UNRISD Research and Policy Brief 8

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Community Responses to HIV and AIDS

The poorest households and their extended families are assuming often overwhelming burdens in response to AIDS, with the support of community organizations. Research findings suggest that connections across communities that enable people to survive and cope urgently need "vertical" links to national and global resources to sustain and transform lives.

The Issue

Every day, according to UN figures, nearly 7,500 people become infected with HIV and 5,500 people die from AIDS. The persistent nature of the epidemic and its increasing incidence in less powerful, more economically marginalized communities signals the need to review past policies and practices. It also draws attention to the fact that the epidemic feeds on and mirrors global inequities. Not surprisingly, the greatest share of HIV infection is concentrated in eastern and southern Africa, where levels of household and gendered poverty are among the highest in the world. Yet in these regions, 90 per cent of the care of people living with HIV and ill with AIDS takes place within households, according to the Joint United Nations Programme on HIV/AIDS. And it is the women in these beleaguered households who shoulder 75 per cent of that care.

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Available evidence in developing countries suggests that the care and consumption burdens of AIDS have largely been met by individuals, households and extended families. It also suggests that networking, collective action, trust and solidarity within communities play a positive role in reducing risk and dealing with impacts of AIDS. But how far is risk prevention reliant on individuals' limited resources and power to act, while risk environments are left unchanged? How much of the impact of AIDS can be absorbed by households and extended families, with limited support from public and private institutions or from public health systems? And where are the examples of wider social responses that challenge the conditions that increase risk and support household recovery? These are among the questions explored in this research project, which

UNRISD Research on Community Responses to HIV and AIDS

Although the AIDS epidemic has been examined from many angles, there is still a paucity of data on how communities themselves are responding to it. The UNRISD project, *Community Responses to HIV/AIDS*, initiated in 2004, commissioned researchers from eight sites across the globe to document what communities—individuals, extended families, households and wider social groupings—are doing about HIV and AIDS, how they are interacting with state and non-state institutions, and the opportunities for—or barriers to—more supportive community environments. This *Research and Policy Brief* summarizes the project findings as they were published the British journal *AIDS Care: Psychological and socio-medical aspects of AIDS/HIV* (Vol. 19, Supplement 1, 2007). The journal issue comprises eight articles, plus introductory and concluding comments by guest editor Rene Loewenson (see UNRISD Sources and Further Reading, below). The research was coordinated by the Training and Research Support Centre (TARSC), a non-profit organization that mentors and carries out research internationally on health and social policy issues. The Royal Ministry of Foreign Affairs of Norway and the United Nations Foundation funded the project.

sought answers in communities in Africa, Asia, the Caribbean and Latin America.

Research Findings

Brazil

- Though the overall number of AIDS cases in Brazil is declining, and a strengthened public health system has made antiretroviral treatment widely available, the "feminization" of the epidemic is alarming, with women in impoverished communities at particular risk. The UNRISD study, which surveyed women aged 15 to 24 in an urban slum of Belo Horizonte, found that information and access to social services are not enough to ensure safer sex practices. Rather, reduced susceptibility to HIV appears to be linked to a woman's autonomy (particularly as it relates to her sexuality, mobility and freedom from the threat of domestic violence) and the kind of relationship she establishes with her partner. While young women are frequently the targets of sexual and reproductive health programmes, they are more likely to access such services, including HIV testing, *after* they become pregnant. Moreover, the few programmes geared toward the empowerment of young women through vocational training tend to reinforce traditional gender roles and do not significantly increase their economic options. The study concludes that HIV prevention hinges on providing young women with wider economic opportunities, getting them into health clinics before they become pregnant, and attracting more men into sexual and reproductive health programmes, especially those that address the issue of domestic violence.

Congo

- In the poor, semi-rural town of Ewo in the Congo, the study found that young men and women engaged in economic activities were less at risk of HIV than those who were not, even in the context of economic and political instability. The most important contributing factors were the revenue earned, the financial and social autonomy it brings (especially important in the case of young women), the training and skills acquired, and the time spent in a productive activity. The study suggests that organized strategies for economic activity require careful preparation in terms of their objectives, activities, incentive systems, training, monitoring and evaluation. They also need to take into account the activities that young people are already carrying out on their own and factors in the local environment that drive the epidemic.

Kenya

- In five informal settlements in Nairobi, Kenya, the study examined the challenges faced by women living with HIV, the support they receive and their perceptions of the future. Predictably, the findings revealed that extreme poverty and abysmal living conditions increased the risks of HIV, along with the chances of acquiring opportunistic infections. Moreover, insecurity tended to curtail income generation and increased the risk of rape and other forms of sexual violence. The coping strategies that women adopted centred around survival and included commercial sex work and the sale of illicit liquor, further increasing their chances of exposure to HIV.

  Numerous non-governmental organizations, including the Kenya Network of Women with AIDS (KENWA), as well as community and faith-based groups provided a range of vital HIV–related services that, paradoxically, were not found in more established residential areas. The sustainability of such services, however, is highly questionable, due to the lack of local resources, weak state support and high dependency on donors. In addition to the upgrading of these informal settlements, the study recommended that comprehensive, sustainable AIDS services be complemented by social networks and community sensitization against stigma and discrimination.

India

- A study of two low-caste labouring communities in India—one in a modernized urban setting, the other in a rural area of a poorly developed state—found that social cohesion was a key factor in good health. The best conditions for a healthy life were found in the less poor rural group, which was characterized by a well-rooted community, collective political power, economic support for migrants and improved working conditions. While higher economic status was associated with better health, this relationship was stronger when combined with improved working conditions, social cohesion at the family and community levels, and political power. Traditional forms of social cohesion are under stress, however, and new forms, more heavily influenced by commercial relations, are proving inadequate to meet household shocks, such as the death of an adult family member. Moreover, neither traditional nor new social norms necessarily protect women. This suggests that social cohesion, without an equitable distribution of power and notions of individual dignity, may maintain oppressive norms and authority over the relatively powerless in the family, community or society.

Thailand

- In Thailand, antiretroviral therapy has altered the complexion of AIDS management. In 2005, the drugs were included as part of a subsidized health scheme and provision became widespread. Access has increased even

further through the legal and political advocacy of the Thai Network for People Living with HIV/AIDS, known as TNP+. Rather than retreating to the dark corners of society, HIV–positive volunteers help the state deliver comprehensive services and assist with follow-up and adherence programmes. As they take on new responsibilities, TNP+ and other similar networks are becoming part of a new social movement that is increasingly prominent in Thai society—shifting the spotlight from those who are stigmatized to the sources of stigma and to the claims and entitlements of those who are infected. These networks are also seeking to broaden access to marginalized groups, including ethnic minorities without full Thai citizenship, who so far have been excluded from services. The study found that as part of this larger advocacy profile, these groups are tackling wider social issues such as national identity and belonging.

Sub-Saharan Africa

- A review of the literature on informal social security systems in sub-Saharan Africa found that extended families, together with communities, are by far the most effective sources of support for people affected by HIV and AIDS, though they remain largely under the radar of governments, non-governmental organizations and international donors. These community safety nets, ranging from burial societies to rotating savings and credit associations to faith-based and community initiatives for vulnerable children, have a number of distinct advantages. They reach households in greatest need, respond rapidly to crisis, are cost-efficient, are based on local needs and available resources, draw from the specialized knowledge of community members, and provide financial and psycho-social support. Their main limitations are a lack of material resources, patchy coverage and reliance on the unpaid labour of already overworked women. Though more systematic evaluation is needed, the study suggests that external support could be productively used to strengthen such safety nets and reach the poorest households.

Uganda

- A study of rural farming communities in Uganda found that female-headed households were more vulnerable to the impact of AIDS than those headed by males, particularly in terms of sustaining livelihoods. Women's opportunities for remarriage were lower than men's, they faced greater risk of losing control over land and livestock, and they accessed less state and private sector support. Moreover, women were more dependent on welfare and credit from non-governmental organizations. Though women were found to play a key role in social networks and resources at the community level, they themselves received little support from many formal community networks and services.

Haiti

- Since the early 1980s, the AIDS epidemic has ravaged the poorest communities in Haiti, which lack even the most rudimentary health care. This study examined the contribution of Partners In Health, a Harvard-affiliated NGO, to the scaling up of HIV prevention and treatment activities and to ongoing efforts to improve primary health-care services. The organization has recruited, trained and supervised a large cadre of community health workers to supervise antiretroviral therapy, identify new AIDS cases and reach out to marginalized populations. The study found that most patients at risk were properly identified, that community health workers facilitated the uptake of service, and that the training they received helped to enhance their own self-image.

Lessons and Implications for Policy

The studies undertaken for this UNRISD project highlight the daunting demands that AIDS places on networks of support across communities, as well as the innovations within those networks. They also underline how worsening economic conditions, policy decisions that cut funding of public health systems and the epidemic itself have all threatened provision of the core public services that are required to support community responses to HIV and AIDS. In the context of extreme global inequalities in wealth, community networks are in danger of becoming conduits for the "horizontal" sharing of poverty unless explicit, systematic and sustained "vertical" connections are made to state and private sector institutions, public authorities, and national and global resources.

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There are new opportunities for such vertical connections, through global public-private partnership and funds, such as the Global Fund to Fight AIDS, Tuberculosis and Malaria, which can bring significant resources into countries to support responses to AIDS. Where health systems have been weakened by decades of cutbacks in public social service provision and underfunding, the reach of these resources often

extends beyond the state, filtering directly into communities through networks of international agencies, faith-based and non-governmental organizations.

There can be no doubt that increased resources, and innovative institutional arrangements, are urgently needed. Yet by their sheer magnitude, such public-private partnerships can have system-wide effects. They may exert pressures to perform in the short term, possibly at the expense of development of longer term institutions and capacities, or create parallel institutional arrangements that challenge the position of public authorities in relation to national initiatives on health. Yet the sustainable success of such public-private partnerships will depend on the effectiveness of the entire health system.

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Networks of civil society groups are now organized globally and offer themselves as the voices of communities within global policy forums. If the first wave of the global response to AIDS built awareness and emergency provision of prevention, treatment and care, there is now need for a second wave that provides strong measures to connect communities to wider resources of support. Elements of this second wave include people's—especially women's and young people's—access to services to know their individual risk, measures to enhance their autonomy and substantial investments to increase their opportunities for decent work. Specific lessons from the studies follow.

Breaking the cycle of insecurity and risk

- While information and awareness of HIV and AIDS are now generally high, there is still poor access to services that enable people to know their own risk. For AIDS awareness to translate into a perception of individual risk, people need access to services that provide counselling and HIV testing. These services are now more widely available, but there are still gaps in coverage and access for those who need them most. Perception of risk is also no guarantee that people will protect themselves. Power imbalances related to gender, wealth and social status influence the control people have over their lives and sexual relationships, and their ability to make and carry out decisions. Many of the studies show, for example, that sexual and physical violence against women in the context of poverty, informal settlements and political instability undermines their autonomy at a profound level. In contrast, open dialogue between individuals and their parents or partners and shared decision making were found to have a positive impact on autonomy, particularly among young people. Access to training, employment and opportunities for decent work were also shown to increase people's self-reliance and ability to protect themselves.

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- Short-term projects and simplistic solutions, especially those aimed purely at awareness, are not enough to reduce the rate of HIV infection. The experience in Ewo, Congo, for example, suggests that interventions that seek to deal with more structural determinants of risk, such as unemployment, especially in conditions of economic or social instability, need to be carefully planned to provide both immediate and longer term incentives. The study suggests that sustained support channelled through local institutions is preferable to short-term bursts of assistance, even if they are larger in scale. The study in sub-Saharan Africa makes the case for integrating external resources within existing networks of community support in caring for orphans, though the experience in Uganda showed that these networks can have their own internal biases. In such cases, non-governmental organizations can fill gaps in support to the most vulnerable households if their presence is sustained.

- Structural determinants of risk need to be addressed if the spread of HIV is to be curtailed over the long term. Poverty and inequality create the conditions for the spread of the epidemic, and the ill health and mortality that result from it increase household poverty. This two-way relationship can predictably worsen until the vicious cycle is broken. A number of options were proposed to break that cycle, including measures to increase access to services, to promote shared decision making between partners, to foster open dialogue in schools, and to promote freedom from threats and violence in society. In all of the studies, there is a common proposal for measures that massively increase investment in decent work.

Building networks of support in response to vulnerability

- Whether it involves caring for orphans in sub-Saharan Africa, managing the consequences of infection in informal settlements in Kenya, or dealing with adult illness in India, households and their extended family connections carry out most of the response to the impacts of AIDS. Household coping mechanisms include the sale

of assets, such as land and cattle, eating into savings and borrowing from various sources, including neighbours. These are complemented by support systems at the community level that may themselves be challenged by household and community poverty. Community-based organizations and faith-based groups and associations are often sources of treatment and care, credit and welfare support, including for school fees, food security and other longer term needs. In Uganda it was noted that women appear more able than men to tap into such sources of non-governmental support. It was also found that women tend to direct those resources to the immediate needs of the family and children's welfare, to a higher degree than their male counterparts.

This finding highlights the valuable role played by women in response to AIDS, and the need to recognize their role through economic or institutional innovation and resources. The organization of women in the slums of Nairobi through KENWA is an example of how women can bring treatment resources into groups who would otherwise be among the least likely to receive them.

- These horizontal forms of community response provide not only material support but also forms of social solidarity that counteract the anger and isolation caused by stigma. The contribution, however, comes at a cost. The tradeoffs made within households and the extra work borne by women are one such cost. The voluntary work that people, often poor women, assume in community organizations takes them away from their own homes and draws heavily from personal resources. The studies also suggest that the withdrawal or weakening of the state has left communities disadvantaged and, conversely, that strong public and community institutions are critical for an equitable response.

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Supporting community responses to HIV and AIDS

- The studies highlight the institutions and resources that increase community power in responding to AIDS. They suggest that associational networks such as savings clubs, community-based organizations, religious and faith-based groups can play a valuable role in enhancing solidarity within communities and are critical to household coping. Some of these institutions have gone beyond coping to transform lives, or are making vertical connections that aid in the redistribution of resources and burdens. The social movement of people living with HIV and AIDS in Thailand and KENWA are examples of such groups, whose ability to change social dialogue and shift mindsets has reached and resonated at the global level.

- Governments have a crucial role to play, in terms of measures that households cannot or will not secure individually. These include policy and legal frameworks; public information; subsidies on public health measures, such as prevention, counselling, treatment and care, related social services and safety nets; and providing, organizing or subsidizing production support. Formal education services build youth awareness, for example, and can reduce gender violence and promote communication on harmful practices.

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States can also provide support to the production and economic systems that buffer the impacts of AIDS, such as small business loans to affected households, or cash transfers and income support to households caring for orphans. Public policies that explicitly seek to reduce household burdens and enable service uptake can go a long way toward reducing risk or mitigating impacts of AIDS.

- Different forms of social networking and community solidarity have the potential to support survival needs. In some settings the support from such community networks, combined with wider social movements and political institutions, can move responses beyond basic survival to a level where they advance and transform social development. It is important for public policy on AIDS to recognize and support community roles, and to strengthen the institutions and processes that connect these roles to national and global resources.

UNRISD Sources and Further Reading

AIDS Care, Volume 19, Supplement 1, 2007. *Special Issue: Community Responses to HIV and AIDS*. Guest editor, Rene Loewenson.

The journal supplement comprises the following contributions.

1. Exploring equity and inclusion in the responses to AIDS, R. Loewenson
2. Autonomy and susceptibility to HIV/AIDS among young women living in a slum in Belo Horizonte, Brazil, A.S. Chacham, M.B. Maia, M. Greco, A.P. Silva, D.B. Greco
3. Effectiveness of small scale income generating activities in reducing risk of HIV in youth in the Republic of Congo, J.C. Boungou Bazika
4. Putting on a brave face: The experiences of women living with HIV and AIDS in informal settlements of Nairobi, Kenya, M. Amuyunzu-Nyamongo, L. Okeng'o, A. Wagura and E. Mwenzwa
5. Contextualising AIDS and human development: Long-term illness and death among adults in labouring low-caste groups in India, R. Priya, C. Sathyamala
6. Expanding community through ARV provision in Thailand, C. Lyttleton, A. Beesey, M. Sitthikriengkrai
7. Under the radar: Community safety nets for AIDS-affected households in sub-Saharan Africa, G. Foster
8. Gender differentiation in community responses to AIDS in rural Uganda, John Mary Kanyamurwa, G.T. Ampek
9. Community health workers as a cornerstone for integrating HIV and primary healthcare, J.S. Mukherjee, Fr.E. Eustache
10. Learning from diverse contexts: Equity and inclusion in in the responses to AIDS, R. Loewenson

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