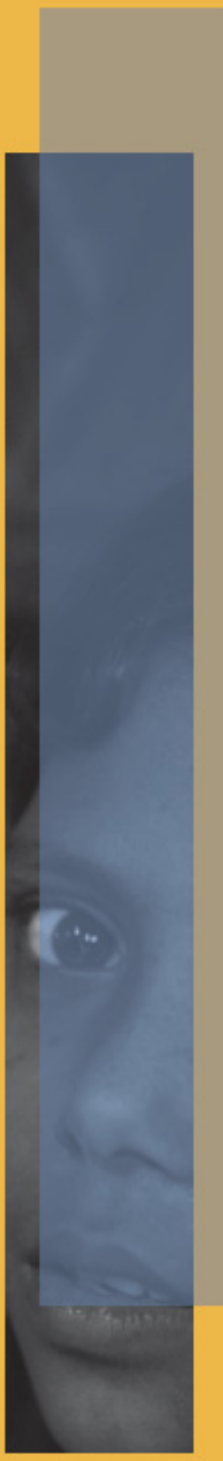
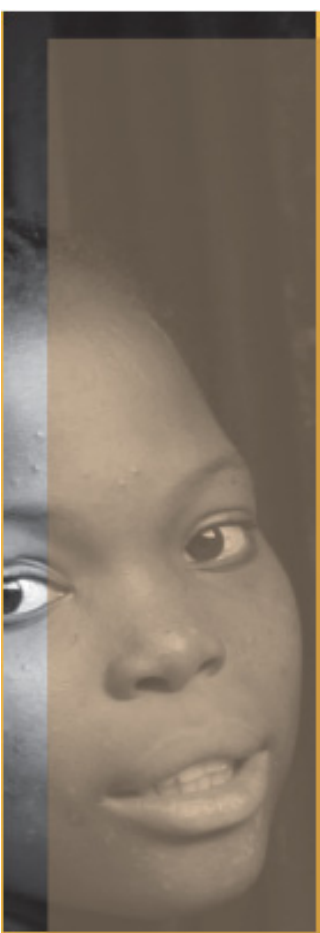


What do we really mean by 'Care and Support'?

progress towards
a comprehensive
definition



Avert
Diana Princess of Wales Memorial Fund
Help The Hospices
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What do we really mean by ‘Care and Support’? Executive Summary

Summary definition of HIV Care and Support:

Points 1 to 4 apply to people living with HIV and point 5 applies to families, friends, care-providers and children affected by HIV (see p.6).

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. **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); 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).

Recommendations

The UK Government and other bilateral donor governments, multilateral institutions and INGOs should:

- Promote and advocate for increased focus on care and support as part of universal access; ensure a more comprehensive and holistic definition of care and support and indicators based on those outlined in this paper; and ensure that support is given equal emphasis with care.
- Build capacity within 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 and that a range of services are provided.
- Promote and advocate for the integration of the broad range of medical care and support into ART programmes in government health sector policies and National AIDS strategies
- Support research at a country level that looks at the cost of care and support on communities. Use the evidence to strengthen government and donor technical and financial support for community responses.
- Support research that draws together best practice from organisations that provide effective comprehensive care and support services and realise the rights of care-providers. Use this evidence to update international care and support guidelines (WHO and UN), and country level National AIDS Strategies and Health policies.
- Provide funding and support to community-based care organisations to build their capacity to provide appropriate care and support services based on the definitions of this report and realize the rights of care-providers to recognition, training, psychological and material support and compensation.
- 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.
- Fund a comprehensive range of care and support programmes through government and civil society.

What do we really mean by 'Care and Support'?

Progress towards a comprehensive definition

Introduction

The Care and Support Working Group is part of the UK Consortium for AIDS and International Development. The working group exists to:

- provide a clear and comprehensive definition of HIV¹ care and support;
- scope the breadth of issues captured within this definition of HIV care and support;
- raise the profile of care and support within the Universal Access continuum;
- ensure care and support is not left out of the advocacy agenda; and, where possible, present consensus policy and practice recommendations on care and support to multilateral institutions, donors, national governments and civil society.

This paper is a collaborative work between the members of working group and represents our agreed joint position on a comprehensive definition of care and support.

Background

In 2005, leaders at the G8 Summit, followed by other UN member nations in 2006 at the UN High-Level Meeting on AIDS, set Universal Access as the framework for both the UN system and, by extension, the country-level response to HIV. As part of their commitment, countries promised to set national level targets to work towards the goal of "universal access to comprehensive prevention programs, treatment, care and support by 2010"².

Up to 2005, many of the global targets for responding to HIV, such as the WHO's 3 by 5 initiative, focused mainly on treatment. This has led to significant progress in the number of people on Anti Retroviral Treatment (ART)³, which in turn has both reduced mortality rates and increased life expectancy of people living with HIV. Many existing healthcare systems are organised to address acute episodic illness only. However, because ART prolongs life, an integrated public health approach that manages the different aspects of chronic disease throughout the course people's illness is necessary⁴. This approach emphasises planned visits and regular follow-ups throughout the course of a chronic disease⁵ and it requires a holistic approach with care being centred on the needs of the patient with links to community resources to help the family and community to care.

The inclusion of care and support in the 2005 Universal Access target was a major step forward in recognising the holistic needs of people living with HIV. However, the indicators identified to measure progress have so far been limited to narrow concepts of care and support, and a significant number of donors and national governments remain unclear on definitions of what constitutes comprehensive care and support. This paper aims to help address these issues.

¹ Throughout this paper, we use the term "HIV" when referring to both HIV and AIDS, in line with UNAIDS guidelines. The term "AIDS" is used when this advanced state of the HIV infection is specifically being referred to.

² United Nations General Assembly Political Declaration on HIV/AIDS, resolution A/RES/60/262, UNGASS 2006, article 20, p3.

³ At the start of 2008 there are just over 3 million people on Anti-retroviral Treatment globally. Stated by Michel Kazatchkine, LSE Lecture February 12th 2008.

⁴ Evidence from models using TB infrastructure to deliver ART to patients in Haiti through a community-based model has shown the benefits of a chronic disease management approach. Farmer P, Leandre F, Mukherjee JS, Claude M, Nevil P, Smith-Fawzi MC, et al. Community-based approaches to HIV treatment in resource poor settings. *Lancet* 2001; 358: 404-409 [Cross Ref] [ISI] [Medicine].

⁵ This is described further in the WHO strategy for comprehensive chronic disease care in the developing world. WHO, 2002 Geneva: Innovative care for chronic conditions: building blocks for action.

The relationship between prevention, treatment, care and support

The interconnected needs of people infected and affected by HIV means that the boundaries between treatment, prevention, care and support can be difficult to draw, especially in developing countries. This is particularly true for treatment, care and support, which are often all provided by the same home-based care organisations.

The diagram below (Fig.1) offers a basic representation of how a comprehensive definition of care and support includes aspects often also considered part of HIV prevention or Anti-Retroviral Therapy (ART) services. Psychosocial support is perhaps the only aspect of care and support that does not overlap. Socio-economic and human rights and legal support are critical across the whole of the universal access spectrum.

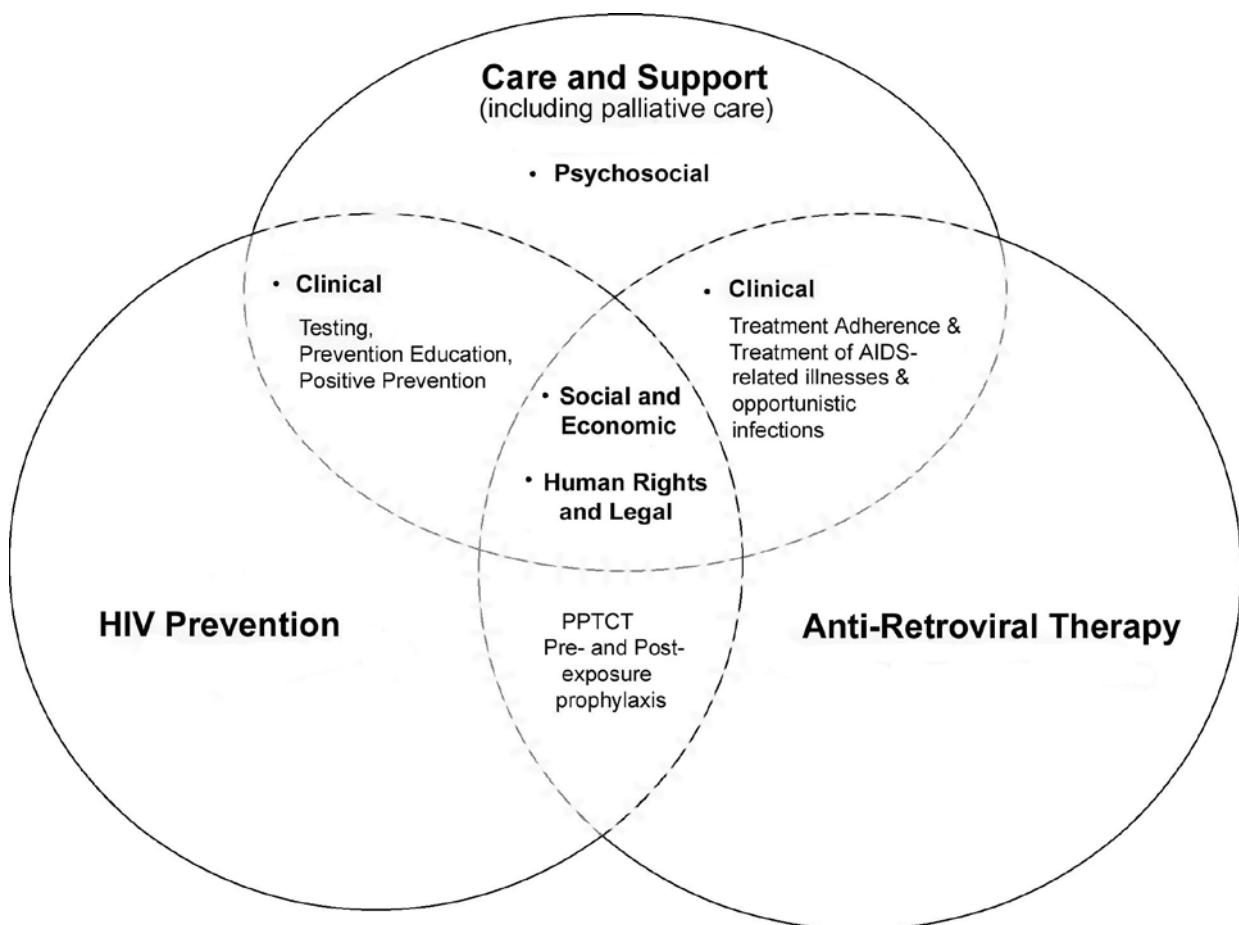


Fig.1 The overlaps between prevention, treatment, care and support services available for people living with HIV, their families, friends and their community

Definition of care and support

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.

This position paper uses an inclusive comprehensive definition⁷ that builds on the definition produced by UNAIDS and WHO in 2004⁸. It is categorised by five interrelated domains:

1. Psychosocial
2. Clinical
3. Social and economic
4. Legal and human rights
5. Family and community

This paper does not attempt to define any distinction or difference between 'care' and 'support' because doing so would facilitate the application of only selective parts of the definition. We present a comprehensive definition of care and support that should, as much as possible, be applied as a cohesive whole.

These interrelated domains of care and support can be made most effective through the application of the following principles in programming:

- Respect for patient autonomy
- Equitable access and inclusive approaches for all individuals, particularly those most affected by HIV.
- Accessibility and free choice of comprehensive information
- Relationships between patient, family and care-provider based on respect and trust
- Integration and respect for non-harmful cultural values, beliefs and customs

1. Psychosocial: including counselling, emotional support and spiritual support⁹ (all part of palliative care); reduction of stigma and discrimination; positive living.

Psychosocial support is a critical aspect of care and support for people living with HIV that addresses non-physical suffering of individuals and family members. It is necessary prior to and after testing, and then throughout the course of the illness, particularly as many people experience stigma, isolation and depression. Access to such support enables people to reduce any sense of isolation, disclose their positive status, live positively and prevent further HIV transmission.

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).

⁷ This definition has been developed from "Walking The Talk: Putting women's rights at the heart of the HIV and AIDS response", VSO & ActionAid, 2007, P.37

⁸ UNAIDS/WHO/UNICEF/FHI/Measure/USAID, "National AIDS Programmes: A Guide to Monitoring and Evaluating HIV/AIDS Care and Support", 2004 p.5-6

⁹ Spiritual care can be defined as one approach to support people to question themselves, their purpose and meaning in life.

Psychosocial support includes **emotional** and **spiritual support**, acceptance and care from family, friends and the broader community, particularly faith groups. It also includes **counselling** from care professionals and support groups within networks of people living with HIV. This support is critical in cases where stigma and discrimination cuts people off from their families or broader community support. Counselling is also recognised as the recommended access point into a range of other HIV services. This is particularly effective when a range of HIV services are all located under at the same site as counselling and testing¹⁰. **Positive Living** is concerned with working with patients to help them take control of their illness by finding ways to stay healthier through choice of diet, moderate exercise, stress management and developing positive attitudes and playing a major role in our own healthcare.

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; alternative/traditional medicine.**

Clinical care is a vital part of a comprehensive continuum of care and support, from the point of diagnosis, for both adults and children living with HIV and their family. The majority of this clinical care, particularly palliative care, takes place in the home and is provided by community home-based care organisations. It includes **testing** (voluntary or provider-initiated), which, with counselling, is considered the gateway to other care and support services. Physical **pain management** necessitates the availability and use of a small carefully selected list of essential drugs for common conditions associated with HIV such as pain, diarrhoea and common infections etc.

Treatment for AIDS related illnesses, opportunistic infections including TB, and other illnesses such as sexually transmitted infections, is often not available or supported with other HIV services and can be very expensive. Yet, up to 70% of people with HIV and AIDS in developing countries are co-infected with tuberculosis (TB) with TB being the leading cause of death among positive people. It is therefore necessary that HIV and TB treatment services are integrated to enable the effective co-management of infection¹¹. Sexually transmitted infections (STI) increase the risk of HIV and AIDS with there being an estimated 340 million new cases of curable STIs every year (WHO website 2008). For people living with HIV these infections can weaken the immune system hence the importance of them being treated. In addition to advice and treatment being offered for STIs in an HIV setting it is also important for sexual and reproductive health services to provide counselling and advice about HIV prevention.

Specific **clinical care provision for children** is an essential component of any definition of clinical care and support. It includes access to early testing for children, access to paediatric formulations for ART and access to cotrimoxazole as a prophylaxis in HIV-exposed and -infected children. Treatment adherence information and support is especially important for children living with HIV whose treatment is often either missed or given in inappropriate quantities. Care-providers can deliver ART in a formulated amount suitable for a child at exact intervals.

ART information and adherence support are an essential service to help people adhere to ARV treatment and thereby prevent the risk of developing resistance to first line regimes. Care-providers and peer networks in local communities usually provide this support very effectively. Adherence information should include basic messages around nutrition and the need for

¹⁰ UNAIDS Best Practice Collection. (UNAIDS) and the World Health Organisation (WHO) 2005. Expanding access to HIV treatment through community-based organisations. A joint publication of Sidaction, the Joint United Nations Programme on HIV/AIDS

¹¹ See "HIV and TB in the context of universal access: what is working and what is not?" Stop TB Partnership, 2007

minimal levels of nutrients and carbohydrates in the diet. This may include actual provision of **nutrition** (where there is an inadequate food basket in the household). We should note here that nutrition information and provision (where necessary) is important for all people living with HIV, whether they have started treatment or not.

Because some people consult a traditional healer for **traditional medicine** before visiting a conventional medical doctor it is essential that care and support programmes take this into account. Relationships of trust need to be established between traditional healers and people working in the formal health care system to facilitate HIV training for traditional healers, as well as develop mutual understanding and effective referral systems¹².

Box 1: What is palliative care?

The term “palliative care” is often used to refer to HIV care and support yet it is important to note that the two terms should not be used interchangeably. The WHO defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”. As such, “palliative care is an essential component of a comprehensive package of care for people living with HIV”, but a comprehensive definition of HIV care and support must include broader medical interventions as well as socio-economic and legal support.

Within the definition outlined here, palliative care includes aspects of:

- Psychosocial care and support - counselling, emotional support, spiritual support, bereavement support
- Clinical care – pain management, treatment of AIDS related illnesses and opportunistic infections, particularly TB and sexually transmitted infections
- Psychosocial and medical care and support for families, friends, care-providers and children affected by HIV.

For a full discussion of the role of palliative care in the management of HIV infection in the era of antiretroviral therapy see the recent DfID Health Resource Centre report “Review of Global Policy Architecture and Country Level Practice on HIV/AIDS and Palliative Care”. Dec 2007

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.

Some of the main social and economic impacts for people living with HIV are loss of labour or education due to illness and increased expense of healthcare and transport¹³. The combination of these impacts often leads to spiralling levels of poverty, food insecurity and nutrition

¹² UNAIDS Best Practice Collection: UNAIDS 2006: Collaborating with Traditional Healers for HIV Prevention and Care in Sub-Saharan Africa: suggestions for Programme Managers and Field Workers

¹³ The impacts will vary according to the assets of the household, its demographic composition and the circumstances in question

problems. Socio- and economic support to mitigate these impacts falls into two broad categories:

1. HIV-specific interventions;
2. Non HIV-specific interventions.

HIV-specific interventions are targeted directly at people living with HIV and their families from government, donors and/or civil society. Economic support can involve specifically **targeted financial support** for people living with HIV through stipends, cash transfers (e.g. DfID makes cash payments to women in Zambia), grants, and micro-credit schemes. Deaths due to HIV also place huge financial burdens on families because they lack the necessary **funds to pay for funerals** and burial societies have been shown to successfully alleviate some of these financial pressures¹⁴. When people are stabilized on ART and well enough to work, a more long-term approach can be effective through **livelihoods interventions** such as income generation, access to loans/banks and land, skills training and employment opportunities programmes. **Workplace policies and programmes** can also ensure appropriate socio-economic support mechanisms for HIV positive staff as well as confront stigma and discrimination. **Capacity building and advocacy support** can be provided to networks and groups of people living with HIV to build their ability to call for their rights to the comprehensive range of care and support services. **Positive prevention**, referring to prevention education, information and services for people living with HIV, is essential for supporting the sexual reproductive and health rights of people living with HIV and for preventing onward transmission. **Help in the home**, including **childcare**, can be essential to allow recovery time when people living with HIV are incapacitated. **Food and nutrition assistance**, through nutrition advice, food parcels, provision of communal land and garden development, are necessary to ensure treatment can be effective; as is the provision of **clean water**¹⁵. Most rural households are dependent on **agricultural inputs and services** to support their income generation and subsistence. Comprehensive care and support responses therefore call for inter-ministerial responsibility that includes the Ministry of Agriculture. **Transport** provision and supported travel can make all the difference in access to other care and support services. And finally, guidance and economic **support for orphans** enables them to provide for themselves or, where necessary, **adoption services** within the community provide a crucial fallback.

Non-HIV specific interventions are interventions aimed at the general public. These schemes often provide a more effective way of ensuring both people infected and affected by HIV benefit. Some of the most effective interventions are broadly covered by the term **social protection** (welfare provision), which might include interventions such as free or subsidized healthcare and school fees, child benefit, disability allowance, pensions, adoption services etc.¹⁶. Social pensions, for example, alleviate the impact of HIV in multi-generational households by providing financial resources for older people to care for family members affected or infected by HIV, particularly orphans and other vulnerable children. **Education** is another non-specific intervention but one that has consistently demonstrated its power to increase treatment adherence through literacy and broadening livelihood opportunities. Targeted financial and material support to families with child carers, particularly young girls, has also been very effective to enable them to stay in school. The provision of services such as education and preparation of schools and teachers to host children living with HIV is very important. The school system needs to have the capacity to support adherence to treatment and care regimens at the same time as fighting the stigma that can impede adherence and access to care.

¹⁴ USAID Success stories 2004 – Ethiopian Burial Societies Turn Their Attention to the Living

¹⁵ USAID Success Stories 2004 - Safe Water Systems Improve Health of People Living with HIV

¹⁶ For example, between 50 and 60 per cent of orphans live with grandparents in Namibia, Botswana, South Africa, Malawi, Zimbabwe and Tanzania, as do 50 per cent in Thailand. See “Ageing and Security: How social pensions can deliver effective aid to poor older people and their families”, Help Age International, 2004

4. Human rights and legal: including legal aid, support and information, human rights legislation (including protection against violence and discrimination; land, inheritance and property rights; labour laws); succession planning; rights awareness-raising and advocacy training.

It is important to strengthen people's rights by giving them help to understand those rights and to provide **legal aid, support and information** (in accessible formats) so that they can claim their rights. Equally, this support will only be meaningful in conjunction with state **human rights legislation** that enshrines and respects the human rights of people living with HIV and supersedes (often negative) customary law. Many people living with HIV experience stigma and **discrimination** and many, particularly women and girls, suffer **violence** and are deprived of **inheritance, property and land**, by their families and broader communities due to their positive status. Many people living with HIV are discriminated against in their work and their rights must be defended through the introduction and effective application of **labour laws**. This also includes **rights training and awareness-raising** for the judiciary, the police and community leaders if rights legislation and policies are to be meaningfully implemented.

5. Family & community: psychosocial (including bereavement support) and medical (all part of palliative care), socio-economic and legal care and support (including prevention information) for families, care-providers and children infected or affected by AIDS.

Whilst it is important to care for and support people living with HIV, it is also important to care for and support those living with, caring for or reliant on someone living with HIV - their families, friends, children and care-providers (primary and secondary – see Box 2 below). In some cases they may also be living with HIV. Elements of all the four above types of care and support are necessary to mitigate the dramatic impact that HIV has on their lives.

Care and support needs of primary care providers

Family or friends who provide care in the home often experience severe psychological stress living with, caring for or coping with the death of people living with HIV. Many care providers are older people who care for their adult children at home. They not only have to cope with the loss of their child, but also often need to provide emotional support to their orphaned grandchildren. Carers themselves can face stigma from people who don't understand the means of HIV transmission and wrongly assume that carers can transmit HIV to the wider community. Psychosocial care and support in the form of **counselling and support groups** is therefore essential for primary care providers. **Bereavement support** for family members both before and after the person with HIV has passed away are also important in preparing people for death of a loved one, supporting them in their grief and helping them to cope with and to come to terms with loss.

Box 2: Definition of primary and secondary care-providers

Primary care-providers are family members or close friends who provide care and support for a person living with HIV and AIDS in their home, in what is often termed the informal sector.

Secondary care-providers are visiting nurses, health workers or community care-providers from NGOs and community and faith-based groups that use staff (paid or volunteer) for care delivery. They are based in the formal sector and provide a range of care and support services.

Because they are often the main source of care for the person living with HIV, it is also essential that they receive training on care provision including some basic **medical training** and **equipment** to help them care. To support this work they also need support in the form of

basic information about HIV, **prevention education** (important both in terms of protecting themselves from infection and also educating those in their care) and, if possible, **respite care** for the person they are caring for.

The negative socio-economic impact of HIV and AIDS often hits families of people living with HIV and AIDS particularly hard. Care responsibilities in the family usually fall on women and girls and are very time-consuming, often requiring them to give up paid employment or schooling to become a fulltime care-provider.¹⁷ Older people, particularly older women provide a large proportion of HIV and AIDS care and do so at a time in their lives when their income earning potential is decreasing, due to declining health and age related discrimination. Time given to caring can exacerbate the economic challenges older people already face.

The economic impact of providing care for people living with HIV and AIDS and orphans and vulnerable children needs to be recognised and carers should be compensated for the care they provide to help mitigate these economic impacts. When parents become too ill or die, extended family members or friends also often take responsibility for vulnerable children or orphans. All of the same **socio-economic care and support mechanisms** recommended above for people living with HIV should therefore be provided for primary care-providers and their families, particularly children and older people¹⁸. Social protection in the form of non-contributory pensions, such as in Botswana and Lesotho, have been shown to make a crucial difference in providing for essential items and reducing financial stress. Many children, especially girls, are also relied upon to be carers for sick parents and smaller children, often missing school as a result.

Care and support needs of children affected by AIDS

The social and economic situations of children (young people from birth to 18 years) varies to such an extent that all children have individual needs depending on their age, their gender, where they live, whether they have sufficient food, whether they have someone who can take care of them, whether they can go to school etc. All children need **love and stable care**, and younger children have additional specific needs that include **active feeding and a stimulating environment** etc¹⁹. The full range of care and support is critical yet often most challenging to deliver in the many cases of orphan-headed households.

Care and support needs of secondary care providers

Given the level of need of local communities for care and support services and the usually limited resources of public health systems in developing countries, secondary care providers are often the main point of contact for people living with HIV and their families. Yet the majority of secondary care-providers in the developing world are women who deliver care with little or no recognition, training, pay or support.

Secondary care providers experience overwhelming pressure and stress due to the sheer numbers of people in need of care and support as well as the emotional and psychological stress of facing illness and death every day. In the absence of external support many care providers form their own groups to share experience and support. But public health systems and home-based care organisations must provide regular counselling sessions and mental health programmes.

Lack of medical and effective care training and equipment also exacerbates stress, affects the quality of care for the patient and puts the care provider at risk of infection. Medical support in the form of accredited and regular in-service training with effective supervision and established

¹⁷ "Walking The Talk: Putting women's rights at the heart of the HIV and AIDS response", VSO & ActionAid 2007, pp.42-44

¹⁸ For further information see "Reducing the burden of HIV and AIDS care on women and girls", VSO, 2006

¹⁹ Richter L, Foster G, Sherr L. 2006. Where the Heart is. Meeting the psychosocial needs of young children in the context of HIV/AIDS. Call for Action.

systems of referral are essential. Basic home-based care kits and protective clothing for care-providers are very often inadequate or non-existent. Without these the standard of care suffers as well as putting both the carer and patient at risk. As will be covered below, support and supervision from health professionals in the public health system can help ensure the quality of care.

Some of the greatest challenges for care providers are the socio-economic impacts on their lives, which dramatically affect their ability to provide care and in many cases drive them into ever-deeper levels of poverty. Many secondary care providers are volunteers but find they often have to use their own funds for travel between patients, new equipment and even to financially support their patients. The sheer numbers of patients also means they have no time for income generation. All the economic support mentioned above should be made available to volunteer secondary care providers but they must also receive a regular financial stipend or comparable material support to ensure they do not use their own resources. Incentives such as regular cash payments or material items such as food, clothes or bicycles recognise their work and also act as incentives and encourage people to care and to continue caring. They must also have effective management to ensure they have sufficient free time to pursue income generation and to meet the needs of their own families. Secondary care-provision must not be synonymous with volunteering however. Not all care-providers define themselves as volunteers and there must be opportunity for care providers to be recognised and paid as community health workers through appropriate career progression. Finally, legal support and advocacy training should be available to ensure care providers can claim these basic rights to care and support.

Responsibility for delivering care and support: Health systems and communities

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, community responses to providing care and support for people living with HIV and AIDS are critical. However, under-funding of health systems, and particularly 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 to deliver care and support as part of an integrated health approach and a comprehensive care continuum, in which National AIDS Plans co-ordinate close working and clear systems of referral between the public health system, community Home-Based Care programmes to 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.

Indicators for care and support

In order to measure the progress made towards the Universal Access commitment seven core indicators were drawn up by UNAIDS²⁰ with the expectation that each country will also set national targets. Currently there is only one core indicator for Care and Support²¹ (See box 2 below).

Box 3. UNAIDS Indicators on Care and Support

Core indicators:

Percentage of OVC (boy/girl) aged under 18 living in households whose household have received a basic external support package.

(The support package could include food, education, health care, family/home or community support. Currently this is one of the least well-reported indicators and special attention should be paid to it.)

Interim Targets:

Enhancing care and support

- Number of income-generation schemes for women care-givers put into place
- Number of legal and social support services for women care-givers and victims of sexual violence
- Number of legal support services for people living with HIV

UNAIDS itself writes that this indicator “is one of the least well-reported indicators and special attention should be paid to it.”²² It should be acknowledged that having a distinct indicator for care and support is a step forward from the previous situation where it was often grouped under the heading of treatment or ignored altogether. For example, the UNAIDS Report on the Global AIDS Epidemic still places treatment and care together in the same chapter and doesn’t mention support. Whilst it is important to recognise that all areas of the HIV response are interconnected, it is also essential that individual aspects of the response aren’t ignored or overlooked. It is perhaps no surprise therefore that indicators and monitoring have reflected this prioritisation and care and support has received less attention than it needs in order to provide a comprehensive HIV response.

We therefore welcome the care and support core indicator but encourage UNAIDS to provide more specific support and clarity on the key aspects that might constitute “external support” beyond the identified “food, education, health care and family/home or community support”. We recommend they expand their definition to reflect the definition outlined in this paper. They will also need to broaden the reporting out from a focus solely on care and support for households with a child affected by AIDS, recognising that adults affected by HIV also have care and support needs. This includes not only adults infected by HIV but also those providing care, particularly women and girls. It is vital that care and support indicators accurately reflect the multifaceted nature of HIV care and support.

The UNAIDS interim indicators (see box 3) start to narrow down the specific aspects of care and support, with a welcome focus on women and care-providers. However many essential aspects of care and support are missing. A representative range of indicators is vital for supporting the development and measuring the impact of care and support programmes and policies. In order to show the real impact they need to reflect both qualitative and quantitative information and cover all the major aspects of a comprehensive approach to providing care and support. As much as

²⁰ http://data.unaids.org/pub/Guidelines/2006/20061006_report_Universal_access_targets_guidelines_en.pdf

²¹ It is this indicator that is also used for UNGASS reporting:

<http://www.ua2010.org/index.php/en/UNGASS/Meeting-UNGASS-Targets/UNGASS-Core-Indicators>

²² UNAIDS, Setting National Targets for Moving Towards Universal Access, 2006, p.19

possible, data should be disaggregated by gender and age (ensuring people under the age of 18 or above the age of 55 are not forgotten). Also, for some indicators, there may be a strong case to focus on a particularly vulnerable group – for example, women’s access to legal services. We look forward to working with governments, donors and multilaterals to develop realistic indicators that better capture the breadth of the comprehensive definition of care and support outlined in this paper.

Recommendations on care and support:

The UK Government and other bilateral donor governments, multilateral institutions and INGOs should:

- Promote and advocate for increased focus on care and support as part of universal access; ensure a more comprehensive and holistic definition of care and support and indicators based on those outlined in this paper; and ensure that support is given equal emphasis with care.
- Build capacity within 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 and that a range of services are provided.
- Promote and advocate for the integration of the broad range of medical care and support into ART programmes in government health sector policies and National AIDS strategies
- Support research at a country level that looks at the cost of care and support on communities. Use the evidence to strengthen government and donor technical and financial support for community responses.
- Support research that draws together best practice from organisations that provide effective comprehensive care and support services and realise the rights of care-providers. Use this evidence to update international care and support guidelines (WHO and UN), and country level National AIDS Strategies and Health policies.
- Provide funding and support to home based care organisations to build their capacity to provide appropriate care and support services based on the definitions of this report and realize the rights of care-providers to recognition, training, psychological and material support and compensation.
- 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.
- Fund a comprehensive range of care and support programmes through government and civil society.

Additional resource list:

General resources on care and support:

Kitahata MM, Tegger MK, Wagner EH, Holme KK. BMJ 2002; 954-957. 'Comprehensive Health Care for People Infected with HIV in Developing Countries': Center for AIDS and STD, University of Washington, Harborview Medical Center.

Save The Children, Helpage International and IDS, 2006, 'Making Cash Count'

UNAIDS. Issue 2 2000. 'UNAIDS Best Practice Collection. The Summary Booklet of Best Practices.' The International Partnership Against AIDS in Africa.

UNAIDS. 2004, 'National AIDS Programmes: A Guide to Monitoring and Evaluating HIV/AIDS Care and Support'

VSO and ActionAid, 2007, 'Walking The Talk: Putting women's rights at the heart of the HIV and AIDS response'

WHO, 2002, 'Community home-based care in resource limited settings'

YRG CARE, International HIV/AIDS Alliance, Horizons Program. 2004. 'Expanding Care and Support in Sputh India: Scaling Up YRG CARE's Patient-Centres Approach'.

Carers:

ActionAid, 2007, 'Women bailing out the state: the real costs of home-based care programmes'

Help Age International, 2007, 'Building Bridges: Home-based care model for supporting older carers of people living with HIV/AIDS in Tanzania'

Ogden, Jessica, Simel Esim and Caren Grown. 2004. 'Expanding the Care Continuum for HIV/AIDS: Bringing Carers into Focus'. Horizons Report. Washington, DC: Population Council and International Center for Research on Women.

VSO, 2006, 'Reducing the burden of HIV and AIDS care on women and girls',

Capacity building:

Family Health International 2005. 'Establishing Referral Networks for Comprehensive HIV Care in Low Resource Settings.'

Palliative care:

DfID Health Resource Centre, 2007, 'Review of Global Policy Architecture and Country Level Practice on HIV/AIDS and Palliative Care'

Harding R, Molloy T, Easterbrook P, Frame K, Higginson I. 2006. International Journal of STD and AIDS 17;400-405. 'Is Antiretroviral Therapy Associated with Prevalence Burden?' Department of Palliative Care, Policy and Rehabilitation, King's College and St Thomas' Hospitals, London

Children:

Firelight Foundation, American Jewish World Service, Bernard van Leer Foundation, Pan African Children's Fund. 2005. 'The Promise of a Future. Strengthening Family and Community Care for Orphans and Vulnerable Children in sub-Saharan Africa.'

USAID 2000. 'Children on the Brink'

USAID 2006. 'Success Stories. Paediatric AIDS Handbook Improves Care.'