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Exploring equity and inclusion in the responses to AIDS

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Exploring equity and inclusion in the responses to AIDS

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Abstract

The HIV and AIDS epidemic feeds on, and worsens, unacceptable situations of poverty, gender inequity, social insecurity, limited access to healthcare and education, war, debt and macroeconomic and social instability. The number of people living with HIV and AIDS continues to increase in several regions, most markedly in sub-Saharan Africa, the Pacific, Eastern Europe and Central Asia. The persistent nature of the epidemic and its increasing incidence in less powerful, more economically marginalised communities signals a need for a critical review of past policy and practice, particularly where this has left unchanged or worsened the risk environments that lead to new infection. Available evidence suggests that the caring and consumption burdens of AIDS have largely been met by households, limiting the capacities for future caring and mitigation of impact. Social cohesion or the collective networking, action, trust and solidarity of society, plays a positive role in reducing risk and dealing with vulnerability but is itself negatively affected by AIDS. This paper introduces the programme of work reported in this supplement of AIDS Care with an analysis of background evidence of community responses to HIV and AIDS. It explores how interventions from state institutions and non-governmental organizations (NGOs) support and interact with these household, family and community responses. How far is risk prevention reliant on individuals’ limited resources and power to act, while risk environments are left unchanged? How far are the impacts of AIDS borne by households and extended families, with weak solidarity support? Where are the examples of wider social responses that challenge the conditions that influence risk and that support household recovery? Through review of literature, this background paper sets out the questions that the studies reported in this supplement have, in various settings, sought to explore more deeply.

Background

In mid-March 2006, Stephen Lewis, the United Nations envoy for HIV/AIDS in Africa, pointed to a ‘legacy of inequality’ and marginalisation, devastating ‘women and girls on the African continent’ and around the world. ‘There is no item more urgent on the international development agenda,’ he said, and yet ‘… things are changing so incrementally on the ground … that we’re losing millions of young women in Africa.’ (UN Department of Public Information, 2006)

By December 2005, there were 40.3 million people living with HIV and about three million people died of AIDS in that year. Each day sees over 13,000 new infections, of which nearly 2,000 a day are in children under 15 years (UNAIDS-WHO, 2005). Globally, sub-Saharan Africa and South East Asia have the highest burden of disease, with increasing epidemics in southern Africa, parts of Asia and Eastern Europe (UNAIDS-WHO 2005).

The epidemic feeds on and worsens unacceptable situations of poverty, gender inequity, social insecurity, limited access to healthcare and education, war, debt and macroeconomic and social instability (Loewenson et al., 2001; Collins et al., 2000).

Growing epidemics in Eastern Europe and Central Asia, the continued rise of mortality due to AIDS in Africa and localised epidemics in injecting drug users and young people in Latin America and Asia signaled that opportunities for prevention and treatment had still not reached many communities. UNAIDS and WHO, in December 2005, pointed to societal inequalities and injustices as continuing drivers of the epidemic (UNAIDS-WHO, 2005).

If the opportunities at global level are to translate into real change in the epidemic, then resources and inputs must reach households and individuals. To do this, more needs to be known about what communities are doing about HIV and AIDS, about the state and non-state institutions they interact with and the opportunities for, and barriers to, more supportive community environments.

This supplement explores and aims to address this knowledge gap. Through the framework of a research programme of the UN Research Institute on Social Development (UNRISD) co-ordinated by Training and Research Support Centre (TARSC) it
examines community responses to HIV and AIDS and the interactions between community, organised civil society and state at community level in preventing the spread of HIV and in mitigating the impacts of AIDS.

**Analysing HIV and AIDS at community level**

The HIV/AIDS pandemic consists of multiple and overlapping epidemics, each with its own distinctive dynamics and character. These different epidemics of HIV and AIDS reflect the biological, social and economic risk environments that lead to and influence the spread of HIV and the susceptibility of different social groups to infection (Loewenson et al., 1997). In this paper ‘susceptibility’ is used to describe the likelihood that an epidemic will develop or a group or individual become infected, while ‘vulnerability’ refers to the features of an individual, household or society which make it more or less likely that an epidemic will have a serious impact. Barnett and Whiteside (2002) outline these different levels of determinants of the epidemic in Figure 1.

The specific determinants of HIV infection are documented in other sources and so are not detailed here (Barnett & Whiteside, 2002; Collins et al., 2000; Decosas 2002; Loewenson et al., 2001). Upstream of the biological and behavioural determinants of HIV infection are a range of social, economic and political factors, including imbalances in access to resources and power; increased poverty and mobility; economic shocks associated with loss of secure employment, production or assets; and economic booms associated with increased inequalities in wealth (Gordon et al., 1998; Im-em et al., 2002; Shah et al., 2002). The persistent nature of the epidemic and its increasing incidence in less powerful, more economically marginalised communities point to the persistence of these underlying risk environments that lead to new infection.

Households are also vulnerable to the impacts of AIDS, with a range of demographic, social, health and economic impacts documented. Increased deaths, fewer births and reduced fertility are reported to change household and community structures. AIDS increases the need for public healthcare and welfare services and challenges household wellbeing. Studies report reduced enrolment and access to quality education; falling labour quality and quantity; losses in household income; falling farm production; shifts towards production of less time consuming but lower quality food crops; and loss of livestock assets and implements (Loewenson et al., 2001; Munthali, 2002).

Few studies have been able to assess the full scope of these impacts on households. Many focus on immediate economic costs rather than longer-term development impacts and few adequately capture the changing relations that result between households and within society. These impacts may, however, marginalise affected households from economic and social opportunity and increase levels of structural poverty (Barnett et al., 2002). In general, better-off households are more able to buffer short-term negative impacts of AIDS, while those living near the poverty line face rapid constraints in cash resources and have fewer options to buy external inputs for production, consumption or caring (Kurschner, 2002).

Yet the demand for caring is not short term: the shift from an HIV to an AIDS epidemic, with a consequent increase in illness and death and a rising population of orphans will scale up vulnerability to significantly higher levels. It cannot be assumed that approaches used during the HIV phase of the epidemic, including those used by communities, will be adequate or sustainable under these new levels of mortality (UNAIDS, 2003).

There is some evidence that the resources within, and social support from, communities do make a difference to households and individuals affected by AIDS and to the risk of HIV infection (Barnett et al., 2002; Decosas, 1998). Under the generic term ‘social cohesion’, a range of characteristics of communities have been described that are associated with lower susceptibility to HIV and vulnerability to AIDS. These include having organisations, institutions and groups that recognise the threat of HIV

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<th>DISTAL DETERMINANTS</th>
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<td><strong>Macro-environment</strong></td>
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<td>E.g. wealth, income distribution</td>
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*STI = Sexually transmitted infection.

Figure 1. Determinants of susceptibility to HIV.
and AIDS; that provide care and support; that are committed to social justice; that have relationships of trust and respect between service personnel and community members; having communities that are responsive to state authority and regulation; and having lower levels of income inequality (Barnett et al., 2002, Decosas, 1998, 2002).

This finding is not unique to HIV and AIDS. There is a body of evidence that social exclusion and isolation is unhealthy. In contrast, social norms and networks appear to improve household welfare and to enhance the efficiency of society by facilitating co-ordinated public action (Kawachi et al., 1997; Marmot, 1998; Wilkinson, 1997).

This raises the questions: to what extent are social networks, institutions and capacities within communities being used to absorb short term burdens of AIDS that exceed household capacities? Are social networks coping with AIDS within communities by pooling what is available horizontally (the ‘horizontal sharing of poverty’)? and how far are they changing risk environments or accessing resources from outside communities to share the burdens of AIDS, including with more powerful and wealthier groups (i.e. ‘driving vertical equity’)?

Understanding community responses

In addressing these questions, the papers in this supplement explore ‘community’ at different levels. The first is the individual, both the HIV infected individual and those affected by the epidemic, as children, spouses or partners, family members, parents, care-givers, co-workers and so on.

The second is the family and household. Although often used inter-changeably, these terms have significantly different meanings. A household can be defined as a group of people, living together, who are usually economically interdependent. The family may involve a much larger network of connections among people, going beyond the household in relationships that include multiple generations, extend over a wide geographical area and are based upon reciprocal rights and duties. The term ‘extended family’ places special emphasis on the role of relatives outside the household in providing economic and social support, such as to survivors from AIDS-affected homes (Foster, 2002).

Beyond the immediate networks of household and family, there are social groupings within the wider term ‘community’ that have common experience or situation by virtue of social class, income level, gender, geographical area, age, ethnic or religious group, political status and other social and economic factors.

Disaggregating responses to HIV and AIDS across these different levels is necessary: Individuals may acknowledge their own infection but hide it from their partners. While individual responses may be negative (denial, reaction), household and family responses may be caring and supportive (Verall et al., 1992). On the other hand, individuals isolated from their families due to poverty or stigma may turn to social group networks for support. Civil society, whether through voluntary associations or non-state organisations, can perform many roles, supporting households, facilitating co-ordinated public action, satisfying shared necessities or interests and engaging the state (Loewenson, 2003).

Community responses to HIV and AIDS

Community responses may be directed at preventing risk of HIV, treating and caring for illness and mitigating and responding to the current and future social and economic impacts of AIDS. As Loewenson and Whiteside (2001) show in Figure 2, all three may be linked in virtuous or vicious cycles.

Responses to risk and susceptibility

Many HIV-infected people do not know that they are infected, given the long incubation period and the still poor access to voluntary counselling and testing programmes in many parts of the world. People, particularly in low-income communities, make decisions based on demands for food, shelter, income and employment and not specifically around AIDS (Rivers et al., 2003). Many HIV-prevention interventions have been based on behavioural change, targeting individuals, households or social groups to act on their perceived risk. There has been less specific intervention around economic policy or employment patterns or other wider social determinants of risk (Barnett et al., 2002). A combination of low or poor risk perception, behaviours, determined by more immediate survival needs and implementation of more limited behavioural interventions, can lead to persistence of these underlying risk environments and of community practices that increase the risk of HIV infection (Verall et al., 1992).

This is exacerbated when there is public silence about risk environments. In South Asia, for example, despite a rapidly growing HIV epidemic, there is a prevailing silence about domestic and workplace violence against women and girls (Shah et al., 2002). An emphasis on the ‘innocence’ of young women prevents them from seeking information about sex or services relating to their sexual health. Unequal gender status means that those young women who know the risks have little power to use this knowledge. Social stereotypes about sexual behaviours, including the acceptability of older men ‘marrying’ much younger women, perpetuates
the epidemic in the next generation (Rivers et al., 2003). Disempowering conditions not only increase susceptibility, they can also undermine the response to infection. Fear of violence discourages women from seeking an HIV test without their partner’s permission or sharing the result if they have been tested secretly (Feldman et al., 2002).

It is not correct to simply attribute these practices to community culture (IRIN-UNAIDS, 2003). Economic disenfranchisement, unemployment and social insecurity amongst youth contribute to violence against women and children (Gupta Rao, 2002). Gender roles and relations at community level have been, and continue to be, deeply influenced by socioeconomic conditions and the manner in which these are reinforced (or negated) by public policy and practice.

Stigma and fear of discrimination have been found to negatively influence caring and support from families and communities (Nyblade, 2001). Blaming the victim is one way people seek to distance themselves from a problem. It makes stigmatised people responsible for taking action on their affliction, rather than society as a whole (Bond, 2002). Groups already ‘scapegoated’ for other reasons, including migrants, commercial sex workers, unemployed youth and poor women, are more vulnerable to such stigma. AIDS-related stigma reflects and reinforces class, gender, sexual and racial inequalities in society (Bond, 2002; Jenkins, 2000; Rivers et al., 2003). Interventions aimed at changing attitudes towards groups who are being stigmatised may leave these underlying causes of stigma untouched.

In such situations explicit intervention is needed to counterbalance the disempowering effects of negative environments on susceptible groups. The opposite often occurs. Many community interventions address high-risk behaviour at the level of the individual, with persuasive methods, such as advice, counseling and peer education, but leave the underlying risk environments unchanged (Jenkins, 2000). Individuals and social groups that are weakened by poverty and inequality face difficulties in directly challenging the biases in services, infrastructures, resources, stereotyping and norms that increase their risk of infection. Hence change needs to be mediated by interventions from other levels: NGO and state institutions may challenge values, norms and practices of more powerful groups, such as men, and signal the unacceptability of sexual violence through social and legal sanctions against its perpetrators (Gordon et al., 1998; International HIV/AIDS Alliance, 2003). Social actions aimed at changing negative practices are reinforced by mechanisms that bring visible state or civil society authority in support of vulnerable groups. Hence, for example, survivors of sexual violence are reinforced by inputs such as rape crisis centres, help-lines, health services, shelters and refuges and training of medical and social welfare personnel (Gordon et al., 1998). Organised civil society networks have also provided social challenge to the political and economic conditions that increase risk and an organised means to overcome barriers in access to services or resources. Women, youth, people living with HIV and AIDS (PLWHA) have formed networks based on shared perception of risk. These networks are becoming more vocal, challenging leaders and demanding direct involvement in decision-making in national HIV strategies and plans, and resources to act directly on poverty and stigma (Msimang, 2001).
Treatment activists have confronted the stigma associated with HIV and successfully challenged the state and private sector at national and international levels to respond to demands for access to adequate treatment.

These actions have moved intervention from the ‘Abstain, Behavioural change, Condom use’ (ABC) of individual behavioural change towards a wider social challenge of risk environments and social organisation around access to resources and services. Social networks bringing together groups with a shared perception of risk of HIV have provided a means for communities to collectively assess problems, debate values, propose solutions and implement change, with varying degrees of formal recognition (Im-em et al., 2002; Leonard et al., 2001). Such networks have grown in number and size around the AIDS epidemic, around workplaces, faith-based organizations, sports activities and beer halls and as networks of HIV-positive persons (Blinkhoff, 1999; Byamugisha, 2002; Feldman et al., 2002; IRIN-UNAIDS, 2003; Ray et al., 2002; Williams et al., 1995).

Several papers in this supplement explore further this social response, how successful it has been in challenging risk environments for HIV and what support it has found from state and non-state organisations.

Responses to vulnerability and to the impacts of AIDS

While collective, social groupings have become more influential in raising the visibility of risk environments and dealing with stigma, it seems to be the individual and family that are taking on the primary burden of caring for the impacts of AIDS (Bharat, 1998).

Studies in India and Zimbabwe indicate forms of support for households affected by AIDS, drawing on relatives and household savings to care for ill people and orphaned children, making donations at funerals, selling assets and food reserves and changing labour roles (Bharat, 1998; Chigovanyika, 2000). Households coping with illness and mortality due to AIDS have themselves tried various strategies to meet consumption needs, including begging, bringing in family members to substitute labour, substituting cheaper commodities, reducing consumption and sending children out to live with relatives (Mutangadura et al., 1999).

Households tend first to rely on strategies that do not require cash, such as intra-household labour reallocation, taking children out of school, diversifying household crop production and decreasing areas cultivated (Mutangadura et al., 1999). While patrilineal systems, such as in Malawi, offer widows and their children support from the relatives of her late husband in her husband’s home village, Munthali (2002) notes that women are better-off in matrilineal systems, as they farm their own land, stay with their own family and can use familiar networks for support. Inheritance of the deceased brother’s wife in patrilineal systems may raise a risk of HIV transmission and the interest in supporting the wife may decline after her property or money is exhausted (Munthali, 2002).

Not all household members benefit equally from this family support. In a Mumbai study, the most supportive care was received by men, even when their female partner was also sick. In-laws often showed little compassion toward widowed, infected daughters-in-law. Individuals without open sores or lesions were better accepted by family members and perceived as less likely to transit the virus (Bharat, 1998).

Poverty, the commodification of social services and the cash economy have made it more difficult for poor households to secure the inputs they need. This leads to strategies that have less positive outcomes for households, like migration in search of new jobs, loans, sale of assets, use of savings, early marriages, dropping out of school in order to head a family, casual labor and piece work (Munthali, 2002). In the worst-case scenario of destitution, households depend on charity, or break up, as household members migrate.

Family and household interventions have been complemented by a range of wider community responses, through social support and self-help groups, savings clubs, microfinance activities and income generation projects, as well as dealing with legal and social practices such as inheritance, mourning periods, funeral practices and gender roles. Through extended family networks, religious networks, traditional healers, NGOs and other networks of social security support, communities have mobilized to protect the rights of individuals and facilitate access to health and welfare services and schooling, provide caring and home visiting support, support groups for PLWHAs and support to food security and other basic needs for ill community members and for affected children (Munthali, 2002; Russel et al., 2000). Wider community networks, organised around religious and social associations, have shared responsibilities among neighbours and relatives, provided employment to families of the deceased, carried out collective production and group gardens for households affected by AIDS and provided counselling and social support (Chigovanyika, 2000).

How widely implemented are these community responses? How far do they provide meaningful levels of social protection to affected households?
There is little systematic assessment of the level of community support taking place and much that takes place within communities is not documented in published literature. Community responses to the epidemic are often hardly known outside their immediate locale. Assessments of community level responses have reported them to be weak, ‘patchy’ and often absent, particularly for the most marginalised members of communities like widowed women or elderly parents (Chigovanyika, 2000; Im-em et al., 2002; Mutangadura et al., 1999; Russel et al., 2000).

Social safety nets within communities of various types are widespread and draw on a tradition of coping with acute shocks and natural disasters. They have been prominent in support of terminal care and fostering of orphans (Foster, 2002; McKerrow et al., 1995).

Existing evidence signals, however, that many of these safety nets are under pressure or have already been weakened. They are undermined by the growth of poverty and economic insecurity, poor living and social environments, migration, and the costs to households of AIDS (Foster, 2002; Kurschner, 2002).

The paper by Foster in this supplement explores further the role these safety nets are playing in support of orphans and vulnerable children and the extent of formal support they receive. Here too the literature signals cause for concern. Despite being given roles in community caring, community safety nets are documented to have received inadequate support from formal and state services, weakening their sustainability (Knodel et al., 2002). Studies of community home-based care have, for example, found significant direct and opportunity costs for families in providing this support, not adequately met through support to households (Foster, 2002; Ntsutebu et al., 2001). Similarly families providing orphan care have been found to be struggling with an accumulating burden of caring for surviving children, with weak support from state or NGOs (Bhargava, 2003; McKerrow, 1995).

Where support is inadequate, there is evidence of negative and sometimes irreversible consequences for households and children, including reports of older children being withdrawn from school to take up paid employment and care for younger siblings (Foster, 2002; Im-em et al., 2002; Lyons, 1998; Mutangadura et al., 1999). Women in patrilineal systems have been reported to lose access to land, productive resources or credit after the death of a spouse but remain responsible for support of minor children (Kurschner, 2002; Mutangadura et al., 1999).

The evidence is, however, anecdotal. There is little systematic evidence of the extent to which networks of support have been able to move beyond coping and caring towards rehabilitating individuals and households as producers and as users of goods and services.

It is also not clear how far household and community networks have been supported by the more formal resources within the state, private sector or civil society. Activities within the extended family sector are often not brought into the public domain unless this is organised by community leaders, civil society or the state. In fact there is some evidence that demands for support are more likely to be made by middle- and higher-income households than by low-income households. Webb (1995) found in a large survey of community responses to AIDS in southern Africa that lower income communities were more likely to take on and see as their responsibility caring for orphans in the community than more affluent communities. He further cites the findings of the Kagera survey in Tanzania, where households that had themselves experienced an adult death from AIDS were more likely to take on foster children from other households than middle-income households, who see government as the primary caregiver (Webb, 1995). The fact that poorer households are more likely and willing to absorb orphans than wealthier households indicates that demand for state and private sector support may be inverse to need, with potentially inequitable outcomes in terms of use of public resources.

How far has the state responded to this household need and supported household and extended family responses?

State support of community responses

Governments play an important role in providing measures that households cannot or will not secure individually. This includes providing policy and legal measures, public information, subsidies on public health measures, providing prevention, healthcare and related social services and safety nets and providing, organising or subsidising production support needed to deal with HIV and AIDS (Ainsworth, 1999; Shah et al., 2002). Such inputs can make a critical difference to household and community responses, particularly in poor communities. In Asia, for example, the economic impact of AIDS was buffered by state measures smoothing consumption and maintaining social safety nets (Ainsworth, 1999).

There are many examples of the positive contribution of state services to reducing risk or mitigating impacts of AIDS. They include the contribution of formal education services to youth awareness (Boyer et al., 2003), of public health services to prevention and care (Nyblade et al., 2001; Republic of
Botswana, 2003) and of public education through policymakers and law enforcement agencies in reducing gender violence and promoting communication on adolescent sexuality and on harmful practices, such as wife inheritance and sexual cleansing (IRIN-UNAIDS, 2003; Ligomeka, 2003; Reid, 1994; Rivers et al., 2003; Stewart, 1995; UNAIDS, 2003).

States have also provided support to the production and economic systems that buffer the impacts of AIDS, including small business loans to households affected by AIDS to sustain production (Kaiser Foundation, 2003), cash transfers and income support to households caring for orphans (Lee et al., 2000; Matshalaga, 2002). These forms of public sector support are themselves constrained by reduced public sector funding, reduced quality of services, barriers to access such as those posed by cost recovery and by social and cultural barriers to what services can do, such as to what can be taught in schools (Altman, 1994; Boler et al., 2003; Matshalaga et al., 2002; Rivers et al., 2003). They have reduced resource flows to the state at a time when the state faces its own challenges to respond to AIDS, both as a service provider and as an employer.

Worsening economic conditions, public policy decisions and the epidemic itself have all threatened provision of the core services needed to support community responses to HIV and AIDS. A report by the WHO (2002) on access to services for HIV and AIDS pointed out that most people in low- and middle-income countries do not have access to several key prevention and care services. The global campaign to treat three million people by 2005 has vastly extended access to treatment but by December 2005 UNAIDS and WHO concluded that ‘at best one in ten Africans and one in seven Asians in need of antiretroviral treatment were receiving it in mid 2005’ (UNAIDS-WHO, 2005; p 5).

Such resource scarcities can intensify social differentials in access to services (Bhargava, 2003; Gupta Rao, 2002; Leonard et al., 2001; UNAIDS, 2003). Men were reported in one study to be more likely to receive clinic or hospital-based treatment than women, due to a mix of clinical, economic and service factors. Surviving widows often had little money left to address their own treatment needs, as the majority of family assets had been spent in treating the husband before his death (Im-em et al., 2002). Even where services are more widely provided, there are social barriers to uptake. For example, while Botswana provides free antiretroviral therapy for all eligible HIV-positive persons, less than 8% of its population knew their HIV status in 2003 because of the stigma connected with HIV (Donnelly, 2003).

Public policy and the design of services can make a difference to this interface between community and state. In Thailand during the economic crisis, for example, households reduced their spending on health by switching to less expensive forms of care, shifting from private to public health sector services. Government health and education expenditure held steady and spending on social safety nets was increased. Free access to the Public Assistance Scheme was extended to the newly unemployed and government subsidies for the Voluntary Health Card Scheme increased. Scholarships were introduced for children who dropped out of school, vouchers issued to children in private schools to keep them enrolled and the education loan program expanded for the children of the unemployed (Ainsworth, 1999). Thai services were thus able to respond to increased demand from households and prevent declines in access to interventions for HIV and AIDS.

In contrast to the high levels of state support in Thailand, in Rwanda more than 90% of spending on AIDS-related interventions is reported to come from out-of-pocket payments by HIV-positive patients. Government and donors were found to play a negligible role in meeting treatment costs, placing a heavy financial burden on HIV-infected individuals. This made household uptake of HIV-related interventions extremely vulnerable to wider economic trends. A pilot introduction of a prepayment insurance scheme into this setting thus made a difference to securing such uptake, improving access to basic curative, preventive and obstetrics services (Schneider et al., 2001).

These examples indicate that public policies that explicitly seek to reduce household burdens and enable service uptake can enhance the interface needed between communities and services for sustained prevention and management of treatment and care. Despite this, many countries have been pressurised through liberalisation and market reforms to privatise health services, promote cost recovery through direct fee payments from users and rely on non-government, vertical targeted interventions to compensate for losses on solidarity based, comprehensive financing systems.

Associational networks within communities and civil society organisations and local government structures play a role in improving the uptake and outcomes of HIV- and AIDS-related services provided by the state and in advocating and building demand for such services (Rivers et al., 2003; Williams et al., 1997). Their contribution lies in challenging social barriers to access, such as social stereotypes and stigma, providing complementary funding and material support and enhancing com-
munication between communities and public services (Byamugisha et al., 2002; SAfAIDS, 2001).

The profile and activism of networks of PLHWA has grown markedly around treatment access, in alliance with unions, employers, religious bodies, women’s and youth organizations, organizations of gay people and other interested groups in the community (UNAIDS, 2003). Treatment activism has shifted mindsets nationally and internationally on rights to treatment, and backed this with court actions to secure these rights in law. This has led to significant private and public sector resource shifts towards treatment interventions. Instead of being undermined by stigma, PLHWA have been collectively organised around their rights to access healthcare and around government and private sector obligations towards them (Fassin et al., 2003).

These networks now face challenges in meeting the bureaucratic and technical demands of service outreach while sustaining grassroots organising and policy advocacy (Blinkhoff et al., 1999; Byamugisha et al., 2002; SAfAIDS, 2001). The paper in this supplement by Lyttleton et al. tracks the experience of the Thai PLHWA movement of these challenges.

How far have these groups been able to advance the equity concerns raised earlier on prevention and care. How effectively are the social networks and capacities within communities able to change (as distinct to simply coping with) the distribution of the costs and burdens of AIDS?

Virtuous cycle of support or vicious cycle of burden shift? Issues for research and analysis

This background analysis of current patterns of susceptibility to HIV and vulnerability to AIDS raise a series of lenses through which community responses to HIV and AIDS can be further explored. The papers in this supplement report on two areas of focus.

The first explores how far prevention interventions adopt social approaches that link individuals at risk within widening social networks, address the underlying social, economic and environmental determinants of HIV and change the risk environments for HIV.

The second area explores whether responses to the impacts of AIDS organise and build mechanisms to share the costs of AIDS and build solidarity and equity in resource and service support for vulnerable households and families. Studies reported in this supplement explore these issues.

The study in Brazil explores how different dimensions of autonomy affect risk prevention in young women living in a slum area in Brazil and uptake of state services for HIV prevention.

Other papers report on community responses to vulnerability to AIDS in extremely poor communities Kenya, Uganda and Zimbabwe: in women in informal settlements in Nairobi, rural women farmers in Uganda and in households absorbing or headed by orphans in Zimbabwe. They examine how far resources and services from state, non-government and other sectors support community coping mechanisms.

The work reported with women from dalit (untouchable) castes in two areas of India explores how such responses within communities are influenced by wider social, political and economic policies and trends and the features of ‘modernisation’ policies that raise the risk of ill health and deplete the resources to respond to it.

The studies in Haiti and Thailand explore more closely the interface between communities and services: in Haiti from the perspective of services and through examining how the organisation of services and of community health workers supports access and outreach to communities, and in Thailand from the perspective of the community networks of PLHWA, in relation to how their changing role in treatment and care challenges wider grassroots and advocacy roles.

The studies use a mix of approaches, qualitative and quantitative, drawn from public health and social sciences. Tracing these social patterns often calls for longitudinal studies and time frames that were not available to the researchers, so that studies used retrospective recall and secondary data to assess changes over time. The epidemic may cause households to disintegrate, so that the studies may not reflect the most extreme negative experiences.

The studies presented, continue to offer further snapshots of the complex and changing environments and responses at community level. However, risk environments and unfair and unsustainable burdens neither originate nor end at community, or even national levels, in a world increasingly governed by global policy and trends. The concluding paper in the supplement draws from the diverse experiences presented to discuss the implications for public policy and human security at all these levels.

As the global shift takes place from a short-term ‘emergency’ focus on AIDS to a longer-term sustainable development focus, the studies seek to strengthen the understanding of those responses that transform lives at community level—that support positive social cohesion and organisation and that strengthen economic stability and security. We ask what longer term structural transformation is needed so that the UN will not have cause to say again, a further decade into the epidemic, ‘... things are changing so incrementally on the ground...’.
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