

Analysis and recommendations for EC/EU actions in care and support for people living with HIV and AIDS, TB and malaria to be considered in the context of the “European Programme for Action to Confront HIV/AIDS, Malaria and Tuberculosis Through External Action”

Introduction:

HIV and AIDS, malaria and TB continue to affect the lives of millions across the globe. Despite global efforts to reduce the spread of HIV, TB and malaria, every day thousands of new infections are happening. The three diseases have a devastating impact on people's lives: they suffer stigma, discrimination and marginalisation, resulting in poor access to prevention, treatment, care and support services.

In the UN Political Declaration on HIV/AIDS, adopted in 2006, world leaders commit to “pursuing all necessary efforts towards the goal of universal access to HIV prevention, treatment, care and support by 2010.”¹ The declaration includes strong targets to improve care and support for people living with HIV, most notably (pregnant) women and children affected by and living with HIV, through providing support, increased protection and rehabilitation to them and their families.

However, the 2008 UN Secretary General's report on Progress towards achieving Universal Access clearly indicates that there are major gaps in the provision of care and support for people living with or affected by HIV, in particular children. There are an estimated 12 million children under 18 have lost one or both parents to AIDS in sub-Saharan Africa, yet the UN report highlighted the fact that in 11 high HIV prevalence countries only 15% of households caring for orphans received support from outside of their communities. The gaps in care are also evident from the lack of data collection in the countries reporting. This is extremely concerning, given the fact that the introduction of and increased access to antiretroviral treatment has improved the length and quality of life of those infected with HIV. For those who are fortunate to receive antiretroviral treatment (ART), HIV has shifted from being a death sentence to chronic disease management, which requires lifelong care and support for people living with HIV.

The *Global Plan to Stop TB: 2006-2015*, launched by UN Secretary General at the World Economic Forum in 2006, provides a comprehensive assessment of the actions and resources needed to implement the WHO's Stop TB Strategy and make an impact on the global burden of TB. Despite successes in some areas, there remains an estimated shortfall of US\$30.8 billion of the \$56 billion needed to fully implement the plan. Furthermore, the alarming rise of drug-resistant TB, and the TB bacilli's combination with the HIV virus, creating a global co-epidemic threaten to reverse progress in the fight against HIV/AIDS, thwart efforts to achieve the Millennium Development Goals, and pose a significant threat to global health security. A recent report by the United Nations Millennium Development Goals Gap Task Force found that access to essential medicines to treat HIV, TB and malaria in developing countries is far from adequate, and substantial gaps exist in efforts to achieve the MDGs.

Link to the Programme for Action

The existing Programme for Action addresses care and support **only in Annex 1**, where it aptly stresses the crucial role that family- and community-based care play in “*alleviating the burden of the disease, including as an alternative to institutional care for orphans and vulnerable children*”.² It also highlights “*a particular focus on children affected by malaria, orphans and vulnerable children affected by HIV/AIDS and elderly people who...are often left*

¹ *The United Nations Political Declaration on HIV/AIDS, 2 June 2006, no. A/RES/60/262*

² *A European Programme for Action to Confront HIV/AIDS, Malaria and Tuberculosis through External Action, COM(2005)179final*

to take care of such children and may need support to this end in terms of social protection or allowances".³ The Programme for Action does refer to the importance of the EU staff engaging in political dialogue on issues related to orphans and vulnerable children and using the "Framework"⁴ to guide this dialogue. While the Programme for Action describes a wide range of EU actions at country and global level on treatment and prevention, it doesn't outline any EU actions on care and support or show the essential links between prevention, treatment and care and support services. As the Universal Access Commitment recognises, with more and more people on treatment and living longer lives, it is no longer possible to only address the need for prevention and treatment. The EC Programme for Action needs to include actions that directly support the delivery of comprehensive care and support services for people infected and affected by HIV. Yet universal access to HIV prevention, treatment, care and support by the end of 2010, will not be achieved as long as people living with HIV are dying of TB. The EU PfA should also emphasise the need for universal access to high-quality TB-HIV care by 2015, including diagnosis, treatment, preventive therapy, and infection control this, including the need increase the provision of isoniazid preventive therapy (IPT) to HIV-positive people, as well as co-trimoxazole preventive therapy (CPT) and antiretroviral therapy (ART) to HIV-positive TB patients. With children accounting for 17% of new infections but only 8% of the infants born to women living with HIV in 2007 tested within the first two months of birth, there is urgent need to improve infant diagnostics, as well as their access to co-trimoxazole prophylaxis, which is currently only used by 4% of HIV-exposed infants.

Care and support for people living with and affected by HIV:

The inclusion of HIV care and support in the 2005 Universal Access target was a major step forward in recognising the holistic needs of people living with and immediately affected by HIV. This has prompted progressive donors to recognise the need to promote a comprehensive definition of care and support, and provide support for a wide range of care and support services. The EC can play a leading role in this process.

An inclusive comprehensive definition⁵ is categorised by five interrelated domains. HIV care and support is intended not only for people living with HIV (domains 1-4 below), but also for all those affected by HIV (domain 5 below). Those affected by HIV include the families and friends of those living with HIV and those who provide care and support from the community⁶.

1. Psychosocial: including counselling services, emotional and spiritual support (all part of palliative care); reduction of stigma and discrimination; positive living.

2. Clinical: testing; prevention of opportunistic infections, symptom control and pain management, treatment of AIDS-related illnesses and opportunistic infections including TB; and paediatric care (all part of palliative care); treatment adherence support and information; nutrition; alternative/traditional medicine.

³ Ibid

⁴ The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS, July 2004

⁵ "What do we really mean by HIV Care and Support? Progress towards a comprehensive definition", UK Consortium on AIDS and International Development Care and Support Working Group, 2008. This definition was built from UNAIDS/WHO/ UNICEF/ FHI/ Measure/ USAID, "National AIDS Programmes: A Guide to Monitoring and Evaluating HIV/AIDS Care and Support", 2004 p.5-6

⁶ Those identified as being 'affected' by HIV in domain 5 are those whose life is heavily affected by the HIV status of another person(s) in their family/community or in their care, irrespective of whether they are living with HIV themselves. The care and support services outlined in domain 5 respond to the particular experience and needs of those who are being 'affected'. For example: A care-provider living with HIV will need a range of care and support interventions related to their role as carer (domain 5) and a range of care and support interventions related to the fact that they are living with HIV (domains 1 to 4).

3. Social and economic: including social protection (such as pensions, allowances, free or subsidized healthcare and school fees, child and disability benefits); targeted financial support (such as stipends, cash transfers, grants and help with funerals); income generation and employment opportunities; workplace policies and programmes; capacity building and advocacy support; food and nutrition assistance and appropriate agricultural inputs and services; clean water; transport; positive prevention; education; orphan support; adoption services; help in the home and child care.

4. Human rights and legal: including access to legal aid, legal support and accessible legal information; human rights legislation and implementation (including violence and discrimination; land, inheritance and property rights; labour laws, birth registration); succession planning, rights-based approach and rights advocacy training.

5. Family & community: psychosocial (including bereavement support) and medical (all part of palliative care); socio-economic and legal care and support (including prevention information).

Care and support that meets the needs of all those infected and affected

Comprehensive care and support must have a family- and community-centred approach. Crucially, family centred responses need to address the specific needs of the most vulnerable, including orphans and vulnerable children. But they must also support family and community carers to meet these needs. Most carers are female and elderly and have little or no support and are generally made poorer by their caring. It is important that interventions promote the wellbeing of carers as well as that of those in their care, particularly children. It is widely recognised that people prefer to be cared for in their home and that children can usually best develop in their family environment and that it is family or community carers that make this possible. Therefore the impact of caring on family members and community carers (particularly women, girls and older people) must be recognised and addressed.

Moreover, the human resources for health crisis has brought forward the important role of caregivers in the good functioning of health systems. Increase of HRH must be a priority in improving care and support for PLWHA. Also, the serious lack of human resources for health, especially in the African context, often results in task shifting, putting a large part of the care burden on, inter alia, volunteer home-based caregivers.

Care and support for people living with TB and TB/HIV Co-infection

Despite being preventable and treatable, TB remains the most common life-threatening opportunistic infection and a leading cause of death among PLWHA.⁷ In Africa, which has the highest rates of both diseases, TB is the leading killer of PLWHA.⁸ Drug-resistant TB strains also pose a particular threat to those with HIV, with mortality rates from extensively drug-resistant TB (XDR-TB) exceeding 95% in Africa.⁹ As of August 2008, none of the three biggest donors (World Bank, Global Fund and PEPFAR) were reporting the proportion of PLWHA being screened for TB within their programmes. The EC should lead these larger donors by making a commitment to do this.

⁷ World Health Organization. 2008. The Three I's: Intensified Case Finding (ICF), Isoniazid Preventive Therapy (IPT) and TB Infection Control (IC) for people living with HIV. Report of a WHO Joint HIV and TB Department Meeting. Geneva, Switzerland, April 2-4, 2008. Online.

http://www.who.int/hiv/pub/meetingreports/WHO_3Is_meeting_report.pdf. Accessed 3 August, 2008.

⁸ WHO. 2008. The Three I's.

⁹ Gandhi N, et al. 2006. Extensively drug-resistant tuberculosis as a cause of death in patients co-infected with tuberculosis and HIV in a rural area of South Africa. *The Lancet*. 368:1575-1580.

In order to provide adequate care and support to people living with HIV and TB it is necessary to integrate TB and HIV services. There is an urgent need for more research on and to provide sufficient drugs, diagnostics and vaccines. The Treatment Action Group's annual report on funding trends in TB Research & Development (covering 2005-2007), found that less than half of the \$9 billion recommended by *The Global Plan to Stop TB: 2006-2015* will be spent on TB Research & Development by 2015. The EC should, as stated in the PfA, deliver a financial contribution that meets its fair share of the financing gap for TB and include an increased investment in research and development.

Responsibility for delivering HIV, TB and Malaria care and support:

The Alma Ata Declaration establishes the importance of community ownership over primary health care, particularly participation in decision-making and delivery of services. In response to the HIV and AIDS pandemic, TB and Malaria, community responses to providing care and support are critical. However, under-funding of care and support services has left nearly the whole burden of the delivery and cost of care and support on poor communities, especially on women and girls. It is the responsibility of national governments and donors to actively support the delivery of care and support as part of an integrated health approach and a comprehensive care continuum. Donors need to support National AIDS, TB and Malaria Plans to co-ordinate close working and clear systems of referral between the public health system, community Home-Based Care programmes and care-providers in the home.

Governments and donors currently provide little direct funding for community home-based care and this is partly due to the fact that they have little awareness of the full costs of providing care on families and the community. More research is urgently needed to understand the impact of the cost of care and support on communities. In addition, a comprehensive range of indicators for care and support need to be developed to make the responsibilities of governments and civil society clear.

Many of the government departments responsible for vulnerable children and families in the countries worst affected by HIV and AIDS, are the so-called 'marginalised' ministries, lacking in organisational capacity and seriously constrained in their abilities to access and utilise increasing amounts of direct budget support. As governments increasingly invest in social protection for families and communities the EC has a key opportunity to address the capacity and organisational weaknesses of social welfare sectors.

General recommendations for EC Actions/Initiatives and Monitoring and outcomes:

Below we have suggested actions/initiatives to actively address care and support for people living with the three diseases using the headings in the current PfA.

EU Actions at Country level

Political and policy dialogue to support country-led strategies to confront the three diseases

- The EU will reinforce its political dialogue with countries to promote an **increased focus on care and support** as part of universal access; encouraging countries to **adopt a more comprehensive and holistic definition of care and support**.
- To help implement policy, the EC will prepare a toolkit for Delegations and services which will include guidelines for policy dialogue, programming guidelines offering advice concerning indicators and monitoring of country efforts and reference documents that specifically **address the rights of adults and children living with**

and affected by HIV, TB and Malaria to a comprehensive continuum of care and support. It will be reviewed and updated periodically. Awareness raising and training will be provided for EC staff.

- The EC and Member States will share expertise with relevant ministries (Health, Finance, Social Services, Agriculture), country co-ordinating mechanisms and Poverty Reduction Strategy (PRS) processes at a country level to ensure **relevant plans and policies include comprehensive care and support for HIV, TB and Malaria** and that a range of services are provided.
- EC Delegations will encourage national HIV and AIDS programmes on care, prevention treatment and support to promote integrated family-centred programming. This will include encouraging the use of different entry points to identify vulnerable families.
- EC Delegations will promote health and disease prevention among staff and implement **workplace policies for people living with HIV, TB and Malaria** building on the ILO Code of Practice and the IFRC Code of Good Practice for NGOs Responding to HIV/AIDS [[Renewing Our Voice: Code of Good Practice for NGOs Responding to HIV/AIDS](#)]. In staff training, delegations will be encouraged to use the training manuals developed by ILO and IFRC and facilitate dialogue between workers (labour unions), employers, communities and the health sector.
- The EC delegations will assist and support staff with HIV and AIDS, TB or Malaria and their families to ensure they are not excluded from the full protection and benefits of **social security programmes** and occupational schemes. This should also apply to workers and their families from social and occupational groups perceived to be at risk of HIV/AIDS.

Capacity building to confront the three diseases

- The EC and Member States will strengthen national and regional programmes to build research capacity that looks at the **cost of care and support on communities** and that draws together **best practice** from organisations that both provide effective comprehensive care and support services and realise the rights of care-providers. Use the evidence to **strengthen government and donor technical and financial support** for community care and support responses to HIV, TB and Malaria.
- The EC will provide technical support to improve countries' capacities to develop comprehensive HIV, TB and Malaria **care and support policies and care for the carer policies.**
- The EC and member states should gather more evidence and share best practices, looking particularly at the **long-term effects of cash transfers** on HIV prevention and care and support in highly HIV-affected countries, and on the impact of linking other social protection services with cash transfers. Particularly explore the impact of social protection mechanisms on children affected by HIV and the carers,
- The EC will provide technical advice for countries to implement financial compensation mechanisms
- The EC and Member States will increase **capacity-building support to community-based organisations** that provide care and support, and to **networks of people**

living with HIV, TB and/or Malaria, to enable them to develop skills around management, leadership, community mobilisation, advocacy and empowerment

- The EU will support community-focused delivery of care and support, based on **strong partnerships and linkages between health services and community organisations**;
- In countries where the EU supports the education sector, the EU will engage in sector and policy dialogue to **support children affected by AIDS to attend school** by establishing and supporting outreach programmes and social protection mechanisms that support school attendance, whilst ensuring that the quality of education services does not deteriorate
- The EC and Member States will support initiatives which increase **treatment literacy for people on treatment and within communities**; this includes accurate and accessible information about medicines, treatment and managing side-effects, how treatment fits in with daily life, how it links with prevention, and how people on treatment can get what they need from health systems and other forms of material and psychosocial support
- Provide technical support and advice to national governments to develop accessible **legal support and advice services**, including legal aid, training for legal officers and national legislatures.
- Support initiatives to **strengthen national civil registration systems**, especially improving linkages between the Ministry of Health and the ministry responsible for birth and death registration in order to integrate civil registration in national HIV strategies, in conjunction with HIV programmes at antenatal and post natal centres, including in preventing mother to child transmission (PMTCT) programmes, hospitals/clinics, immunization and voluntary and counselling testing facilities, and lifeskills programmes at schools.

Financial resources to confront the three diseases

- Provide funding for a **comprehensive range of care and support programmes** through government and civil society. In particular, ensure support to community-based care organisations to build their capacity to provide appropriate care and support services based on realizing the rights of the most disadvantaged and the rights of care-providers to recognition, training, psychological and material support and compensation.
- Provide funding for **cash transfer programmes** benefiting the most disadvantaged, including those living with or seriously affected by HIV, TB or Malaria, and children and their carers, in line with the recommendations of the Commission for Africa – \$2 billion immediately rising to \$5-6 billion annually by 2015¹⁰.

¹⁰ UK Commission for Africa (2005) *Our Common Interest: Report of the Commission for Africa*, UK Commission for Africa available online at <http://www.commissionforafrica.org/english/report/introduction.html>