed a 'fishbowl' (see Tips for Trainers). Women sat in the middle and answered the men's questions whilst the men sat around the outside and listened to the answers without speaking and visa-versa. This method combined with body-mapping resulted in detailed talk about sexual pleasure and intimacy and raised issues for further exploration. In an evaluation six months later, people reported a more enjoyable and safer sexual life; one participant reported on 'embarking on a new life of pleasure with my wife – I am now able to satisfy her, which I never did before'.

Spirits lift when pleasure, intimacy and love are part of the discussion of sexual safety and people become really engaged at an effective level.

rather than giving us a sense of the complexity of gender and sexuality. For example, the widespread messages that men in Africa are promiscuous, rough and indifferent to female pleasure, and that women are submissive victims and do not expect pleasure, drives the epidemic and are as disempowering and didactic as any lecture. Also, these messages are

A health worker demonstrates how to use a condom for a small crowd of men on a village road in India



Photo: © 2001 Nrityanjali Academy. Courtesy of Photoshare

based on possibly racist, feminist, elitist assumptions that blame and deny people their complexity, diversity and humanity. Women don't always want to be assertive, and men can feel very vulnerable.

Gender inequality does result in norms that give men power over women's sexuality and entitle them to satisfy their sexual desires at whatever cost to women, who are expected to be submissive. These norms make both men and women vulnerable to sexual ill-being and they need to be addressed. But this should not be the only discourse. Imagine a sex-positive culture with sexual intimacy and satisfaction seen as essential to the well-being of men and women. This culture can be seen in group discussions in Zambia and Ghana when men and women feel comfortable to talk outside – often Christian – norms, about their search for sexual pleasure with a partner or alone. Participatory workshops on how to be a better lover have a very different ring to them than those teaching people how to prevent disease – but may serve the purpose just as well, if not better. Using techniques such as body mapping to explore turn-ons and turn-offs – as Lucy Shillingji taught us some years ago – and to allow women and men to learn about their own, and others', erogenous zones

and about forms of pleasuring that they may never have tried. This is an approach to the epidemic that places intimacy, pleasure and respect for the rights and needs of sexual partners at the heart of HIV prevention at the same time as respecting women's and men's right to pleasure – rather than treating them as the owners of bodies that must be better controlled.

Whose agenda counts?

All community mobilisation and participatory planning involves sharing of ideas and negotiation between different groups. The group initiating the planning process might be an insider group of activists or an outside organisation or a mixture of both. Whoever initiates the process will have an agenda and boundaries in mind, based on needs, resources and values. The agenda might be focused as in preparing the community for the introduction of a new STI treatment package or a broader package of interventions as described above. At times, the mobilisation and participation is similar to social marketing research, where the organisation wishes to understand people's knowledge, attitudes and practices around an intervention in order to make a persuasive marketing campaign.

All those initiating and facilitating community-based planning will place boundaries on which interventions favoured by community members are acceptable, partly related to their values. Many outsiders would not accept the two community strategies outlined below. Many older people in communities favour the use of disciplinary measures to promote good behaviour in young people. A chief in Ghana, for example, explained how when she realised that her daughter had a boyfriend, she sent her to the teacher to be beaten severely. The girl stopped her relationship and is now nearly qualified to be a teacher and the chief was proud of her successful action. She goes around the village at dusk with a stick to chastise boys and girls who are out and about. In Zambia, some elders think it best that boys and girls who can't control their sexual feelings in their early teens marry in order to stop AIDS, as they are too small to fit condoms. But then, how many donors and governments are willing to supply smaller condoms?

The rights of transgendered people to live their lives without discrimination, molestation or sexual violence may never appear on a PRA 'community action plan', nor is it likely to find communities calling for measures that enable sex workers to have safer working conditions or that give adolescents better access to condoms. Work in sexual and reproductive rights makes a powerful case for the importance of a rights basis to participatory work if it is to address the vulnerability of particular groups. Simply 'asking the community' what they would like is not enough, and may be positively harmful.

Donor funding for sexual and reproductive health is increasingly subject to conditionalities related to agendas which resonate with those of conservative leaders in some countries, with an impact that extends even to the most progressive of governments. The US President's Emergency Plan for AIDS Relief (PEPFAR), for example, has earmarked one third of prevention funding for 'abstinence only' programmes, and is heavily promoting fidelity in marriage and reserving condoms for 'high risk' groups such as those involved in the buying and selling of sex. Delaying the start of sexual activity and reducing numbers of sexual partners have both been important in reducing HIV transmission in Africa, but in the context of choices which include condoms. The PEPFAR position makes it easier for leaders and local people who disapprove of young people being sexually active to deny them information and access to condoms, and increasingly difficult for those who believe in choice to enable this to happen.

To apply such an approach in countries with an HIV prevalence of 20-35% in which most sexual encounters are risky

Box 5: Realising rights and ensuring justice...

A key aspect of rights-based work is ensuring that people have access to information about their rights. In Zambia, PPAZ and the Alliance are holding workshops with policy-makers, government and traditional service providers, community and religious leaders, civil society organisations and young people to discuss existing policies and rights, assess their implementation and barriers to this, identify channels of communication and make an action plan to promote their implementation. Useful tools included a values clarification on contentious issues where people are asked to agree or disagree with statements related to the rights and then explain to each other their points of view. This is an opportunity to share knowledge and values and resulted in change in the participants, for example of whether young people should have information on and access to condoms. Participants who thought that young people were being 'spoilt' by rights education were challenged by the young people present through a drama showing the consequences of denying them their rights, for example to bodily integrity and life-saving information.

Another key dimension goes beyond enhancing access to justice to ensuring the accountability of judicial systems – especially to poor women. Ann Sutherland and Felicia Sakala (2002), working with the YWCA of Zambia, used participatory diagramming tools with women to explore their experience of gender violence. The diagrams were so powerful that they moved the women to develop a strategy for enabling women to have better access to justice, and to be treated more fairly by the courts. Women pressing for their rights to be respected by the law were supported in the courts by a large group of fellow women, who sat to observe the conduct of the judge and monitor the proceedings to ensure justice was done.

– let alone in northern countries, with their problems of high rates of teenage pregnancy, soaring adolescent STIs and insistently rising HIV rates – is highly problematic. There is no evidence that abstinence only programmes have an effect on sexual debut or its consequences, one way or the other (Kirby, 2002:6). And evidence shows that sexuality education, including information on contraception and safe sex, does not result in earlier sexual activity and when people do become sexually active, they are more likely to use protection (Grunseit *et al.*, 1997).

It is distressing to talk with young people in Africa who are aware of the risks and try hard to abstain, but don't succeed. It is just as distressing to talk to those who would rather be able to use condoms than have unprotected and risky sex, but simply cannot afford to buy them. Abstinence promotion doesn't take into account the reality of sexual desire, the need for young people to learn about safe sex for future activity or the widespread exchange of sex for basic needs. The impact of such programmes on provision for those who do have sex makes them more problematic still. National leaders are denouncing condoms and fidelity is promoted as

A community in Kapata, Zambia identifies the HIV-affected households – those with widows, orphans, or chronically ill patients



Photo: © 2002 Elizabeth Serlemitsos/CCP, Courtesy of Photoshare

safe, in countries where sexual culture, sexualised media and relational norms show the frequency of sexual circulation – with serial monogamy, multiple and parallel partners, high divorce rates, and a not insignificant number of men buying sex. Condoms are being re-stigmatised, supplies are being cut and advocacy to make them widely available in large numbers is facing challenges of a different order.

Rights-based approaches: new directions, new possibilities?

Despite the retrogressive moves that threaten much that has been gained in the last decade or so, the last decade has seen an explosion of interest in human rights and in what is being called a 'rights-based approach' to development (Nyamu-Musembi and Cornwall, forthcoming). Many countries have signed up to CEDAW (Convention to Eliminate All Forms of Discrimination Against Women) and CRC (Convention on the Rights of the Child), which provide the basis for rights to full and comprehensive information about sexuality and reproduction, and to reproductive and sexual health services, freedom from punishment and abuse, early marriage etc. These documents have been drafted and promoted by outside donors and signed by urban elites. More work is needed to educate the people who might make the most

use of them on their content and benefits, promote their implementation and demand that they be upheld.

For some, a rights-based approach goes beyond currently existing legal rights to embrace a way of doing development that focuses on enabling people to recognise and claim their entitlements, including from those closest to them – not just from the state (Petchesky, 1998; Cornwall and Welbourn, 2002). By reframing the way in which we think of participatory work on issues like sexuality and having children, rights-based approaches make us think about the importance of enabling everyone to enjoy the right to make their own sexual and reproductive choices, the right to safe and satisfying sexual relationships and the right to choose when and whether to have children. Rights-based work also has an important role to play in enabling people to have different relationships with providers and with the judiciary, regarding them less as those who give favours than those who are obliged to respect, protect and fulfil everyone's human rights.

As the examples in Box 5 illustrate, participatory methods can be used to explore people's perceptions of the rights they have, to help people to gain greater awareness of the rights they might claim – turning a sense of unfairness into a more active sense of entitlement, and from there into a demand for rights – and to enable people to organise collectively to demand

what is rightfully theirs. The challenge for those working with participation in SRH in the future is to use these new applications of participatory methodologies to bring about the transformations in practice that can really begin to enable women and men to realise their sexual and reproductive rights.

Conclusions

Used with sensitivity and with the appropriate follow-through and support to break the silence on issues of sexuality and pleasure, to build solidarity through shared experience or to devise locally owned and appropriate strategies to realise sexual and reproductive rights and well-being, participatory

approaches are a powerful weapon in the struggle for rights. As in other areas of development work, participatory methods can easily become a quick fix and be used to generate a shopping list of solutions or rubber stamp already-intended projects. The tokenistic use of participatory processes can end up reinforcing existing power structures and shoring up the very values and norms that put women's and men's well-being – and, in some contexts, their very lives – in jeopardy. And in something as personal and highly charged as sexuality and reproduction, great care is needed to use these approaches with respect and feeling. But when used sensitively and well, these approaches really can make a life-affirming difference.

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