

**Workshop on HIV/AIDS and Family Well-being**  
**28-30 January 2004, Windhoek, Namibia**  
*United Nations Department of Economic and Social Affairs*  
*Division for Social Policy and Development*

**Annotated Agenda**

**Introduction**

This document is the principal framework for our work during the three-day Workshop in Namibia. Please read it in advance and undertake the appropriate preparations, including answering the questions at the end of each agenda item, collecting necessary documents and information materials, and consulting your colleagues as needed. This will allow us to use our Workshop time in a constructive and productive manner.

In addition, please bring any relevant policy documents to the Workshop, as well as any materials (such as publications) you may have that illustrate existing models/examples, to which you might refer during the discussion. Please note, however, that you are not expected to make presentations. The Workshop will be conducted as a series of participatory brainstorming sessions.

We look forward to seeing you in Namibia.

**Background**

HIV/AIDS is recognized as more than just a health issue – it is an issue of development, of economics, of security, and of human rights. Indeed, Goal # 6 of the Millennium Development Goals (MDGs) relates to combating HIV/AIDS, malaria and other diseases (*Target 7: “By 2015, to have halted and begun to reverse the spread of HIV/AIDS”*). HIV/AIDS is seriously affecting progress toward reaching the other MDGs, including the goals to reduce income poverty, reach universal primary education, achieve gender equality, reduce hunger, and improve child health.

Family is a significant and often indispensable component of the societal capacity to cope with social, economic and other stresses, such as the HIV/AIDS epidemic. However, little attention has been given by policy makers to the threat HIV/AIDS poses to the “integrity and functioning of the family”<sup>1</sup>, in terms of social integration and intergenerational relations. Further exploration is needed on the impact of HIV/AIDS on the family unit and family networks, including how it has affected family roles and relationships, including intergenerational relationships. It is important that governments develop, and implement, policies and programmes to address the HIV/AIDS epidemic through support and protection to families and family networks.

**Objectives**

The overall objective is to contribute to the development of policies and programmes which strengthen the capacity of families and family networks to cope with HIV/AIDS.

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<sup>1</sup> “AIDS and the Family: Policy Options for a Crisis in Family Capital”, p. 172.

More specifically, the Workshop objectives are to:

1. Explore the effects of HIV/AIDS on the family unit and family networks, changing generational roles, and related social integration issues. This will include ascertaining the role of cultural and traditional beliefs and practices in affecting the spread of HIV/AIDS and the impact of these practices on families.
2. Identify coping mechanisms at different societal levels to mitigate the impact of HIV/AIDS on the family.
3. Review existing policies and programmes to determine how they respond to the needs of families affected by HIV/AIDS at different stages of impact.
4. Develop a policy framework and recommendations for addressing family issues and changing intergenerational roles in HIV/AIDS policies and strategies.
5. Identify further capacity-building needs and knowledge gaps for follow-up activities.

### **Proposed agenda**

1. Key issues related to the impact of HIV/AIDS on generational roles and intergenerational relationships within the family.
2. Existing HIV/AIDS policies and analysis of their responsiveness to the needs of families and communities.
3. Draft policy framework for addressing the impact of HIV/AIDS on family well-being, including recommendations for strengthening families' abilities to cope.
4. Policy-oriented research priorities in developing policy responses to the impact of HIV/AIDS on the family unit and family network.
5. Key areas for policy makers and programme managers to consider in developing policy responses.

### **Agenda Item 1. Key issues related to the impact of HIV/AIDS on generational roles and intergenerational relationships within the family.**

The impact of HIV/AIDS is widespread and well documented. However, little evidence exists on how HIV/AIDS affects the family unit and family well-being. The impact of HIV/AIDS on generational roles and intergenerational relationships within the family may include the following:

Demographic impact. In many countries, HIV/AIDS is wiping away advancements made in extending life expectancy. HIV/AIDS has also greatly impacted child mortality – most children who are infected at birth or through breastfeeding will develop AIDS and die by the age of five.

Economic impact. The epidemic has many employment and labour market implications. Loss of workers to AIDS-related illnesses or caregiving roles leads to productivity decline, loss of earning and loss of skills and experience. In the household, families lose income as HIV-positive family members fall ill. Medical expenses increase and other family members may have to be removed from work or school to provide care. After death, family members left behind, such as orphans,

widows and older persons face economic uncertainty, which, among other things, increases child labour.

Household impact. As seen from above, the HIV/AIDS strongly impacts on the household in economic terms. Furthermore, the epidemic destroys families, as parents die and children are sent to live with relatives, often grandparents. Roles within the household are reversed, and become confused. Even before death occurs, households suffer greatly, due to stigma and discrimination. Caregivers are less able themselves to work. Families are forced into debt, owing to care-related costs, funeral expenses, and/or withdrawal from productive employment in order to take care of orphaned children.

Intergenerational roles impact. Youth may have to drop out of school, to care for family members or to earn a living to support HIV-positive family members. Due to deaths of young parents, grandparents often have to provide economic and psychological support to orphaned children. Adequate support, however, does not exist for older family members and grandparents to undertake these roles.

Orphans. Currently, approximately 14 million children are living without one or both parents, due to AIDS. This number will continue to rise, as the number of adults dying of AIDS increases. In many countries, with rapidly growing epidemics, the number of orphans will increase dramatically in the future. There is not enough assistance provided, however, to the extended families and family networks who often take in the orphans, nor for the orphans themselves, who face enormous vulnerabilities and risk.

The effects of HIV/AIDS on the family unit and family networks, generational roles, and related social integration issues still need to be explored in most countries. This includes ascertaining the role of cultural and traditional beliefs and practices in affecting the spread of HIV/AIDS and the impact of these practices on families. Factors for consideration in elaborating and analysing policies and programmes include:

- Circumstances which make certain families more vulnerable to HIV.
- Risk behaviours within the family once a member is infected (including vulnerability of female family members).
- Disclosure of HIV status within the family: psychological and other aspects.
- Redistribution of time and resources (economic, education, health) to provide care and support functions.
- Stigma and discrimination.
- Neglect of children and older persons (including increased vulnerability of children to sexual exploitation).
- Disintegration of family after death of family member due to AIDS.
- Redistribution of roles within the family (such as grandparents looking after grandchildren).
- Effects of a “generation of orphans”.
- The extent and functioning of family networks and the community affected by HIV/AIDS.
- Effect of HIV/AIDS on courtship, marriage and death rituals (such as life-cycle transitions).

*Questions for discussion:*

- *What are the key issues related to the impact of HIV/AIDS on the family unit and family networks in your country?*

- *How has the HIV/AIDS epidemic affected generational roles and intergenerational relationships within the family in your country? In particular, how are older persons assuming the role of caregivers? What are the success and constraints of this?*
- *How are communities addressing the growing problem of orphans? With what successes and constraints?*
- *What work has been undertaken to determine: a) the situation facing families and family networks; and b) how to best respond to the challenges? Who has been doing this work: government, non-governmental and community based organizations, international agencies, others?*

**Agenda Item 2. Existing HIV/AIDS policies and analysis of their responsiveness to the needs of families and communities.**

To address the HIV/AIDS epidemic, it is necessary to develop and implement policies and programmes, which support and protect families and family networks, focusing in particular on reinforcing healthy family relationships, protecting and increasing family resources, and strengthening the resilience of families and their ability to cope in changing environments.

The relevant policy options could include the following:

- Prevention policies focused on the family rituals (including the elimination of child marriage, discrimination against girls and women in areas such as property and inheritance).
- Prevention policies focused on reducing risk for vulnerable families (such as general or targeted prevention education efforts, and voluntary counselling and testing).
- Policies to assist and strengthen families with HIV-positive family members (including efforts to improve the quality of life and extend the productive life for HIV-positive persons; minimize intra-familial transmission of infection; and address food security and health care issues).
- Policies to lessen stigma and discrimination for families affected by HIV/AIDS.
- Policies to promote and facilitate community support to families affected by HIV/AIDS (such as education and health care subsidies, social safety nets, help in caregiving duties).
- Policies to assist and strengthen families after the death of family members (including food security, social safety nets, and education issues, promotion of human rights in areas such as inheritance).
- Overall policies, which protect and strengthen families and family networks (such as income-generation, alleviating the loss of labour, land and capital issues, education, formation of self-support groups for grandparents, youth, orphans, etc. to reduce further vulnerability).
- Policies that support orphans.
- Policies that support community-based organizations, including organizations of people living with HIV/AIDS.

Existing policies and programmes need to be reviewed to determine how they respond to the needs of families affected by HIV/AIDS at different stages of impact. In this regard, it is important to identify the existing family and community *coping mechanisms* at different societal levels that mitigate the impact of HIV/AIDS on the family.

*Questions for discussion:*

- *In your opinion, what are the most important priorities for policy action to support families and communities in mitigating the impact of HIV/AIDS?*
- *What are the major family and community coping mechanisms, which you can observe in your country, in connection with the HIV/AIDS epidemic?*
- *What national or local-level policies and programmes currently exist to help families and communities cope with HIV/AIDS? What are the principal focuses of these policies and programmes? Describe and briefly analyse both successful and unsuccessful models of existing policies and programmes.*
- *Describe the link, if any, between HIV/AIDS policy and policy for family protection. Please consider: 1) prevention policies, which focus on reducing risk for vulnerable families; 2) care and support policies, which focus on assisting families with HIV-positive family members; and 3) overall policies, which focus on combating stigma and discrimination, strengthening families and family capital, and supporting orphans.*

**Agenda Item 3. Draft policy framework for addressing the impact of HIV/AIDS on family well-being, including recommendations for strengthening families’ abilities to cope.**

A policy framework could be developed which focuses on reaching key family well-being *targets* and *goals*. The framework presented in the form of a chart below strives to organize possible policy actions within three policy *domains* and link them to different *stages* of HIV/AIDS impact on the family. It should be emphasized that the proposed framework does not aim to confine the consideration of policy options to a single schema or universal matrix, and is introduced here for the purpose of provoking and informing the discussion at the meeting.

Policy Domains	Stages of HIV/AIDS family impact	Family well-being targets/goals						
		Diminished economic vulnerability	Reduced risk for and prevented spread of HIV/AIDS	Avoided stigma and discrimination	Supportive family and community networks	Mitigated effects of “Generation of orphans”	Intergenerational cohesion	Improved care and support functions of family
I. Reinforcing healthy family relationships	Pre-HIV+ family member							
	Family affected by HIV/AIDS (HIV+ family member)							
II. Protecting and increasing family resources								
III. Strengthening the resilience of families in changing	Family affected by HIV/AIDS (family member with AIDS)							

<i>environments</i>	<i>Family after the death of family member due to AIDS</i>				...			
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*Questions for discussion:*

- *What do you think about the proposed policy framework? Is it helpful? Are there any essential considerations, which are missing from the presented concept?*
- *Could you suggest possible policy actions to fill the empty cells of the chart?*

**Agenda Item 4 Policy-oriented research priorities in developing policy responses to the impact of HIV/AIDS on the family unit and family network.**

In order to develop policies that more effectively assist families and family networks to cope with the impact of HIV/AIDS on the family unit and family networks, it may be necessary for additional research to be undertaken in countries. It is important to examine what research facilities/entities already exist within countries, what major studies have been undertaken, and what the priorities are for additional research. It is necessary for research to focus on developing and/or expanding policies and programmes to effectively respond to HIV/AIDS. Research should therefore be policy-oriented and action-oriented.

*Questions for discussion:*

- *Please review the factors and issues listed under Agenda item 1 above.*
- *What research questions could you formulate under each research priority? In other words, what do we need to know in order to properly address the challenges to family unit and family networks of the HIV/AIDS epidemic?*
- *How can research be used to review existing policies and programmes, with the aim of scaling up and expanding successful responses?*

**Agenda item 5. Key areas for policy makers and programme managers to consider in developing policy responses.**

It is a challenge for all policy makers and programme managers to not only develop appropriate policy responses to HIV/AIDS, but also to ensure that policies translate into concrete actions and programmes. In addition, programmes should be monitored and evaluated, so that successful actions can be replicated, and less successful actions can be modified or discarded. To this end, policy makers and programme managers may need to take stock of existing strengths and weaknesses within their departments, ministries, and/or organizations.

*Questions for discussion:*

- *Taking account of the factors and issues discussed under agenda item 1, how can conceptual considerations and practical solutions be translated into policy for your country? What steps*

*will need to be taken? What existing resources are at hand? What can you do as an immediate step?*

- *What are the major gaps in the ability of your government to develop, implement and monitor policies and programmes to address the challenges of HIV/AIDS to family?*
- *Please identify major areas of policy development, implementation and monitoring where additional efforts to strengthen existing capacity are required?*
- *What forms of international assistance you feel are necessary?*