International Labour Office

# Contributing to the fight against HIV/AIDS within the informal economy:

## The existing and potential role of decentralized systems of social protection

Strategies and Tools
against Social Exclusion and Poverty

ILOAIDS
Programme on HIV/AIDS
and the World of Work

# Contributing to the fight against HIV/AIDS within the informal economy:

# The existing and potential role of decentralized systems of social protection

Working Paper

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## Contents

## List of abbreviations

| | |
|---|---|
| ARV | Anti-retrovirals |
| DSSP | Decentralized systems of social protection |
| EPI | Extended Programme of Immunization |
| HIV/AIDS | Human immunodeficiency virus/acquired immune deficiency syndrome |
| HMIS | Health micro-insurance schemes |
| ILO | International Labour Organization |
| ILO/AIDS | ILO's Programme on HIV/AIDS and the World of Work |
| NGO | Non-governmental organization |
| PMTCT | Prevention of mother-to-child-transmission |
| STD | Sexually transmitted diseases |
| STEP | Strategies and Tools against Social Exclusion and Poverty |
| TB | Tuberculosis |
| UN | United Nations |
| UNAIDS | Joint United Nations Programme on HIV/AIDS |
| UNGASS | UN General Assembly Special Session |
| VCCT | Voluntary and confidential counselling and testing |
| WHO | World Health Organization |

## Executive summary

Over the past four years, the Strategies and Tools against Social Exclusion and Poverty (STEP) programme of the International Labour Organization (ILO) has been exploring the potential and supporting the development of decentralized systems of social protection (DSSP) as mechanisms to increase social protection in health. Recognizing the threat posed by the HIV/AIDS epidemic to the goal of decent work, the ILO has established a global programme on HIV/AIDS and the World of Work (ILO/AIDS) and has developed a *Code of practice on HIV/AIDS and the world of work*. The code provides guidance on preventing HIV/AIDS and mitigating its impact in the world of work, and applies to all aspects of work, formal and informal. This joint paper reviews the ad hoc evidence and explores the potential of DSSP to contribute to the fight against HIV/AIDS, thereby also contributing to the application of the code of practice in the informal economy.

The paper focuses on systems set up by associations and organizations in civil society to cover workers and households that do not have access to statutory systems of social protection. It places particular attention on the role of health micro-insurance schemes (HMIS), which constitute a dynamic innovation in terms of community mechanisms to face health-related risks. A number of illustrative examples are included, mostly in text boxes and endnotes.

DSSP generally, and HMIS in particular, are typically thought of as mechanisms to overcome financial obstacles to accessing health care and are often referred to as systems of community financing for health. Indeed, they can make an important contribution in this realm. However, many DSSP also perform a social role that may be as important, and potentially more important, in the fight against HIV/AIDS. This social role strengthens community capacity to take collective action relating to prevention and care. It also facilitates linkages of individuals and households affected by HIV/AIDS to support structures that provide a variety of social services. DSSP can create a bridge to social services and national programmes enabling these to channel resources to the local level. Thus, they can increase the capacity of national HIV/AIDS programmes to penetrate deeper into communities and reach individuals and families in need.

In the conclusion, the paper lists concrete actions to understand more fully the role of decentralized systems of social protection in the fight against HIV/AIDS and –

most importantly – to further translate their potential into reality. Finally, it notes that the increased understanding and experience will be relevant not only for DSSP, but also for many other types of community-based organizations and associations.

On 25 October 2001, the ILO became the eighth co-sponsor of the Joint United Nations Programme on HIV/AIDS (UNAIDS), bringing to the Programme its understanding of and expertise in the epidemic in the world of work. Director-General Juan Somavia said, "AIDS has a profound impact on workers and their families, enterprises and national economies. It is a workplace issue and a development challenge."[1]

As an initial contribution to the fight against HIV/AIDS, the ILO developed a *Code of practice on HIV/AIDS and the world of work*. It was approved by consensus in May 2001 at a tripartite meeting of experts from all regions and formally launched in June 2001 by the ILO Director-General at the UN General Assembly Special Session (UNGASS) held in New York. The code provides practical guidance to policy-makers, employers' and workers' organizations and other social partners for formulating and implementing appropriate workplace policies, prevention and care programmes, and for establishing strategies to address the situation of workers in the informal sector.

The ILO's global Programme on HIV/AIDS and the World of Work (ILO/AIDS) supports the application of the code at national and enterprise levels through advisory services for governments and the social partners, a programme of education and training, and other technical cooperation activities to enhance the capacity of constituents to develop and implement workplace policies and programmes. An education and training manual that will help guide the use of the code and its adaptation to different sectors and situations is under development.

As the ILO moves forward with providing support for the application of the code, it recognizes that, "While information and experience in addressing HIV/AIDS in large-scale formal enterprises is beginning to be accumulated, the same cannot be said of the informal economy or small enterprises, where the majority of workers are to be found."[2] With respect to the informal economy, the ILO also recognizes that "One approach which should undoubtedly be investigated more thoroughly is the development of prevention and care programmes in the context of the mutual health funds which are being established by small enterprises and informal economy operators in many countries, particularly in Africa, and which are being promoted through the ILO's global Programme Strategies and Tools against Social Exclusion and Poverty (STEP)."[3]

This paper describes efforts being developed by the ILO to strengthen the capacity of groups of workers and their families, particularly those in the informal economy, to organize action for the prevention of HIV/AIDS and for the care of those affected by HIV/AIDS. In line with one of the major recommendations emanating from UNGASS, the approach is grounded in communities' activities and mobilization, to enable them to rise to the challenge of HIV/AIDS. The approach builds on the extensive experience gained by ILO/STEP and its development partners in exploring the potential of decentralized systems such as micro-insurance to extend coverage of social protection in health.

# 1 The centrality of community-based action in the fight against HIV/AIDS

Since the 1980s when HIV/AIDS was first acknowledged as a major public health concern, the fight against the HIV/AIDS epidemic evolved from being centred on medical action to being focused on communities. There is now general consensus that the most effective strategies for combating the pandemic are community-based and multi-sectoral. Indeed, the majority of prevention and care activities are undertaken within households and communities and – typically – the majority of resources for these actions come from the communities themselves through a variety of coping mechanisms.

Analysis of the epidemic has made clear that women suffer disproportionately from its negative impact. Because of social, economic and cultural inequalities between men and women, they face the heaviest burden from the spread of the epidemic. The responsibility for providing care and support to household members who have contracted the disease falls predominantly on women. The same is true for providing support and care to increased numbers of dependants in the household due to AIDS-related deaths in the extended family. In view of their traditional role as caregivers, women are also the most important stakeholders when it comes to issues relating to prevention and care.

> "The outcome of the battle against AIDS is decided within the community. People, not institutions, ultimately decide whether to adapt their sexual, economic and social behaviour to the advent of AIDS. Government and non-governmental organizations can only influence, either constraining or facilitating people's responses to HIV and AIDS."
>
> (Phayao case study, UNAIDS, April 2000)

UNAIDS has explicitly adopted approaches aiming at strengthening the communities' own coping strategies. However, there are still genuine difficulties in finding effective community-based approaches that can be generalized to regional and national levels so as to make a significant impact beyond a limited number of communities.

DSSP represent community-based coping mechanisms. Much of the experience gained through the development and functioning of these systems can be applied to the design and development of national HIV/AIDS programmes.

## Decentralized systems of social protection: Examples of community-based coping mechanisms

# 2

DSSP can be categorized as systems that increase the capacity of individuals and households that are part of an organized group to face a variety of negative occurrences (risks). The DSSP increase security by enabling individuals and households to decrease the negative consequences of risks. Most cannot significantly decrease the negative consequences of acute risks such as floods or earthquakes that affect entire communities. These systems are most effective in enabling individuals and families to decrease the negative consequences of risks that affect only a small portion of the community at any given time, such as illness or temporary inability to earn income. They also typically have systemic incentives to engage in preventive actions that decrease exposure to risk.

This document focuses on community-based DSSP set up to cover households that do not have access to statutory systems of social protection. These vary widely. They range from systems that aim primarily at protecting income and employment such as savings and credit schemes,[4] to systems that have social protection in health as their primary objective, such as health micro-insurance schemes (HMIS). Irrespective of their primary objective, they typically entail some form of membership which, depending on the system, may imply different types of duties and responsibilities. Some of these relate to the degree of solidarity or mutual help provided by the scheme. For example, some risk-sharing is inherent in schemes where the savings of individuals form the basis for loans or benefits to members (village banking). Greater degrees of solidarity and risk-sharing are inherent in systems of insurance whereby membership requires periodic contributions to access benefits in time of need.

Because the DSSP are typically established as a result of locally driven processes, they vary enormously in terms of size, primary objectives and operational capacity. Their differences can be viewed as strengths, to the extent that they reflect the separate realities of the different organized groups in civil society. However, the high degree of variation makes it difficult to draw broad conclusions that are applicable to all DSSP. This should be kept in mind when considering their potential contribution in the fight against HIV/AIDS.

Among DSSP, micro-insurance is of particular interest. It constitutes a dynamic innovation in the health field and has demonstrated significant potential in enhancing the capacity of communities to cope with health issues and to interact with

providers of health and other services. Micro-insurance is also relevant in enabling communities to address the HIV/AIDS pandemic to cover other risks, such as expenses linked to death – whether or not it is caused by AIDS – and to assure children's education.

The term health micro-insurance is used loosely to include schemes referred to by a variety of terms, including mutual health organizations, mutual health funds and community-based health financing schemes.

The term "micro" refers to the limited capacity of the members to contribute, which also limits the size of the financial transactions and the benefits package, not to the scale of the scheme. In practice, most HMIS are relatively small, counting less than a few thousand beneficiaries. Worldwide, such schemes are relatively few in number but are growing rapidly. They exist in such countries as Bangladesh, Benin, Burkina Faso, Cameroon, Congo, Côte d'Ivoire, Ghana, Guinea, India, Kenya, Mali, Nepal, Nigeria, the Philippines, Rwanda, Senegal, South Africa, the United Republic of Tanzania, Togo, Uganda, Dominican Republic, Ecuador, Guatemala, and Nicaragua.[5]

Like all systems of insurance, HMIS are based on the pooling of resources and the sharing of risks among the members of the group.[6] There is increasing evidence that pooling of risk and resources are particularly important to poor communities because they can significantly increase their level of security. Belonging to the pool means that households are less threatened by the possibility of having to decapitalize – deplete their savings and/or sell their assets – in order to cover medical costs.[7] Thus, HMIS can constitute a mechanism for excluded households to decrease their vulnerability to illness and help them to confront health-related expenditure that might lead them into – or further into – poverty. The schemes can make the greatest difference to the lives of women, easing their burden of caregivers thanks to the increased access to needed health services and by increasing their level of security.

HMIS, as referred to throughout this document, differ from commercial health insurance schemes in fundamental ways. They are typically not-for-profit and hence do not have the selection of risk as a central strategy.[8] They are also typically characterized by a high level of social cohesion among the members, stemming from being part of the same community. Contrary to commercial insurance, members usually know each other directly or

In many countries there are examples of hospitals that have established schemes to increase access of the local population to health services, including services related to HIV/AIDS. The Kisiizi Hospital Health Plan (KHHP) in Uganda covers the costs of testing and counselling and of opportunistic diseases, thereby furthering its work related to HIV/AIDS.

indirectly, and are therefore more likely to take collective action and to engage in mutual help activities.[9]

The civil society associations and organizations that have established HMIS vary. Schemes have been set up by informal trade associations[10] and informal economy cooperatives,[11] by faith-based organizations,[12] by village associations and by women's or youth associations. Some development organizations that are best known for their provision of micro-credit have introduced health micro-insurance schemes, typically to protect their members against the financial risks brought about by health problems.[13] Local and regional governments have introduced schemes within the context of health sector reform.[14] There are also NGO health providers, many of which are faith-based, that have set up HMIS. For the purposes of this document, the HMIS being considered are those where the governance structure resides primarily within a community-based group in civil society rather than within an NGO or development organization.

The structures that provide support to the schemes also vary according to the context. They may be national or international and typically include both governmental and non-governmental institutions. Examples of support structures are:

- networks, federations and NGOs set up with the specific objective of providing support to HMIS – these could be international, regional,[15] national or sub-national;[16]
- informal trade associations and movements of workers in the informal economy that provide support to individual trade groups[17] – typically established to defend the rights of workers in the marketplace, they are increasingly becoming involved in action to help members meet their other needs;
- NGOs that are directly or indirectly involved in the provision of health care – many of these may themselves be actively engaged in the fight against the HIV/AIDS pandemic. Support may be financial, as in the case of subsidies or

The "Concertation entre les acteurs du développement des mutuelles de santé en Afrique de l'Ouest et du Centre" is an example of an international network. It has a web site (see www.concertation.org) and also uses workshops and newsletters for tracking and sharing local, country and subregional activities related to health micro-insurance. The "Concertation" receives technical and financial support from a number of international partners including: the ILO's global Programme STEP, Partnership for Health Reform Plus/USAID, the Association Internationale de la Mutualité, Deutsche Gesellschaft für Technische Zusammenarbeit (GTZ), the Belgian Alliance Nationale des Mutualités Chrétiennes, the French Réseau d'Appui aux Mutuelles de Santé and the Belgian Union des Mutualités Socialistes.

The Association guinéene de bien-être familial (AGBEF), active in the fight against sexually transmitted diseases, including HIV/AIDS, is providing support to local communities in the establishment of HMIS in order to facilitate access to health services, and in particular to reproductive health services. Similar action is being taken by the Association sénégalaise de bien-être familial (ASBEF).

preferential fees for beneficiaries of the scheme, or technical, such as for the checking of drug prescriptions;

- micro-credit institutions – while some micro-credit institutions have set up their own HMIS, others support the establishment or functioning of schemes, for example by using regular capacity-building sessions with loan groups to cover health education topics and/or by directly promoting HMIS membership among the groups;

- local government structures – especially in countries that have made significant strides in the process of decentralization;

- a variety of other national and international NGOs – these may operate at community, district or national level.

## Decentralized systems of social protection and HIV/AIDS

# 3

DSSP can be found in areas where prevalence rates of HIV/AIDS are high as well as in areas where they are still low. HIV/AIDS can pose a threat to the viability of the systems. When members of a savings and loan scheme are affected by HIV/AIDS, either directly by contracting the disease, or indirectly by having to care for others who are ill or who have been left behind by an AIDS-related death, they may be unable to repay loans and may jeopardize the viability of the scheme. In the case of HMIS, the prevalence of HIV/AIDS introduces significant risks of increases in claims and, in the worst scenario, bankruptcy by the scheme because of inability to cover the claims. Short of bankruptcy, increasing claims can also mean increased premiums in order to meet the claims.

However, on the positive side, DSSP can play an important role in the fight against HIV/AIDS. Ad-hoc evidence shows that as the first cases of AIDS appear among members of schemes, they are typically dealt with on a case-by-case basis. The benefits that DSSP can provide on their own are limited. Even HMIS do not – cannot – cover all the health-related costs. However, the schemes make an effort to link individuals and households to other care and support services, including those being provided through national HIV/AIDS programmes. The ad hoc evidence also shows that, when faced by this situation, the DSSP begin a process of reflection on what actions to take in order to face the pandemic. This type of reflection may also begin within schemes that are in areas of low HIV/AIDS prevalence. It may result from specific situations faced by the scheme, such as having migrant workers among their beneficiaries who are at disproportionately higher risk of contracting HIV/AIDS, or from educational efforts undertaken by government and/or NGOs active in the fight against HIV/AIDS.

> "Micro-insurance is not merely another form of insurance or health care financing. It is a form of social organization, based on the concepts of solidarity and risk-pooling, which involves the active participation of the groups' members."
>
> Source: **World Labour Report 2000: Income security and social protection in a changing world**. ILO, 2000, p. 87.

HMIS and, more broadly, DSSP have been widely considered as mechanisms to reduce financial barriers to health care. In fact, they are often clustered under the broad heading of systems of community health financing. This characteristic is indeed important in terms of their contribution to the fight against HIV/AIDS. However, their broader social role is also

of central importance. This relates to how DSSP can improve people's lives by increasing the voice of individuals and groups that were previously excluded, by enhancing their linkages to institutions that provide social services and by strengthening their ability to participate, negotiate, change and hold accountable institutions that affect their well-being. Thus, DSSP can effectively contribute to improving the situation of women.

The description of the potential contribution of DSSP to the fight against HIV/AIDS, outlined in the next portion of the document, comes from knowledge to date of how the systems are functioning and, in some cases, from extrapolations that stem from existing practices. The description is in no way meant to suggest that individual DSSP should engage in all of the actions outlined. As emphasized earlier, the schemes vary widely in terms of their size, gender composition and governance structure, as well as in terms of the context in which they operate. These factors influence their potential to contribute to the fight against HIV/AIDS.

It is also important to emphasize that the document does not wish to suggest that DSSP should be used to shift ever-greater responsibility and burden on communities to face the pandemic. On the contrary, the aim is to actively explore how the decentralized systems can serve to channel greater support and resources from governmental as well as non-governmental institutions to those in greatest need, especially women.

## 3.1 Effective and potential contribution as it relates to health care

An important appeal of DSSP comes from their role in organizing resources to increase access to health care. This, as well as a number of other ways in which DSSP can contribute to the fight against HIV/AIDS in strengthening health systems,[18] are considered below.

- **Access to health care services** – DSSP are already making a difference by enabling members living with HIV to access health care more easily. Increasing access to care is the primary objective of HMIS. Benefit packages cover, in varying degrees depending on local situations, treatment of opportunistic infections and elements of palliative care which are not only linked to HIV/AIDS. Some also cover HIV testing as part of outpatient services. Individuals and households benefit from this insurance coverage whether or not they are aware of their HIV status. Other DSSP, such as those primarily aimed at ensuring income security, may also contribute to increased financial access to health care.

  For HMIS, there is legitimate concern on the part of the schemes that covering the expenses needed for the care of patients with HIV/AIDS may jeopardize their

financial stability. Therefore, they need to strengthen their capacity to determine how to include care and treatment of HIV/AIDS-related illnesses in their benefits package so that it maximizes HIV/AIDS-related health care coverage without jeopardizing the viability of the scheme. Work along these lines has already begun by HMIS in some countries.[19]

Even where HMIS are considering amending their benefits package to include HIV/AIDS-related illness, it is unlikely that they could cover the cost of anti-retrovirals (ARV) because it is still very high relative to the level of contribution affordable by members. This situation could change rapidly if the ARVs become available in either public or private pharmacies and health centres at an affordable – perhaps subsidized – price. In that context, HMIS can play a role in enabling national HIV/AIDS programmes that may provide subsidies for ARVs to reach individuals in communities that may otherwise be difficult to reach.

HMIS can further contribute to the fight against tuberculosis (TB), particularly in countries where there is an explicit national commitment and a corresponding policy to fight TB, accompanied by subsidies to ensure financial access to TB testing and treatment. In these contexts, HMIS can work in collaboration with the health delivery points to promote and perhaps to administer TB tests and to facilitate access to appropriate treatment. This type of action is especially relevant where TB cases are increasing as a direct result of HIV/AIDS. It is of particular interest to explore how experience in this area will lead the way towards an

*In the village of Ngongo in Mali, no children have died of malaria since a HMIS has been established. According to the managers of the scheme, this is not only because services are more accessible, but also because women now bring their children to the health centre early thanks to the health information made available to them by the scheme. The scheme also organizes peer education activities among adolescents to increase knowledge and responsible behaviour, particularly with respect to reproductive health. In addition, the scheme promotes ante-natal care by requiring pregnant women to attend at least four sessions in order to be eligible for delivery benefits. The prevention extends immediately to their newborns. The scheme promotes immunization positively by providing mothers with the Extended Programme of Immunization (EPI) booklet free of charge, and negatively by not covering EPI illnesses if the proper immunization schedule was not followed. Other schemes are helping to prevent malaria by facilitating access to mosquito nets.*

*A number of HMIS are already engaged in HIV/AIDS information and education activities. In Zabre, Burkina Faso, the HMIS Leere Laafi Bolem undertakes village-based educational activities in the 83 villages where it has members. Working with village committees, it reaches well beyond its membership of approximately 5,000. The educational activities are organized with the support of the Initiative Privée et Communautaire contre le SIDA au Burkina Faso (IPC/BF).*

important role in facilitating access to ARVs when they become available at affordable prices.

- **Prevention** – DSSP are effective mechanisms for health promotion to the degree that the health of their members is a central objective. This is the case for HMIS, for which prevention is also an effective way to contain its costs.

  DSSP can promote health through educational activities that raise awareness on the importance of protection and appropriate health-seeking behaviour. This can be complemented by action within the community, for example to increase the availability of condoms. In addition, HMIS can encourage prevention through the design of the benefits package.

- **Voluntary and confidential counselling and testing** – VCCT embodies the linkages between prevention and care as well as the articulation between the services that need to be provided by the health delivery points and the actions that can be taken by individuals and communities. The very presence of a scheme that covers some elements of treatment and care related to HIV/AIDS can be an incentive for people to undergo testing. There is evidence that people are more likely to use VCCT when they know that some form of treatment is accessible.[20] In addition, as noted above, HMIS can design their benefits package to promote ante-natal visits, thereby contributing to the uptake of VCCT among pregnant women and to the prevention of mother-to-child-transmission (PMTCT).

  Many hospital-based HMIS cover the costs of HIV/AIDS testing and counselling and some link it to other benefits. The community-based, Ishaka Hospital Health Plan in Uganda, established by the hospital to increase access of the local population to health care, strongly advises pregnant women to undergo an HIV/AIDS test during antenatal sessions.

  HMIS could do more in the promotion of VCCT. Where the laboratory infrastructure and distribution system for test kits exist, they could include the cost of testing in the benefits package and link it to ensuring the result of the test is received and to pre and post-test counselling. Potentially, they could play a role in the administration of the tests, devising community-based solutions to address issues of confidentiality, partner notification and possible stigma.

  Another important contribution could be in providing counselling. This would not only provide a direct benefit to members but could represent a way for the scheme to facilitate links to systems of community-based care as well as to institutions or organizations providing other types of needed non-health services. This social role of the scheme is elaborated in the next section.

In addition, HMIS can improve the capacity of health providers to deliver health services. An important reason is that they render payments to health facilities more regular. This enables health providers to improve planning and to take greater advantage of economies of scale in the purchase of drugs and equipment.

## 3.2 The broader social role of decentralized systems of social protection

Possibly, the most important contribution of DSSP in the fight against HIV/AIDS relates to their role in decreasing the exclusion of individuals and households and enabling them to participate more actively in issues related to their health. Where they contribute to strengthened solidarity, the ability of individual members to face their problems will be greater, to the degree that they are less isolated and are supported by the group. Within the group, DSSP can play an important role to:

- **Address stigma and discrimination** – The issues related to stigma and discrimination prevalent in a particular setting are bound to be reflected within a DSSP. Thus, there is the danger that, if members of a DSSP are faced with HIV/AIDS, they may "disappear" rather than confront the stigma that could ensue from their approaching the DSSP for assistance. However, on the positive side, many DSSP manifest a high degree of social cohesion, as well as a commitment to a social role and a willingness to go out of their way to care for members, to the point of making important exceptions in order to cover their needs.[21] In view of this, they can provide a conducive setting for addressing issues of stigma and discrimination. Their efforts in this area can be enhanced through partnership with associations of people living with HIV/AIDS. One area that would need special attention, in this context, is the confidentiality of medical records of members.

DSSP can also increase the capacity of the community to interact with government and non-governmental institutions that affect the well-being of their members. They can facilitate linkages and partnership between the community and institutions that provide a multitude of social services. Beyond this, they can serve as a community-based mechanism to channel resources to the local level. In the context of the fight against HIV/AIDS, this constitutes perhaps the greatest untapped potential. They can serve to:

- **Link beneficiaries to needed services** – As noted earlier, ad hoc evidence shows that since DSSP recognize their limitations to covering the needs of beneficiaries affected by HIV/AIDS, they provide support by linking individuals, families and communities to a variety of service providers (government, not-for-profit and private) that can assist members not only with health problems, but also with the provision of psychosocial support, support with the planning for the well-being of

the children (including their education), legal support relating to issues of inheritance and financial support to cover costs of burial and loss of income. The linkages to the services may be institutionalized or informal. Examples already exist where HMIS reach agreements – sometimes contracts – with NGOs or government institutions whereby the HMIS identifies and refers household and individuals in need so that they can benefit from services.[22] Some of the services may be provided by or through national HIV/AIDS programmes.

- **Channel resources to the local level** – To the extent that DSSP are truly community-based and governed by democratic principles, they are responsive to community needs and accountable to their members. They can therefore be used by government and NGOs to channel resources and penetrate deeper into communities so as to reach those in greatest need.[23]

  A direct, but limited way for governments and NGOs in general, and HIV/AIDS programmes in particular, to channel resources to individuals and households affected by HIV/AIDS is to cover the membership fees of families that cannot afford them. In health schemes, these may take the form of matching funds or grants.[24] In the area of education there are also examples where contributions made by families towards the education of their children are matched by scholarships from NGOs or government programmes.

  Government institutions and NGOs can channel more substantial support through the DSSP by providing them with grants or subsidies to undertake local action. The channelling of resources may entail a contractual agreement between the support structure and the DSSP that defines the responsibilities of each of the parties. The local level action can be related to prevention or to care and would typically benefit the community broadly, not only the members of the scheme. The grants or subsidies can provide the necessary resources for DSSP to take on the activities described in the previous sections more fully.

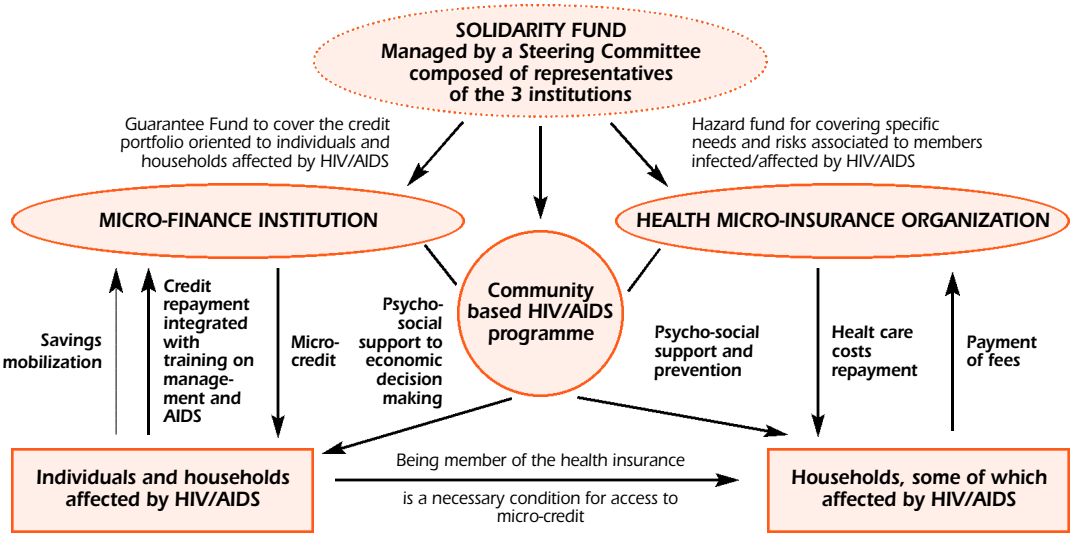
The last two points – link to support services and channel for resources to reach local level – are essentially two aspects of the central concept that the contribution of DSSP in the fight against HIV/AIDS is directly related to their ability to increase the access, by individuals and households in need, to available resources. For DSSP, the partnership with support structures is needed to strengthen their capacity to assist individuals and households affected by HIV/AIDS. Indeed, in view of the significant limitations of the contributory capacity of the members of the group, the impact of DSSP on prevention and care of HIV/AIDS would be very limited if the schemes relied solely on the contributions from their members.

For the support structures, the partnership with DSSP can represent a way to increase their effectiveness in the fight against HIV/AIDS by enabling them to reach

individuals and households that may otherwise be excluded. It can be especially important for HIV/AIDS organizations and associations of people living with HIV/AIDS based in urban areas to extend their reach to populations in rural areas.

The effectiveness of this partnership in addressing the pandemic is further enhanced to the extent that the support structures encourage the exchange of experiences among the different schemes and are themselves part of national and/or international networks that encourage the dissemination of lessons learned and facilitate the replication of positive experiences.

Burkina Faso provides an example of a partnership being developed among three support structures that are confronted daily with HIV/AIDS and are convinced that their individual impact on the epidemic will be much more effective if there is a greater integration of their approaches. One of the organizations has the fight against HIV/AIDS as a primary goal. It is the «Initiative privée et communautaire contre le SIDA au Burkina Faso» (IPC/BF), the in-country partner of the international NGO "Step Forward for Children" and the International HIV/AIDS Alliance. The other two are AQUADEV, an international NGO specialized in micro-finance, and ILO/STEP, which has been providing support to health micro-insurance. At the International Conference on AIDS and STDs in Africa, held in Ouagadougou, Burkina Faso in December 2001, they presented the intermediate results of a common reflection. The following diagram describes the synergisms envisioned.[25]




Source: Poster presentation, International Conference on AIDS and STD in Africa, Ouagadougou, December 2001, Aquaved International, International HIV/AIDS Alliance, IPC/BF and ILO/STEP

The impact of DSSP with respect to HIV/AIDS will be greater and more permanent if positive experiences serve as building blocks for national systems of social protection, where these benefit from direct or indirect government support. In this context, ILO is providing support to programme and policy development in a number of ways, all of which can be further sharpened to highlight issues relating to HIV/AIDS.

One major area of work is the analysis of the existing legal, administrative and policy context to see how it can be made more conducive to support local level action. Related to this is the analysis of how existing "classical" systems of social protection and decentralized systems can be linked so as to develop truly national systems of social protection. Progress along these lines would have a fundamental impact on the national capacity to face the HIV/AIDS pandemic.

# Conclusion and possible next steps

# 4

DSSP will not, by themselves, resolve the HIV/AIDS crisis. Nonetheless, they can make an important contribution to the fight against the pandemic, in particular to groups of workers in the informal economy. A number of actions, suggested below, are envisioned to more fully understand the role of DSSP in the fight against HIV/AIDS and to strengthen their potential. In order to pursue these actions effectively, partnerships among actors involved in the areas of DSSP and HIV/AIDS will be crucial, within the ILO, with the other UNAIDS co-sponsors and with other international partners.

- **Research and analysis on the impact of HIV/AIDS on work and workers in the informal economy** – Very little attention has been given to the impacts of HIV/AIDS on human capital in the informal economy, and few initiatives on HIV/AIDS are targeting informal economy workers, despite their economic importance and growing numbers. The analysis needs to consider the different effects of the pandemic on women and men, and cover health and non-health problems brought about by the pandemic, including the care of children who have lost one or both parents.

- **A systematic analysis of existing DSSP to draw lessons on how they address HIV/AIDS** – The bulk of the analysis needs to be undertaken by existing DSSP, using participatory processes. In this way, it can simultaneously serve to raise awareness and understanding of HIV/AIDS among the DSSP involved and lead to concrete local action. To do this most effectively, the analysis needs to associate key stakeholders and support structures, also providing them with the opportunity to assess how they can more effectively channel their resources. Thus, it can serve to facilitate the development of joint action in the context of the fight against HIV/AIDS. It can also create specific opportunities to promote openness about HIV/AIDS and reduce the associated stigma and discrimination among the participating schemes.

  The analysis needs to ascertain if and how DSSP establish linkages with governmental and non-governmental institutions and if and how these serve to channel resources to households affected by HIV/AIDS and to increase their access to needed services. ILO/STEP has begun to promote this analysis among the DSSP that are part of its existing networks and among its development

partners. A more systematic effort should lead to greater understanding not only of the existing and potential contribution of DSSP, but also of the factors that influence this potential.

- **Further action and experimentation** – By giving greater visibility to the contributions already being made by DSSP and support structures in the fight against HIV/AIDS, the process of assessment and analysis of current ways to address the pandemic can both increase confidence in their ability to make a difference and point to ways in which they can do more. It is essential that support be provided from local, national and international levels to promote additional community-based action identified as being effective. Initiatives targeting informal economy workers and their families must recognize that their needs and realities often differ from those of other workers.

  While much can be drawn from existing practices, support also needs to be provided for further experimentation of ways in which DSSP can contribute to the fight against HIV/AIDS. Of particular importance is the experimentation and documentation of experiences aimed at enhancing the capacity of DSSP to serve as mechanisms through which support structures at national and international levels can channel resources to the community level. Experimentation with providing specific subsidies to DSSP needs to continue, as does the analysis of ways in which local systems can be articulated with "classical" systems of social protection.

- **Dissemination and application of lessons** – The dissemination of lessons also needs to be undertaken together with DSSP. ILO/AIDS, ILO/STEP and their development partners can facilitate the sharing of lessons regarding the contribution of DSSP in the fight against HIV/AIDS among DSSP and relevant stakeholders at national, regional and international levels and promote the application of the ILO code of practice to the specific challenges faced by workers and their families in the informal economy. Dissemination of experience at national level needs to be done in ways that not only influence the DSSP, but also inform the design of national HIV/AIDS programmes and the decisions relating to resource allocation. Experience also needs to be more systematically shared at international level so as to be considered by the international community in decisions regarding support being provided to countries.

  Concrete ways to disseminate the experience include incorporating it in training tools and capacity-building activities being organized at local, national and international level. Existing training materials and courses used to assist organizations and associations in civil society to establish new schemes and to strengthen existing ones can be revised to incorporate a sharper focus on

HIV/AIDS. New materials may also need to be developed. Within the ILO both ILO/STEP and ILO/AIDS are working in close collaboration with the International Training Centre in Turin in organizing decentralized training courses on HMIS and activities on the implementation of the ILO code.

The increased knowledge, understanding and mobilization resulting from these actions would not be limited to decentralized systems of social protection. Much of the experience would also be directly applicable by other groups in civil society (cooperatives, informal trade associations, community-based organizations) that may not – or not yet – have a structured system of social protection.

**Notes**

[1] Speech by Juan Somavia, Director-General of the ILO, UNGASS, 25-27 June 2001, New York.

[2] ILO. 2000. *A threat to decent work, productivity and development*. Document for discussion at the Special High-Level Meeting on HIV/AIDS and the World of Work, ILO, Geneva, 8 June 2000.

[3] ibid.

[4] See ILO/Social Finance Unit Working Paper No. 25 for a more in-depth analysis of the strategies for HIV/AIDS mitigation and prevention adopted by micro-finance institutions.

[5] ILO/STEP. 2000. *Health micro-insurance: A compendium* (Geneva, ILO/STEP).

[6] The concept of pooling of resources and sharing of risk can be illustrated by the following example: a group of 10,000 individuals estimate that, on average, their probability of having to pay for a delivery is 4% in any given year. The cost of such care is $50. Assuming no additional costs or benefits from pooling, all members of the pool would be fully covered if each paid a yearly premium of $2. When resources are pooled, the cost of a delivery is borne by all members of the pool, thereby making it financially accessible for each of the members who actually need to use it.

[7] WHO. 2000. *The World Health Report 2000 – Health systems: Improving performance* (Geneva, WHO), Chapter 5.

[8] Like all insurance systems, micro-insurance needs to be set up in ways that minimize adverse selection (when people with a higher than average health risk join a scheme in a proportion higher than what they represent in the population as a whole).

[9] The importance of this social cohesion and its relationship to the likelihood of HMIS to make special efforts to assist members in need was documented in a working paper on the capacity of HMIS operating in Dakar, Senegal, to intervene in support of PLWA, Institut de recherche pour le développement (IRD), December 2000.

[10] One of the largest and best known is the integrated insurance scheme that is part of the social protection initiatives undertaken by the Self-employed Women's Association (SEWA) in India.

[11] An example in the Philippines is the health insurance programme set up by Novadeci, a cooperative of small market vendors and micro-enrtrepreneurs (mostly women ) operating in Novaliches.

[12] For example, the Atiman Health Trust Fund in Tanzania is organized around Christian parish communities.

[13] Examples in Asia include the Gremeen Kalayan health insurance scheme in Bangladesh created by the Grameen Bank and the scheme created by the Groupe de recherche et d'échanges technologiques (GRET) in Cambodia. In Africa, examples include schemes set up by FINCA in Uganda.

[14] The Bukidnon Health Insurance Programme (BHIP) and the Guimaras Health Insurance Project (GHIP), both in the Philippines, were initiated by the regional government together with NGOs and other social stakeholders.

[15] An example of a national federation is the Union technique de la mutualité (UTM) in Mali; the Community Based Health-Financing Association (UCBHFA) in Uganda is an example of a national network that facilitates exchange among HMIS and provides technical support.

[16] An example at sub-national level is the Coordination des mutuelles de Thiès in Senegal.

[17] Examples of informal trade associations or movements can be found in most countries. In Tanzania, the informal trade movement VIBINDO has been providing direct support to trade groups in the establishment and functioning of HMIS. In Senegal, the national federation of fishermen, FENAGIE-Peche, provides assistance to local unions of fishermen to set up HMIS. As at 2002, five schemes are functioning in different locations.

[18] As per the WHO definition, health systems include "all activities whose primary purpose is to promote, restore and maintain health".

[19] In Burkina Faso, a methodology has been developed to calculate an insurance premium for HIV/AIDS-related health risks. It includes the cost of ARV treatment and makes it apparent that, if it were included without the benefits of a subsidy, the resulting premium would not be affordable for most members.

[20] UNAIDS. 2001. *Together we can* (Geneva, UNAIDS).

[21] See IDB working paper, op. cit.

[22] For example, the Mutuelle des volontaires de l'education nationale et des maîtres contractuels of Senegal works with the NGO SOS. Children's Village to find a placement for orphans in difficult situations.

[23] For example, thanks to a subsidy from an NGO, the mutual health scheme *Wer-wer-le*, established by the Programme de femmes en milieu urbain in Dakar, Senegal, is establishing a special fund to assist individuals and households, especially children and older people, facing financial obstacles to access to health care.

[24] For example, in Rwanda, a church group paid the enrolment fee for 50 individuals to join the HMIS associated with the health centre of Matayzo. All of them were members of an AIDS association. UNAIDS case study: *Paying for HIV/AIDS services – Lessons from National Health Accounts and community-based health insurance in Rwanda, 1998-1999*, September 2000.

[25] The original diagram included a differentiation among individuals and households of different economic status. It showed that the beneficiaries/members of the micro-finance organization and the micro-insurance institution were made up primarily of the poor and the very poor and that these institutions, as well as the community-based HIV/AIDS programme, envisaged actions in favour of the destitute.

Annex 1

# The ILO global Programme Strategies and Tools against Social Exclusion and Poverty (ILO/STEP)

The STEP global Programme was launched in 1998. Located within the Social Protection Sector of the ILO, it constitutes a mechanism to promote knowledge development and innovation in two interlinked areas:

- the fight against social exclusion and poverty;
- the extension of social protection, especially in health.

With respect to the latter, STEP has placed particular attention on health micro-insurance, recognizing its potential to increase the access of workers and families in the informal economy to health care services of quality. Programme activities include the following major objectives:

1. enhance understanding of how different mechanisms, including micro-insurance, can contribute to improved access to health care;
2. encourage experimentation and development of systems of social protection that reach workers in the informal economy who have little or no access to formal systems of social protection;
3. explore ways to create or strengthen linkages between decentralized and national systems of social protection, to increase their effectiveness in ensuring access to health care to the population in greatest need;
4. promote the use of the greater understanding of decentralized systems of social protection and their relationship to national social goals in the context of national legal and policy reform and to inform the international debate on the extension of social protection.

Concrete activities include providing direct assistance in selected countries, operations research and policy analysis. Within countries, STEP provides technical support at both local and national levels, placing particular emphasis on the linkages between the two. Thus, STEP works with organizations of workers and of employers, women's groups, civil society organizations, cooperatives and health service providers. Concurrently, it engages national and local government and non-governmental institutions and a variety of international development and UN organizations in addressing major policy and operational issues regarding social protection in health. STEP also supports the establishment and strengthening of support structures and networks that can provide sustained assistance to decentralized systems of social protection in health.

The knowledge development is also pursued through training activities and production of tools and publications at country and international levels (please refer to http://www.ilo.org/public/english/protection/socsec/step/intro/publs). Rather than defining and disseminating "pre-packaged" models, STEP works with existing schemes and relevant stakeholders to document experience (e.g. through case studies) and to develop tools (e.g. manuals) and training materials. STEP privileges participatory methodologies also because the documentation and exchange of experiences with stakeholders promote the further development and extension of innovative systems of social protection.

# The ILO Programme on HIV/AIDS and the World of Work

Annex 2

The ILO's commitment to HIV/AIDS resulted in the creation of the global Programme on HIV/AIDS and the World of Work (ILO/AIDS) in November 2000. This received the support of representatives of the ILO's tripartite constituents from around the world.

**The Programme objectives are:**

- to raise awareness of the economic and social impact of HIV/AIDS in the world of work;
- to help governments, employers and workers address HIV/AIDS through technical cooperation, training, and policy guidance on prevention, care and social protection;
- to fight discrimination and stigma related to HIV status.

The Programme's activities are based on the promotion and implementation of the ***ILO code of practice on HIV/AIDS and the world of work***, which forms the cornerstone of ILO efforts against HIV/AIDS. This code, developed through tripartite consultations in 2001, received the support of the UN Secretary General and UN system at the General Assembly Special Session on HIV/AIDS, New York, 25-27 June 2001, as well as of corporations, labour organizations and NGOs.

The code is intended to help reduce the spread of HIV and mitigate its impact on workers and their families. It contains fundamental principles for policy development and practical guidelines from which concrete responses can be developed at the enterprise, community and national levels in the following key areas:

- **prevention** through information and education and practical support for behaviour change;
- **non-discrimination and protection** of workers' rights, including employment security, entitlement to benefits, and gender equality;
- **care and support**, including confidential voluntary counselling and testing, as well as treatment in settings where local health systems are inadequate.

**Programme activities include:**

- **research and policy analysis** on HIV/AIDS issues in the world of work;
- **development of education and training programmes** – to support the implementation of the code of practice, exchange experience, and strengthen the capacity of governments and the social partners to respond to HIV/AIDS;
- **technical cooperation projects** which support and strengthen the development of workplace policies and programmes on HIV/AIDS;
- **advice to governments and the social partners** on integrating workplace issues in national AIDS plans, and on revising labour laws to address HIV/AIDS;
- **technical meetings** at global, regional and national levels to raise awareness of the urgency of the impact of AIDS in the world of work, present the code and mobilise the ILO's constituents;
- **fact-finding and programme development missions** in Africa, Asia, the Caribbean, and Central and Eastern Europe.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