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Gender inequality, care and the AIDS pandemic

HIV and AIDS reporter, 21 April 2009

Feature: Gender inequality, care and the AIDS pandemic

Recommended readings:

- Men and care in the context of HIV and AIDS: structure, political will and greater male involvement
- Caring from within: key findings and policy recommendations on home-based care in Zimbabwe
- Walking the talk: Putting women's rights at the heart of the HIV and AIDS response
- Mind the gap: HIV and AIDS and older people in Africa
- Gender and care cutting edge pack

Latest additions:

- Reducing the burden of HIV & AIDS care on women and girls
- The political and social economy of care in a development context: contextual issues, research questions, and policy options
- Continuing care for mothers, children and families following prevention of mother-to-child-transmission of HIV
- Human rights guidelines for pharmaceutical companies in relation to access to medicines: the sexual and reproductive health context
- The Global Fund: managing great expectations

Announcements

Feature: Gender inequality, care and the AIDS pandemic

In contexts marked by high HIV prevalence, the need for intensive and long-term care is severe, both in terms of physical care - feeding, bathing, dressing, monitoring drug

intake, transporting patients to health facilities - but also emotional care, such as counselling.

Yet in many of the countries hardest hit by the pandemic, under-investment and depleting numbers of health care workers have decimated the public health sector. Health sector reforms have also led to greater commercialisation of health care and a heavier reliance on private payment and user fees. The result is that institutional health care has become unaffordable for many, shifting responsibility for the care of people sick due to AIDS onto unpaid or poorly paid family and community members.

Gender stereotyping and discrimination mean that women and girls provide the majority of this care, while possibly also being HIV positive and in need of care themselves. In South Africa, for example, a national time-use survey found that women carry out on average eight times more care work than men (for all illnesses). This can undermine their rights and limit their opportunities – posing a fundamental obstacle to gender equality and well-being. For example, girls may have to drop out of school to help with domestic and income-generating activities in cases where their parents are sick, or in households which are child-headed.

Care responsibilities can also exacerbate poverty - squeezing time available for income-generating activities and making it difficult to continue with formal waged labour. Yet, opting for more flexible self-employment or part-time work in order to accommodate caring responsibilities means forfeiting the higher earnings available from waged work. Older women carers may be in a particularly precarious position - research in South Africa and Mozambique found that ‘grandmothers’ were selling off financial assets or using up savings in order to pay for medical treatments and transportation for relatives living with HIV/AIDS.

In the light of the crushing impact of AIDS-related care on women’s day-to-day lives and on the opportunities available to them, more attention urgently needs to be given to supporting carers in the work they do. Care provision should be a central and budgeted component of HIV/AIDS responses, and be addressed in gender-sensitive ways – including through the development of gender-sensitive indicators, such as the proportion of men trained as home-based carers.

Responses need to start with the priorities and coping strategies of carers themselves. Governments, donors and NGOs need to recognise the expertise of those who provide care in households and communities, and involve home-based care organisations and networks in the design, implementation and monitoring of HIV programmes at all levels. Support is also needed for peer learning and networking among home-based care providers, to facilitate the transfer of knowledge, skills and strategies, and to provide spaces for organising.

To ensure that carers receive the support they need to carry out their vital work without undermining their rights and dignity, such inclusive, bottom-up responses are key. It is clear that carers’ combined expertise can be a central force in tackling the epidemic,

provided that others are prepared to listen and act.

This feature is adapted from the new BRIDGE Cutting Edge Pack on Gender and Care, see: www.bridge.ids.ac.uk/reports_gend_CEP.html#Care

More information:

- Siyanda, hosted by BRIDGE
www.siyanda.org/
- The UN Commission on the Status of Women, 53rd session, March 2009: “The equal sharing of responsibilities between women and men, including care-giving in the context of HIV/AIDS”
www.un.org/womenwatch/daw/csw/53sesspriorityhtm.htm
Videos of the presentations, and papers presented at the conference
www.un.org/womenwatch/daw/csw/53sess.htm
- The Huairou Commission
www.huairou.org/index.html
- The Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS)
www.saf aids.net/
- The BRIDGE ‘Women and Girls Living with HIV/AIDS: Overview and Annotated Bibliography’
www.bridge.ids.ac.uk/reports/BB18_HIV.pdf
- ‘Because I am a Girl: The State of the World's Girls 2007’, Plan UK
www.plan-uk.org/pdfs/plan_uk-girls_report2007.pdf
- HIV and AIDS, and gender, Eldis HIV and AIDS Resource Guide
www.eldis.org/go/topics/resource-guides/hiv-and-aids/gender
- HIV and AIDS treatment and care, Eldis HIV and AIDS Resource Guide
www.eldis.org/go/topics/resource-guides/hiv-and-aids/treatment-and-care

Recommended readings

1. Men and care in the context of HIV and AIDS: structure, political will and greater male involvement

Authors: D. Peacock; M. Weston

Publisher: United Nations [UN] Division for the Advancement of Women, 2008

What drives the enormous burden of AIDS-related care which falls on women and girls? What strategies are needed to reduce this burden? Rather than focusing only on ways to increase men's participation in shouldering a more equitable share of the burden of AIDS-related care, this paper by the United Nations Division for the Advancement of Women starts out with an analysis of the structural forces that affect how AIDS care is provided. It argues that, on the one hand, global economic policies, particularly structural adjustment policies, have led to the erosion of the public sector and the displacement of

care into the household and onto women and girls. The authors show how on the other hand, the burden of AIDS care is driven by a lack of political will and the failure of governments to invest sufficiently in AIDS care.

The paper emphasises that government policies often underpin these norms and recognises that gender norms are a key cause of the excessive care burden on women. The authors show how in most countries, for example, paternity leave is much shorter than maternity leave and sometimes does not exist at all. This further entrenches an image of women, and not men, as carers. The authors show how government inaction is not inevitable. Activism by civil society can make a big difference as shown by the achievements of South Africa's Treatment Action Campaign (TAC). To ensure that governments act on the binding commitments they have made, the paper argues that civil society organisations need to play a more activist role. This will require building new skills and relationships - including with trade unions and other social movements. It also necessitates that donors become more willing to fund advocacy work.

Available online at: www.eldis.org/go/topics/resource-guides/hiv-and-aids&id=42906&type=Document

2. Caring from within: key findings and policy recommendations on home-based care in Zimbabwe

Authors: Health and Development Networks (HDN)

Publisher: Southern Africa HIV/AIDS Information Dissemination Service, 2008

In Zimbabwe, as in many parts of sub-Saharan Africa, home-based care (HBC) plays a vital role in the response to HIV, as overwhelmed public health systems fail to meet care needs. This joint publication from HDN and SAfAIDS provides an overview of experiences and lessons learned in the implementation of eight Irish aid-funded projects in Zimbabwe. The document guides HBC implementers, policymakers, regional and international organisations, and donors in designing and prioritising HBC programmes, creating policies and targeting funding to make a real difference to people's lives at the local level. In addition to summarising the main findings of the current project, it presents sets of specific recommendations.

The authors show how various policy gaps currently hamper the efficient and effective delivery of HBC services and, amongst other advice, recommend that practical, clear guidelines should be developed to promote the recruitment and involvement of men in care work, including HBC services. An extensive list of recommendations is provided relating to care giving in HBC. The authors highlight how caregivers are at the heart of HBC interventions and therefore appropriate policies and guidelines should be put in place to provide incentives and psychosocial support to caregivers. The document details how effective partnerships between affected communities, NGOs, governments and international organisations are essential to HBC and this should be reflected in future HBC-related policies. Community involvement is also praised as it helps to strengthen

HBC activities, but the authors warn that implementers and policymakers must ensure that many people in the community are involved as care-givers.

Available online at: www.eldis.org/go/topics/resource-guides/hiv-and-aids&id=42907&type=Document

3. Walking the talk: Putting women's rights at the heart of the HIV and AIDS response

Authors: Nick Corby; Nina O'Farrell; Mike Podmore; Carmen Sepúlveda Zelaya; ActionAid International

Publisher: Voluntary Service Overseas, 2007

This report from VSO and ActionAid focuses on the gender inequalities and challenges faced by women and girls who provide care for people living with and affected by HIV and AIDS. A distinction is made between primary care providers, family members or close friends who provide care and support in the home, and secondary care providers, visiting nurses, health workers or community care providers from NGOs or community groups. The report argues that neither primary nor secondary care providers are sufficiently supported or recognised for their care-providing efforts. Older women and younger girl carers are hit particularly hard because they tend to be missed by state support programmes. Recognising this, some countries are now targeting support for older women carers, such as Botswana and Lesotho which have introduced a non-contributory pension fund. Other potential forms of support for primary care providers include cash transfers, loans and microcredit schemes.

The report calls for the rights of secondary care providers to be recognised, including the right to a fair wage. One positive example can be found in Mozambique where the government has introduced legislation to ensure that care providers receive 60 percent of the minimum wage. However, these wages are still very low and can be hard to access. The authors recommend that multilateral organisations should ensure that international guidelines, such as the World Health Organization Care Guidelines, are updated to directly support the remuneration of care providers. They highlight how governments should increase the provision of social protection mechanisms to support primary care providers. In addition it is argued that civil society must create and strengthen local, national and regional community and home-based care alliances, to allow care providers to share knowledge, skills and resources.

Available online at: www.eldis.org/go/topics/resource-guides/hiv-and-aids&id=34998&type=Document

4. Mind the gap: HIV and AIDS and older people in Africa

Authors: R. Albone; E. Cain

Publisher: HelpAge International, 2008

Large numbers of older people are themselves living with HIV. Many are also taking on vital caring responsibilities for loved ones living with HIV and the children orphaned by AIDS. This briefing from HelpAge International, aimed at the European Union (EU) and member states, highlights the vital support that many older people provide to their children and grandchildren in contexts of HIV. It also cites examples of interventions that have changed the lives of older people and those who depend on them. A number of international policy commitments are outlined which recognise the role of older people in caring for those affected by HIV. These include the 2001 UN Declaration of Commitment on HIV/AIDS which pledges to adjust and adopt economic and social development policies to address the specific needs of older carers.

The document calls for a major shift in the HIV response to involve and support older people by including them in care and support programmes, and by setting up targeted social protection schemes to respond to the needs of older carers. It calls on the EU and member states to work in partnership with African governments and civil society to develop national HIV and AIDS strategies that are inclusive of older people, and to increase practical support to older people, including those with caring roles. The authors recommend that African governments collect more comprehensive data about older carers, and ensure a more sophisticated analysis and understanding of their role, so that they can be better supported.

Available online at: www.eldis.org/go/topics/resource-guides/hiv-and-aids&id=42908&type=Document

5. Gender and care cutting edge pack

Authors: E. Esplen

Publisher: BRIDGE, 2009

Providing care can be both a source of fulfilment and a major burden. For women and girls in particular, their socially prescribed role as carers can undermine their rights and limit their opportunities, capabilities and choices - posing a fundamental obstacle to gender equality and well-being. This Cutting Edge Pack from BRIDGE assesses how it might be possible to move towards a world in which individuals and society recognise and value the importance of different forms of care, but without reinforcing care work as something that only women can or should do. The pack discusses why care is such an important issue for development work and social justice activism, especially in the face of emerging 'care crises' such as ageing populations and the HIV pandemic.

Drawing on diverse examples of initiatives taking place in countries across the world, it considers what strategies offer the best prospects for change. Several sections focus specifically on the impacts of providing care in contexts marked by high HIV prevalence, and on the approaches needed to better respond to the needs and priorities of community

and home-based care providers. The document recommends that donors should fund capacity building of grassroots care-givers, women's organisations and networks, and organisations and networks of people living with HIV and AIDS, to enable care givers to advocate for their rights and represent themselves in local, national and international decision-making forums. The author also argues that donors should support the creation and/or strengthening of local, national and regional home-based care alliances of care providers for people living with HIV and AIDS, to allow care providers to share knowledge, skills, strategies, lessons learned and resources, and to provide spaces for mutual support and organising. Governments should ensure that gender-sensitive care provision is an integral and budgeted aspect of HIV and AIDS policies and programmes.

[adapted from the author]

Available online at: www.eldis.org/go/topics/resource-guides/hiv-and-aids&id=42963&type=Document

Latest additions from the HIV and AIDS resource guide

1. Reducing the burden of HIV & AIDS care on women and girls

Publisher: Voluntary Service Overseas, 2006

This policy brief from VSO highlights the crisis in delivering equitable health care for people living with HIV and AIDS, and the overwhelming burden it places on women and girls. It identifies changes that VSO is advocating for and provides recommendations to key stakeholders for policy and programme change. The document argues that the caregiver has a right to be valued, supported and receive appropriate compensation and the patient has a right to care of a high quality. Community caregivers are profiled and the impact on women and girls assessed. The authors argue that this impact is unsustainable.

The document argues that policy and practice must change to reduce this burden on women and girls. Also the authors highlight problems surrounding policy accountability and highlight the importance of also holding governments and international institutions to account on these issues. Three key changes are put forward which could relieve the burden of care. First, caregivers must be recognised for the support that they provide. Second, there must be a greater involvement of men and boys in delivering home based care and third, public health systems must be strengthened. Recommendations are also provided for stakeholders and international institutions.

Available online at: www.eldis.org/go/topics/resource-guides/hiv-and-aids&id=42965&type=Document

2. The political and social economy of care in a development context: contextual issues, research questions, and policy options

Authors: S. Razavi

Publisher: United Nations [UN] Research Institute for Social Development, 2007

Historically and across a diverse range of countries, women from disadvantaged racial and ethnic groups have tended to provide care services to meet the needs of the more powerful social groups, while their own needs for care have been downplayed and neglected. This paper by the United Nations Research Institute for Social Development traces the evolution of ideas in the area of gender and care, and analyses some of the main strands of thinking. The author analyses the contribution of feminist economics to the conceptualisation, as well as the measurement and valuation, of the unpaid economy, including its care components. The author shows how in approaching the issue of care from their distinct disciplinary perspectives in social policy and sociology, gender analyses of welfare regimes have contributed to the theorisation of care in important ways, some of which intersects with the work of feminist economists.

The strengths of this literature are reviewed in the paper and it is argued that ideally, society should recognise and value the importance of different forms of care, but without reinforcing care work as something that only women can or should do. This is especially important given the well-known and adverse consequences of such gendering: women's financial precariousness and their exclusion from the public domain. The paper considers the renewed interest in social policy, trailing after the high neoliberalism of the 1980s that was epitomised by the 'social investment state' allegedly focused on productive and active welfare, and on investing in children's opportunities. It asks what the implications of these ideas might be for the redesign of social policy, what space is likely to be given to issues of care and whether gender equality and women's movements' claims for services and supports are likely to be accommodated in this new welfare vision.

Available online at: www.eldis.org/go/topics/resource-guides/hiv-and-aids&id=42964&type=Document

3. Continuing care for mothers, children and families following prevention of mother-to-child-transmission of HIV

Publisher: Women, Children and HIV, 2007

This module for continuing care for mothers, children, and families following prevention of mother-to-child transmission of HIV (PMTCT) programmes seeks to provide a Caribbean approach to linking HIV-infected women and their families with ongoing HIV care, treatment, and support needs after participation in a national PMTCT programme. It details how to carry out field visits which allow participants to observe and interact with healthcare workers and clients who are in PMTCT, HIV care and treatment and social

welfare settings.

The authors detail how this experience will help participants to better understand client flow, the national system of comprehensive care, and various barriers to the delivery of comprehensive care. This guide provides general advice in setting up a meaningful practical experience with the understanding that individual country experiences will vary. There are 6 parts to this field visit guide:

- planning the field visit
- conducting the field visit
- after the field visit
- suggested time line for field visit
- sample field visit interview guide
- sample evaluation form

Available online at: www.eldis.org/go/topics/resource-guides/hiv-and-aids&id=42552&type=Document

4. Human rights guidelines for pharmaceutical companies in relation to access to medicines: the sexual and reproductive health context

Authors: R. Khosla; P. Hunt

Publisher: The Human Rights Centre, University of Essex, 2008

This briefing points out that access to essential medicines is a fundamental element of the right to health. It examines the role of the pharmaceutical industry in ensuring access to medicines generally and in particular for sexual and reproductive health.

Sexual and reproductive health are key elements of the right to the highest attainable standard of health. There is a strong link between HIV/AIDS and sexual and reproductive health. The international community agrees that the MDGs will not be achieved without ensuring access to sexual and reproductive health services and an effective global response to HIV/AIDS. The availability of antiretroviral therapy (ART) has significantly reduced AIDS morbidity and mortality in developed countries. Yet in developing countries, where 95% of HIV positive people live, the overwhelming majority still does not have access to life-sustaining medication.

This briefing argues that in association with international institutions and CSO's pharmaceutical companies can play an important role in ensuring access to vaccination thus meeting their human rights obligations. It provides guidance for ensuring the availability and accessibility of vaccinations for immunisation against serious sexual and reproductive health problems, such as HPV. Some of the recommendations for pharmaceutical companies include:

- The company should adopt a human rights policy statement which expressly

- recognises the importance of human rights generally, and the right to the highest attainable standard of health in particular, in relation to the strategies, policies, programmes, projects and activities of the company.
- The company should integrate human rights, including the right to the highest attainable standard of health, into the strategies, policies, programmes, projects and activities of the company.
 - The company should always comply with the national law of the State where it operates, as well as any relevant legislation of the State where it is domiciled.
 - The company should refrain from any conduct that will or may encourage a State to act in a way that is inconsistent with its obligations arising from national and international human rights law, including the right to the highest attainable standard of health.
 - Whenever formulating and implementing its strategies, policies, programmes, projects and activities that bear upon access to medicines, the company should give particular attention to the needs of disadvantaged individuals, communities and populations, such as children, the elderly and those living in poverty.
 - The company should also give particular attention to the very poorest in all markets, as well as gender-related issues.
 - Pharmaceutical companies should develop culturally appropriate information packages to avoid a negative reaction against the vaccination. Critically, if access is to be enhanced, prices must come down

Available online at: www.eldis.org/go/topics/resource-guides/hiv-and-aids&id=42529&type=Document

5. The Global Fund: managing great expectations

Authors: R. Brugha; M. Donoghue; M. Starling

Publisher: The Lancet, 2004

This paper published in the Lancet, tracks early implementation experiences of the Global Fund to Fight AIDS, Tuberculosis and Malaria in four African countries: Mozambique, Tanzania, Uganda, and Zambia. Interim findings are based on interviews with 137 national-level respondents.

The paper finds that:

- Members of country coordinating mechanisms (CCMs) - country-level partnerships, which were formed to develop and submit grant proposals to the Global Fund - were often ineffective at representing their constituencies and encountered obstacles in participating in CCM processes.
- Delays in the dissemination of guidelines from the Global Fund led to uncertainty among members about the function of CCMs.
- Respondents expressed most concern about the limited capacity of fund

- recipients—government and non-government—to meet Global Fund conditions for performance-based disbursement.
- Delays in payment of funds to implementing agencies have frustrated rapid financing of disease control interventions.

The paper concludes that new and existing donors need to coordinate assistance to developing countries by bringing together funding, planning, management, and reporting systems if global goals for disease control are to be achieved.

[Please note: To read this article, you will first need to register with The Lancet. This process and access to the article is free of charge.]

Available online at: www.eldis.org/go/topics/resource-guides/hiv-and-aids&id=42473&type=Document

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Announcements

Conference: Africa Regional Symposium on HIV and AIDS in Institutions of Higher Learning

Dates: 18 – 22 May 2009

Location: Nairobi, Kenya

The theme of this conference is ‘Exploring Evidence, Strengthening Action’. The 3-day Symposium will primarily focus on sharing of policy, research and practitioner experiences, ideas and knowledge and assisting participants to design and roll out effective and multi-layered HIV and AIDS responses in tertiary institutions - especially in Sub-Saharan Africa.

More details available online at: www.eldis.org/go/topics/resource-guides/hiv-and-aids/hiv-events-and-opportunities&id=36434&type=Item

Training: Rational Management of Medicines - a focus on HIV/AIDS, Tuberculosis and Malaria

Dates: 1 – 13 November 2009

Location: Ifakara, Tanzania

This two week course, run by the Swiss Tropical Institute, aims to enable health professionals to understand and apply the concepts and principles of essential medicines and rational medicine management with a focus on the diseases of poverty HIV/AIDS,

malaria and tuberculosis. This is in order to recognise the need for a national and international medicine policy environment, to improve knowledge and skills and to gain practical field experience for rational medicine management within different health system contexts.

The course is most suited to health professionals and managers with at least two years experience in international health and the pharmaceutical sector. It will be conducted in a rural area of Tanzania and will be complemented with field visits experience to address the know-do gap and the system approach to diseases of poverty. The course is unique in combining theoretical knowledge with the reality of a rural district and the questions and skills related to medicine access.

More details available online at: www.eldis.org/go/topics/resource-guides/hiv-and-aids/hiv-events-and-opportunities&id=42976&type=Item

See the complete list of announcements at: www.eldis.org/go/topics/resource-guides/hiv-and-aids/hiv-events-and-opportunities

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- Health Resource Guide - <http://www.eldis.org/health/index.htm>
- Health Systems Resource Guide - <http://www.eldis.org/healthsystems/index.htm>
- HIV and AIDS Resource Guide - <http://www.eldis.org/go/topics/resource-guides/hiv-and-aids>

The HRC provides access to technical assistance and information for the Department for International Development (DFID UK), and its partners, in support of pro-poor health policies as well as health systems, service delivery and public health topics and programmes.

Eldis currently includes descriptions and links to over 4,500 organisations and over 22,000 full-text online documents covering development and environmental issues. It can be searched or browsed free over the Internet.

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Contact details:

IDS Health Development Information Team
Institute of Development Studies, Sussex
Brighton BN1 9RE, UK

Email: hdi@ids.ac.uk
Tel: 44 1273 915 791