UK Consortium on AIDS and International Development

POLICY BRIEFING March 2012

PAST DUE: REMUNERATION AND SOCIAL PROTECTION FOR CAREGIVERS IN THE CONTEXT OF HIV AND AIDS

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EXECUTIVE SUMMARY

In sub-Saharan Africa, an estimated 90% of care for people living with HIV and AIDS is done in the home by family or community-based caregivers.[1]

2011 brought groundbreaking advances in HIV prevention and treatment,[2] which, if fully implemented, hold the hope that we can reach the goal of an AIDS-free generation. Community mobilisation and service delivery have been identified by the UNAIDS Investment Framework and its Treatment 2.0 agenda as central strategies in realising this goal. Family and community caregivers have been at the heart of the community response to HIV since the beginning of the epidemic. Evidence has shown that the services they provide have played a significant role in helping to scale up antiretroviral (ARV) treatment and tuberculosis (TB) therapy, as well as linking patients to care and testing.[3]

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Recognising and compensating caregivers for their work will lead to better care for people living with HIV, and a more sustainable workforce with the potential to contribute to strengthening health systems overall. It will also address the right to fair wages long denied to the women who provide care and support services to the vast majority of people living with HIV around the world.

In line with human, women's, and labour rights standards, secondary caregivers must be given the choice to be remunerated for the work they do. We must debunk the notion that paying women caregivers will interfere with the spirit of community volunteerism. Volunteerism should always be an active choice, one that few secondary caregivers are provided with. Further, the unpaid work of caregivers must also not be seen as a cost saving or programme efficiency during this protracted economic downturn. On the contrary, introducing paid employment for women caregivers makes sound social, political, and economic sense particularly during economic crises, which impact severely on women.[4]

Current methods of compensating caregivers vary hugely but can include salaries, social protection, stipends, in-kind payments in the form of uniforms and supplies, access to credit and economic development opportunities, and various other incentive programmes for volunteers. All of these are critical for caregiving work because they ensure that caregivers are, at a minimum, not made poorer by the work they do. However, a growing body of evidence demonstrates that community-based secondary caregivers are essential human resources for achieving HIV and primary healthcare goals, and an emerging movement of health advocates argues that they should be paid salaries. Those who choose to volunteer or are unable to immediately meet the criteria to become a paid secondary caregiver should be provided with training, equipment, supervision, and financial support to cover their volunteer costs. Primary caregivers caring for family members should be able to access social protection to make up for income lost because of caregiving duties and the increased costs associated with caring for their relatives.

Donors, implementing governments, and non-governmental organisations have finally begun to recognise the importance of paying and extending social protection for caregivers. For too long caregivers within the HIV sector have been excluded from the broader discussion about the potential benefits of large scale community healthcare worker programmes. This brief makes the following recommendation:

Recommendation

Governments, donors, and international institutions should include costs and strategies for the remuneration of caregivers in budgets, programme plans, and technical guidance related to their role in the response to HIV. Compensation for primary caregivers should take the form of social protection and remuneration for secondary caregivers should take the form of salaries.

WHO ARE THE CAREGIVERS?

Caregivers in the HIV context are often referred to as lay or community caregivers. But it is important to further define this group into primary and secondary caregivers in order to develop appropriate remuneration and social protection strategies:

Primary caregivers

These are both adults and children who care for other family members in their homes. The majority of primary caregivers are women, often older women, who are looking after adult children and grandchildren. But primary caregivers are also children, often young girls caring for sick parents, grandparents, and siblings.[5] Because this work takes place within the extended family, it is outside both the formal and informal economies, and therefore invisible.

Secondary caregivers

These are community caregivers or other health workers who work as individuals or staff (paid or volunteer) of clinics, non-governmental

organisations (NGOs) and faith based organisations (FBOs). Some secondary caregivers also self-organise into community-based organisations (CBOs) and networks.[6] They often maintain a heavy schedule of home visits to community members living with HIV or caring for vulnerable children.

The link between primary and secondary caregivers

Secondary caregivers are a critical source of support for primary caregivers, providing advice and supplies to help them to care effectively for family members. Secondary caregivers also often accompany primary caregivers through the process of accessing health care, social protection in the form of social grants or cash transfers, as well as legal and other forms of social support. Many secondary caregivers are also primary caregivers to their own family members.

Caregivers are predominately women

Caregiving is generally considered "women's work" and as such it is undervalued, stigmatised, and usually without pay. The role that women typically play as custodians of their community's wellbeing and the heroic tasks they have assumed in the context of HIV should be recognised. But it must also be acknowledged that many women do not have much choice about whether to take on caring roles. Social and cultural gender norms often mean that women who refuse caring roles are ostracised or pressured to conform, and men who take on caring roles can be ridiculed and their masculinity questioned. Lack of remuneration for secondary caregiving work should be considered a form of structural discrimination against women that exacerbates their vulnerability to poverty and ill health. It should be listed alongside extremes of gender inequality such as the denial of access to property and inheritance rights, early marriage, and a raft of other women's rights abuses. Some have called the legions of unpaid caregivers a "conscript" army that is, *de facto*, subsidising the health sector, relieving the state of the lion's share of the burden of health expenditures.[7] A recent analysis of the rights violations inherent in unpaid care work argues that a woman's burden of care limits her ability to take part in civil and political life and to enjoy the education, leisure and enjoyment of life as enshrined in the Universal Declaration of Human Rights.[8]

> The goals of DFID's *New Strategic Vision for Women and Girls* would be furthered by global policies to remunerate and extend social protection to women caregivers and strengthen the community health worker sector. Community caregivers effectively integrate HIV and sexual reproductive health at the community level, ensure that young women are not conscripted into care work and can stay in secondary school, help women protect their property and inheritance rights after the death of a husband, and refer women victims of violence to appropriate social services.
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> See the UK Consortium Policy Paper entitled *Girls and Women: Mainstreaming HIV and AIDS into DFID's strategic vision* for recommendations on how DFID can better ensure that their efforts to promote gender equality could also achieve positive changes to address the gendered nature of the HIV and AIDS epidemic.

Caregivers are grandmothers and children

HIV has caused a shift in household structure and responsibilities. At a time in their lives when older people may have expected to be supported and cared for by their adult children, many find themselves the primary caregivers for their own children, for other family members living with HIV,[9] and finally for their orphaned grandchildren. In fact, 40-60% of orphans and other vulnerable children in high burden countries in east and southern Africa are cared for by their grandmothers.[10] The care relationship between grandparents and children is two way. Children living in households headed by older people often have more and physically heavier household duties. They have the burden of earning an income and many also provide care to their ageing grandparents.[11] Despite these challenges, research shows grandparent care is the preferred

option to other types of care if parental care is not possible.[12]

Caregivers are sex workers, drug users, men who have sex with men (MSM), and transgender people

In concentrated epidemics, key affected populations whose behaviours are often criminalised by the state are left to care for one another in the face of intense discrimination by both formal and community-based healthcare workers. Social protection measures often miss, or purposefully exclude, these populations, resulting in no relief whatsoever for the care burdens they bear.

Similarly, NGOs, CBOs, and FBOs running home-based care programmes are known to exclude key affected populations from the ranks of secondary caregivers. As a result, there are now a growing number of home-based care programmes run by and for sex workers, MSM, transgender people, and drug users.[13] These groups play a vital role serving their own communities and sensitising health providers about their right to healthcare, including to HIV and primary care that is tailored to their specific health needs.

Men as caregivers

Caregivers are predominately women, but innovative programmes that work with men to overcome gender stereotypes related to care work have begun to change this. For instance, DFID has supported Sonke Gender Justice to run gender sensitisation workshops that have led to men's involvement in organised caregiving in the Eastern Cape of South Africa and the emergence of male role models in the care and support context.[14] Older men are also caregivers of children orphaned as a result of AIDS, often grandchildren.[15]

WHAT DO HIV CAREGIVERS DO?

While the nature of home-based care has changed in recent years with increased access to antiretroviral therapy (ART), it remains as crucial as ever. Care and support services are needed from before diagnosis and throughout the course of HIV-related illness regardless of ability to access ART.[16] Before treatment was available, caregivers gave much of their time to nursing bedridden sick people. Today, they are more able to focus on providing a wide range of services including psychosocial, physical, socio-economic, nutritional, and legal support, referrals to medical care, and support with ART adherence. Nevertheless, still less than 50% of those in need of ART globally are receiving it.

"Care and support services are needed from before diagnosis and throughout the course of HIV-related illness regardless of ability to access ART."

Primary caregivers looking after children, both living with HIV and those who have been orphaned or otherwise affected by the epidemic, also take on many caring responsibilities. These range from ensuring children's access to health care and education to providing adequate food, shelter, clothing, and other basic needs.

Secondary caregivers are generally represented as non- or para-professional health care providers with basic training in primary health care, sanitation, and counselling for people living with HIV and other chronic illnesses, providing services in the sick person's home. In reality, caregivers do significantly more than this, acting as integrators of community and formal health systems, linking clients to primary health care and development support, and providing legal, social, and psychological counselling. Among the services they provide are:[17 18]

Psychosocial counselling and support

Caregivers provide ongoing psychosocial counselling including bereavement counselling, succession planning support groups, and life skills support for people living with HIV, orphans and other vulnerable children. This often includes interventions targeted at key affected populations and survivors of violence.

Clinical, referral, and adherence support

Caregivers provide adherence support for ART, Prevention of Mother-to-Child Transmission

(PMTCT), TB and medications to prevent opportunistic infections. They assist clients to handle the side effects of some of these medications, are involved in tracking clients who are lost to follow up and provide bed care, wound care, and personal hygiene to bedridden people living with HIV (PLHIV).

Behaviour change communication and education

Caregivers are involved in community education on HIV testing, treatment and prevention, family planning, and sexual health, including the distribution of prevention and family planning commodities.

Socio-economic services

Caregivers are engaged in livelihood, income generating, vocational skills and training activities to raise resources for their own caregiving efforts and to help their clients. They also distribute resources such as clothes and school fees and help ensure that clients have the documentation required to receive government benefits (birth certificates, wills, medical records, etc.).

Nutritional services

Caregivers perform nutritional screening and distribution of food rations to clients. They also counsel clients receiving ART about nutritional issues related to treatment. They assist their clients to increase their food security through gardening, farming, and feeding programmes.

Advocacy, human and legal rights activities

Caregivers conduct campaigns against stigma and discrimination and advocate for better and more services and funding for HIV. They also facilitate solutions to cultural practices such as wife inheritance and land grabbing, which are both triggered by, and leave people more vulnerable to HIV. They refer and accompany clients to legal services.

Health and community systems strengthening

Caregivers build partnerships and linkages to increase coordination among church groups, government, farming groups, health professionals, hospitals and clinics, social workers, traditional leaders, NGOs, religious leaders, caretakers, traditional healers, and birth attendants. Some caregivers are also called upon to collect statistics on HIV prevalence and the numbers of orphans in communities, for governments and NGOs. This is an important function in disease surveillance.

THE IMPACT OF THE WORK OF CAREGIVERS

Unfortunately, the focus on ART has led many to the mistaken belief that as ART becomes more readily available, care and support services become redundant. In fact, this could not be further from the truth. Studies consistently show that there are physical and psychological symptoms at all stages of HIV infection, including for those on ART[19] for which caregivers provide crucial services and support.

For those who have access to ART, the evidence is now clear that care and support services are critical to promote early enrollment and retention in HIV services; improve ART adherence; encourage early use of ART and prophylaxis for opportunistic infections; reduce morbidity and death; improve physical wellbeing and quality of life; improve social support; and reduce stigma and discrimination.

The sad reality is that globally, 50% of people in need of ART still lack access. Care and support services are the only HIV services that can mitigate AIDS-related illness and make all the difference to the quality of life of those with AIDS related infection.

Secondary caregivers are a core component of community systems. They are the critical links with broader health and social protection systems. They refer patients to clinics and hospitals, demonstrating the capacity of caregivers to stimulate demand in, and access to, formal health systems. They strengthen community systems through "a*n approach that promotes the development of informed, supportive communities and community-based structures, enabling them to contribute to longer-term sustainability of health and other interventions at community level, and to the development of an enabling*

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and responsive environment in which these contributions can be effective."[20]

Secondary caregivers are also community deliverers of social protection mechanisms — particularly socio-economic services and human rights and legal support—and as such are crucial in helping to mitigate the social and economic impacts of HIV on individuals and households. UNAIDS writes that these services also help "*address the multiple social determinants of the epidemic – income inequalities, gender inequalities, social exclusion – and thus contribute to a reduction in new infections" as well as "address demand side barriers to access HIV services with potential to improve prevention, treatment and care and support outcomes*".[21]

THE ECONOMIC AND SOCIAL COSTS OF UNPAID CAREGIVING

For primary caregivers, the costs of caring for HIV-positive family members can be devastating; some studies estimate that the cost of care for people with HIV is twice as high as those with other diseases.[22] In Mozambique the average monthly cost of caring for an orphaned or vulnerable child is estimated at $21, and for a person living with HIV, $30. Yet the average monthly income for an older person, usually responsible for the caring, is just $12.[23]

Secondary caregivers, even those receiving stipends or salaries, draw upon their own limited resources for the costs of transport to visit clients and supplies with which to care for them. For example, in a study of 1,366 secondary caregivers, 87% reported using their own money to cover the considerable transport costs of visiting clients or accompanying them to the hospital.[24]

Family and community-based HIV caregivers report that they face discrimination and negative treatment from employees in hospitals and clinics. This is due in part to the low status attributed to home-based care work and the fact that many caregivers are very poor, often living with HIV themselves, and representing key affected populations. Further, the low valuation of caregiving work by formal healthcare workers, and caregivers' constant exposure to illness, death, dying, and HIV stigma, leads to high levels of isolation, burnout, fatigue and a general decline in their health and wellbeing.[25]

THE PERSONAL, SOCIAL, AND POLITICAL VALUE OF PERFORMING A CARING ROLE

Despite the burdens enumerated above, both primary and secondary caregivers experience their work as a source of pride and personal satisfaction. They also often recognise it as an expression of their faith, their love of and commitment to their families, and their commitment to developing their communities. A study of child primary caregivers shows that children can construct a positive identity around their care work, in some cases perceiving it as a source of strength and happiness.[26] A sense of self-worth and communal solidarity has sustained volunteer caregivers facing the most difficult of circumstances since the beginning of the epidemic.[27] Networking, organising, and peer learning among caregivers also has the potential to increase their political and decision-making

power at the community level.

However, while all these initiatives certainly help secondary caregivers, it is clear that for formal non-volunteer work, remuneration is an important recognition of personal, social, and political value.

THE CHANGING PROFILE OF COMMUNITY CAREGIVERS IN THE HIV RESPONSE

With the introduction and scale-up of ART we have seen a dramatic increase in funding for the HIV response. Most of the investment has been channeled, understandably, to the expansion of AIDS treatment. The limited funding available for care and support[28] has sometimes covered incentives, but has rarely covered recurrent costs such as salaries for secondary caregivers.

In recent years, two trends have brought us closer to the full recognition and compensation of caregivers; firstly the growing recognition of the importance of community health workers in reducing the burden on health professionals, and secondly the importance of community health workers in scaling up and extending the reach of crucial health services to populations that are not usually reached by formal health systems.

Task shifting

In 2006 the WHO issued guidance that recognised the role community health workers could play in reducing the pressure on over-burdened and insufficient medical professionals and called for a "task shifting" approach.[29] This approach involved the devolution of many of the tasks typically performed by medical staff to individuals generically described as 'community health workers'. Unfortunately these initial guidelines only really referred to government-employed community health workers and gave scant attention to non-government community health workers such as secondary caregivers. The guidelines also barely touched on how these workers taking on new roles would be supported, apart from stating that "*countries should recognise that essential health services cannot be provided by people working on a voluntary basis if they are to be sustainable.*"[30]

This position has improved in the last couple of years with increasing evidence of the effectiveness of community health workers[31] and the recognition that secondary caregivers are an important part of these cadres.[32] A 2010 study on community health workers in five countries by the WHO and the Global Health Workforce Alliance makes a strong case for a range of incentives for community health workers and recognises the growing donor willingness to finance human resources for health. However, the guidance falls short of promoting financial incentives, arguing that donor funding is unsustainable in the long run and government financing is not yet sufficient to fill the gap.[33]

Scale-up and reach

The recognition of the importance of the community-based response (including the work of caregivers) for scaling up HIV services and reaching the most vulnerable and hardest to reach is relatively new. UNAIDS' treatment platform launched in 2010, Treatment 2.0, is one of the first global HIV/health initiatives to identify the positive impact community caregiving and community mobilisation have on scaling up and extending the reach of HIV testing, treatment adherence, prevention practices, and reductions in stigma.[34]

MODELS OF COMPENSATION FOR CAREGIVERS

A comprehensive investigation of remuneration and social protection policies worldwide is outside the scope of this paper. However, we will draw out a number of models of compensation in use and start to explore their strengths and weaknesses with the aim of stimulating further research and planning for a global effort to devise and promote rights-based and sustainable remuneration and social protection polices for caregivers.

Social protection and incentives for primary caregivers

For primary caregivers, two types of support are

critical. The first is economic support through social protection mechanisms that may include care grants and allowances, cash or food transfers (see case study 1)[35], microcredit, income generating activities, and old age pensions. UNAIDS considers social protection for people affected by HIV as one of the 10 priorities in its 2009-2011 Outcome Framework, with an emphasis on ensuring access to social and cash transfers for primary caregivers.[36] Social protection should be HIV-sensitive, not HIV-exclusive, strengthening anti-poverty, health promotion, and development efforts overall. This approach is backed up by evidence that shows that in poor countries with high HIV prevalence rates, targeted cash transfer programmes to the poorest of the poor tend to have substantial AIDS mitigation impacts.[37]

While cash transfers are an important aspect of social protection, UNAIDS and care and support advocates embrace a broader view of these protections to include predictable financing for social welfare ministries, initiatives to promote access to services (i.e. school fee waivers), child protective systems strengthening, strengthened family and community support services for excluded and vulnerable groups, and legislative and policy reform designed to repeal anti-human rights laws that criminalise key affected populations.[38]

The second type of support for primary caregivers is related to their caregiving role and includes psychosocial support, including access to counselling, basic training in physical care, and provision of caregiving equipment. Primary caregivers, particularly grandparents, also need support in caring for their grandchildren, including guidance and training in taking on a parenting role in later life and the intergenerational challenges that may result. Secondary caregivers are critical for delivering this range of support to primary caregivers.

CASE STUDY 1: HIV-sensitive social protection for primary caregivers – The Kalomo Scheme, Zambia

In 2004 the Zambian government implemented a far-reaching social cash transfer scheme designed to reduce starvation and extreme poverty in 10% of the most destitute and incapacitated households in the pilot region (approximately 1,000 households). The programme prioritised elderly primary caregivers looking after orphans and vulnerable children and the chronically sick. Identification of the neediest families based on the criteria above was done by grassroots Community Welfare Assistance Committees using a multi-stage, participatory process involving village headmen, the community, and the District Welfare Assistance Committee.

An evaluation of the programme by UNICEF, based on assumptions drawn from data on national HIV prevalence and mortality rates, estimates that 70% of the households reached through the Kalomo scheme were AIDS-affected. Other results of the scheme included a decrease in target households living on one meal a day from 19.3% to 13.3%, and a 3% increase in school enrolment rates among 7-18 year-olds.

The AIDS impacts of social protection schemes, as pointed out above, are often based on assumptions and anecdotes because most low income countries do not yet have consistent social protection policies and programmes in place. The empirical evidence base on the AIDS mitigation impacts of social cash transfer schemes in these settings is still small. Operational research is urgently needed to guide national policy development and scale-up of cash transfer programmes that will reach people living with HIV and AIDS and their caregivers. A comprehensive set of recommendations to guide this research can be found on page 23 of the "Impact of Cash Transfers on Children Affected by AIDS", UNICEF, 2007.

Source: *The Impact of Cash Transfers on Children Affected by AIDS*, UNICEF, 2007

Incentives for secondary caregivers

As has been mentioned above, many secondary caregivers are provided with some form of incentives, although these vary considerably and are often insufficient. All secondary caregivers should receive adequate and ongoing training, supervision, equipment, uniforms, access to counselling, transport support (either compensation for transport costs or provision of bicycles), and reimbursement of out-of-pocket costs. An example is the Catholic Relief Service's HIV programming which recommends a comprehensive volunteer motivation package consisting of training and working materials, food incentives, transportation allowance and/or support, facilitating access to credit, income generating activities, "caring for the caregiver" activities, regular training and supervision, and recognition of the volunteers by their communities.[39]

Training, consistent supervision, and psychosocial support for caregivers should be considered not just as incentives, but as critical components of any caregiving programme. An extensive study of volunteer caregivers across Africa revealed that one-third of the 1,366 women interviewed had not received any training on HIV care, and 52% of those who had only received a single training before embarking on home visits.[40] In South Africa, studies show that approximately 89% of caregivers show signs of depression.[41] Lack of training exacerbates the stress and trauma associated with caring for the chronically ill and dying, and degrades the quality of care services provided. As part of all caregiver schemes, employers should provide long-term, continuous training, mentoring, and supervision programmes, and sustain and enhance community-driven psychosocial support strategies devised by, or in consultation with, caregivers.

Incentives and training are a crucial component in sustainability

Ndola Ecumenical Hospice Association (NEDA) in Zambia provides its 33 home-based caregivers with a ration of mealie-meal, monthly clothing in the form of a chitenge, T-shirt, and training shoes, and an umbrella. The caregivers have got together to keep chickens and sell eggs to supplement their income. The organisation has invested a lot of time in training the home-based care workers, and they receive monthly updates of the training. This combination of incentives and training has created a group of caregivers who have pride in what they do, are significantly skilled, and are committed to continuing their work. An indication of this is that some of the care workers have been with NEDA for over eight years.

Information from Internal Grant Monitoring Report from the Palliative Care Initiative of The Diana, Princess of Wales Memorial Fund

Livelihoods support and a career pathway for volunteer caregivers

Large cadres of caregivers, driven by strong community spirit and often religious conviction, freely choose to volunteer their time. These volunteer caregivers should be encouraged and fully supported in all the ways outlined above. It is critical that volunteer caregivers are not made poorer by the work they do. At a minimum, all out-of-pocket expenses should be reimbursed. However, recognising that they also need to make a living, a range of livelihoods support and time to pursue income generation is also key.

- *Livelihoods support*
  For volunteer and unpaid caregivers there should be a limit to the hours they can work (maximum of 20 hours a week) to ensure that they have time to pursue their own livelihood activities, and provision of income-generating training and activities, savings, and credit schemes.
- *Career pathway*
  For volunteer and unpaid caregivers there should be professional training and career progression opportunities that will give them the skills to be paid for what they do. In an example, Ethiopia's national Health Extension Worker Programme entitles paid community health workers to distance course learning and hands-on training that qualify them to become registered nurses. Guidelines are being developed to allow them to continue

their professional career even into higher degrees of qualification such as bachelors, masters and PhD degrees, subject to their fulfilling university entry requirements.[42] Such programmes should also be made available to volunteer or unpaid caregivers so that they have an opportunity to become accredited as paid community health workers if that is their goal.

Volunteering should be a choice

There are many secondary caregivers who are currently called 'volunteers' simply because they do not get paid. However, they do not choose to volunteer and would like to be remunerated for their work. These caregivers have a right to a living wage as do all workers. Given the economic constraints facing many of the countries with a high burden of HIV, it is understood that a sustainable remuneration solution may not be immediate. But this should never be an excuse to avoid the issue. A clear and time-bound path to remuneration is critical.

Stipends for secondary caregivers

A first step on a career path for unpaid or volunteer caregivers is the introduction of stipends either by non-governmental organisations employing caregivers or by the government. Some NGOs employing caregivers give stipends when donor funding allows. For example, the Stephen Lewis Foundation insists that all secondary caregivers in programmes they fund are provided with a stipend. The challenge for many NGOs is that donor funds tend to be short-term and the stipends are usually unsustainable beyond the life of the grant. Stipends are more sustainable when underwritten by government as part of the health system or a public works programme. Some country governments such as South Africa have initiated a national stipend for secondary caregivers but deliver this through NGOs. (See case study 2).[43]

Government salaries for secondary caregivers

In some cases, national governments provide salaries directly to secondary caregivers as members of a paid community health workforce. A good example of how this is possible in resource-poor countries with the support of external donors is the introduction of health surveillance assistants in Malawi (see case study 3).[44]

While this model may hold great promise for the future of remunerating and properly integrating community caregivers as respected and supported members of the health system, we need to be aware of a number of potential pitfalls:

- *Government takeover of NGO- or CBO-led programmes can limit effectiveness*
  Many caregivers fear that if home-based care programmes are taken over by government, bureaucracy, corruption, and cash-strapped health programmes will hinder their effectiveness. *A nuanced and careful approach to government absorption of NGO/CBO-led home-based care programmes must be considered when planning for scale-up so that they can maintain high-quality services.*
- *Blocked involvement of key population groups*
  Another well founded worry is that governments often refuse services to sex workers, MSM, transgender people, drug users, and migrants. *It is important that, where this is the case, services for these groups are delivered by NGOs and CBOs, and discrimination of these groups in government service provision is challenged.*
- *Inappropriate roles for caregivers and ineffective integration within the health system*
  The holistic approach to care undertaken by community-based caregivers tends to involve them in many aspects of health care promotion and community development (see list on pages 4 and 5 on what caregivers do). *It will be critical to assess the optimal number of tasks caregivers can be expected to deliver and ensure that they are effectively integrated with, and not duplicative of, primary health care and community development activities taking place in a given community.*
- *Accreditation and professionalisation that excludes current caregivers*
  History has shown that once community-

based caregiving activities are professionalised or accredited, women already at work in communities are replaced by people with more education and clinic-based experience. *Accreditation programmes and policies must be developed through intensive consultation with active community caregivers. Further, all efforts should be made to fill newly created paid home-based care positions with caregivers already working in communities.*

- *Macroeconomic impediments to long term sustainability*
  Government expenditures on health are often limited by public sector wage ceilings imposed by governments. These ceilings are usually a response to IMF restrictions designed to promote macroeconomic stability. In

CASE STUDY 2: A national community health worker policy in South Africa

In the 1990s, the South African government began supporting NGOs to employ caregivers to promote voluntary HIV testing and support directly observed TB therapy. By 2003, home-based care workers were integrated into the government's Comprehensive Care, Management and Treatment Programme guiding ARV rollout. In 2004, the government included home-based HIV caregivers and early childhood development practitioners in its Extended Public Works Programme as a bridge to formal employment for informal or unpaid workers. A study of the impact of the implementation of the South African community health worker policy in the Free State observes that HIV caregivers play a bridging role among patients, the wider community, and the health system. They amplify the voices of people living with HIV and build community knowledge and expertise on health systems.

Key Elements of National South African Community Health Worker Policy 2004 (National Department of Health 2004):

- It allows for both generalist and single-purpose community health workers (proposing better coordination of the latter at community level).
- Community health workers to receive a stipend but will not be government employees and will be employed through civil society initiatives.
- The preferred model is a government–NGO partnership where government provides grants to NGOs that employ the community health workers.
- Although voluntarism will continue to be encouraged, volunteers should not be employed more than a few hours a week without remuneration. Volunteers should also not be misled into believing that they will necessarily get paid work.
- Trainees should be residents of communities where they will work and be selected by those communities.
- Community health workers should have a support system, e.g. be part of an NGO/CBO and have access to a referral system.

The same study also points out that the South African programme suffers from ambiguous remuneration policies. The state has deliberately avoided absorbing caregivers into the civil service, and instead finances NGOs to pay them stipends. The intent of this, as shown in the policy above, is to foster government-NGO partnerships and an NGO/CBO-led support system for caregivers. The result, however, is that NGOs are seen as little more than disbursers of stipends and the caregivers attached to them do not have the same employment rights as other health workers. The stipends paid to home-based caregivers under the Extended Public Work Programme are lower than those paid to men engaged in infrastructure development, essentially formalising the gendered stigmatisation of care work in the context of a government programme.

Source: Schneider, Hlophe, et al., *Community Healthworkers and the Response to HIV/AIDS in South Africa: Tensions and Prospects*, Oxford University Press, 2008

addition, bilateral and private donors are resistant to supporting recurring costs, especially for public sector salaries. They cite sustainability and donor-dependency concerns and fail to recognise that building human resource capacity is a critical piece of health systems strengthening. *Both of these policy trends need to be addressed if scale-up and remuneration of community health worker initiatives are to succeed.*

VALUE FOR MONEY

Numerous studies have shown that community care and support services and social protection are both effective and cost efficient.[45] This has been recognised notably in UNAIDS' Treatment 2.0 approach as well as in the UNAIDS Strategic Investment Framework. The Investment Framework recognises that: care and support services are key programmatic activities; community mobilisation and community service delivery are social and programmatic "critical

CASE STUDY 3: Upgrading the training and management of paid community health workers in Malawi

In 2004, the strain the HIV epidemic placed on Malawi's health system led to the introduction of an "Emergency Human Resources Programme", funded in part by DFID and the Global Fund to Fight AIDS, TB, and Malaria. Under this programme, 10,000 health surveillance assistants (HSAs) carry out activities ranging from voluntary counselling and testing, ARV treatment adherence, cholera treatment and oral immunisations to family planning education. The HSAs are paid approximately $80 dollars per month and are provided with 8 to 10 weeks training at the start of their employment, usually after they leave school, although a high-school level certificate is not required. The programme also aims to strengthen the professional health sector by boosting in-service training for doctors and nurses, topping off salaries, and importing doctors.

Studies of this programme show that since its inception there has been a significant scale-up of the number of patients on ART in Malawi, as well as a decrease in the proportion of patients initiating treatment in late stages of their HIV disease from 25% in 2005 to 9% in 2010. Health advocates, such as those in the newly formed Frontline Health Workers Coalition, associate this programme with Malawi's achievement of cutting its under-5 death rate by 59% since 1990.

A study by Voluntary Service Overseas (VSO) and the Malawi Health and Equity Network (MHEN) points out that the HSAs were originally hired to be environmental health monitors, data collectors, and researchers, but increasingly they have been called upon to carry out nursing duties such as giving injections and administering drugs, skills for which they have little or no training. In 2010, the Malawian government committed to recognising the training and development needs of all health workers, not just professional staff. In an innovative pilot project in Ntcheu district, the government enlisted VSO and MHEN to address a key need of the HSAs: supportive supervision from their management. After a comprehensive management assessment, upgrades such as supervisory toolkits were instituted, as well as performance based management processes focused on identifying key training needs and feeding them into district training and development programmes. HSAs have begun to report increased satisfaction with their roles, and the government is considering rolling out this management and training programme nationally as an important step toward strengthening its health and community systems overall.

Source: *Improving Management and Supervision Solutions for Health Surveillance Assistants in Malawi*, VSO Malawi, 2011

enablers"; and social protection is an important development synergy.[46]

The Investment Framework envisages that increasing investment in community mobilisation (which includes community service delivery), from $0.3 billion in 2011 to $1 billion in 2020, would lead to major efficiency gains in the HIV response overall.[47] These figures were based on the estimated number of people in need, coverage levels, and unit costs based on available data on community health worker programmes.[48] In addition, the framework makes estimates of the cost of the HIV sector synergies with broader social protection as US$2.1 billion in 2011, declining to US$1.5 billion in 2020.[49]

While this attention to the effectiveness and value for money of community care and support services and social protection is very welcome, there are limitations in the Investment Framework's costing of various aspects of care and support, community mobilisation, and social protection mechanisms. The current calculations do not take into account a full package of care and support services or the remuneration of caregivers. The Investment Framework authors recognise that costing data is fragmented and piecemeal. They have called for in-depth country level costing exercises to enable more holistic, detailed and accurate data, optimally generated in close consultation with the community stakeholders who deliver care and support services. This research is critical to ensure that the cost savings anticipated through the implementation of the Investment Framework are not made off the backs of poor women caregivers.

Going forward, it is critical that we develop a full picture of what each component of care and support will cost, in order to make informed policy and funding decisions at national and global levels. It has long been known that community systems and services are under-resourced and donors have struggled to know how to fund them effectively. In recent years there has been some important work to articulate the central features of community systems and the importance of building their capacity, in particular the 'Community System Strengthening Framework' of the Global Fund to Fight AIDS, Tuberculosis and Malaria. The Global Fund states: "*Community organisations and networks have the unique ability to interact with affected communities, react quickly to community needs and issues and engage with affected and vulnerable groups*" but, *"In order to have real impact on health outcomes, however, community organisations and actors must have effective and sustainable systems in place to support their activities and services*".[50]

Investing in social protection and remuneration of caregivers

Both social protection and remuneration for caregivers are investments in strengthening health and community systems. As the OECD reports, it is widely recognised that social protection "*reduces poverty, stimulates the involvement of poor women and men in the economy and contributes to social cohesion and stability*".[51] Remuneration of caregivers will be a critical contribution to the quality of health and social care and long-term sustainability of community systems. For example, the cost of remuneration can be offset by the savings generated by higher rates of survival and subsequent increased life expectancy for patients with low CD4 T-cell counts accessing ART.[52]

How much will remuneration cost?

There have been a very limited number of studies conducted to estimate the cost of remunerating caregivers. A recent study by Columbia University's Earth Institute estimates that one million community health workers (both generalists and those with expertise on maternal child health) will be needed to cover all of Africa's approximately 500 million inhabitants. The estimated cost of this scale-up will be approximately $2.3 billion per year.[53]

These costs include salaries of approximately $80 per month per health worker, 12 months of classroom and on-site training, backpacks and mobile phones, management, supervision, and overhead costs. The community health worker will generate additional costs depending on their responsibilities, which this study defines as monitoring for malnutrition, treating diarrhoea disease, testing and treating malaria, de-

worming, treating pneumonia, screening for TB, screening pregnant mothers for HIV, and ambulances. The estimated $2.3 billion excludes family planning services (estimated to cost $1.6 billion a year) and testing of the general population for HIV (estimated to cost $745,000 a year) since there is no consensus among public health specialists about whether these services should be provided by community health workers.

While the data and methods backing up this study require further scrutiny, this is the type of bold, large-scale costing exercise that is needed in order to develop a global agenda to remunerate caregivers in the HIV context.

RECOMMENDATIONS

Governments, donors, and international institutions should include costs and strategies for the remuneration of caregivers in budgets, programme plans, and technical guidance related to their role in the response to HIV. Compensation for primary caregivers should take the form of social protection and remuneration for secondary caregivers should take the form of salaries.

The following steps must be taken to achieve this goal

- Governments, donors, multilaterals, and NGOs should recognise the important contribution of primary and secondary caregivers, and their role in achieving HIV and other health and development goals.
- Implementing governments should ensure that social protection measures reach older and younger primary caregivers (grandparents and vulnerable children) and do not exclude key affected populations including sex workers, drug users, men who have sex with men, transgender people, and migrants.
- Donor and implementing governments, multi- and bilateral organisations, NGOs, and civil society organisations should carry out ambitious costing exercises to determine what it would cost to remunerate and extend social protection to caregivers in developing countries.
- Governments, donors, and NGOs should recognise secondary caregivers as community health workers with nationally recognised and salaried roles in health systems.
- Implementing governments should engage primary and secondary caregivers and people living with HIV in the design of all remuneration and social protection policies and practices.
- The Global Fund to Fight AIDS, TB, and Malaria should strengthen guidance on remuneration of caregivers in the context of its Community Systems Strengthening agenda, and prioritise proposals which include sustainable remuneration policies for caregivers.
- UN Women should play a leadership role calling for the remuneration of HIV caregivers as a strategy to reach MDG 3 and MDG 6, including holding governments accountable to commitments made in the outcome document of the 53rd Commission on the Status of Women on the theme "The equal sharing of the responsibilities between men and women, including caregiving, in the context of HIV and AIDS".
- WHO and the Global Health Workforce Alliance should more directly deal with the issue of remuneration, and map out a clear pathway towards remunerating secondary caregivers and community health workers more broadly.
- Until social protection is available to primary caregivers and remuneration is established for non-volunteer secondary caregivers, a full package of incentives and support should be provided.

For further discussion and programmatic recommendations on strengthening the work of caregivers in the HIV context, please see the following publications:

Care and Support: the Forgotten Pillar of the HIV Response
The UK Consortium on AIDS and International Development, 2011

http://www.aidsconsortium.org.uk/Care&Support/Publications/Care&SupportAdvocacyDoc2011.pdf

Walking the Talk: Putting Women's Rights at the Heart of the HIV and AIDS Response
VSO and Action AID, 2007.
http://www.actionaid.org.uk/101068/walk_the_talk_on_womens_rights_and_hiv_and_aids.html

Valuing and Compensating Caregivers for their Contribution to Community Health and Development in the Context of HIV and AIDS: An Agenda for Action
The Huairou Commission, 2010.
www.groots.org/Download/HC_compensations-report.pdf

Will We Achieve Universal Access to HIV/AIDS Services with the Health Workforce We Have?
World Health Organisation (acting as host organization for, and secretariat of, the Global Health Workforce Alliance), 2010.
http://www.who.int/workforcealliance/knowledge/resources/uareport_en/en/index.html

ACKNOWLEDGEMENTS

The author of this paper is Julia Greenberg (The Fremont Center).

Thanks for contributions and peer review: Rachel Albone (UK Consortium C&S WG / HelpAge International), Mike Podmore (UK Consortium C&S WG / International HIV/AIDS Alliance), Claire Morris (UK Consortium C&S WG / Help the Hospices), Olivia Dix (The Diana Princess of Wales Memorial Fund), Laura Ross-Gakava (The Diana Princess of Wales Memorial Fund), Shannon Thomson (Tearfund), Stuart Kean (UK Consortium CABA WG / World Vision International), Kate Iorpenda (UK Consortium CABA WG / International HIV/AIDS Alliance), Sam Avrett (The Fremont Center), David Barr (The Fremont Center), Robin Smalley (mothers2mothers), Shannon Hayes (Huairou Commission), Becca Asaki (Huairou Commission), Gitau Mburu (International HIV/AIDS Alliance).

The development of this policy brief was coordinated by Nick Keeble with support from Joanna Allan and Deborah Laycock all at the UK Consortium on AIDS and International Development.

Design by Jessica Drury.

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7 *The Implications of HIV and AIDS on Women's Unpaid Labour Burden*, UNESCO, 2010 http://www.genderandaids.org/index.php?option=com_content&view=article&id=995:the-implications-of-hiv-and-aids-on-womens-unpaid-labour-burden&catid=72:the-care-economy-and-womens-unpaid-work&Itemid=106
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[27] For instance, the Home-Based Care Alliance, a network of indigenous secondary home-based care groups with 24,648 members across 12 countries in Africa, reports that through self-organising and advocacy, 207 members of their Kenyan chapter are now represented in local decision-making structures. In one region, the National AIDS Control Programme gave the Alliance free office space and supported them to help collect accurate statistics on HIV prevalence in their district.

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FURTHER INFORMATION

The UK Consortium on AIDS and International Development is a network of over 80 not-for-profit, faith-based and academic agencies. Based in the UK, with strong links to governments, international and multilateral agencies, the Consortium has been working at the heart of the response to HIV and AIDS for 25 years.

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