Policy Workshop on HIV/AIDS and Family Well-being Windhoek, Namibia 28 – 30 January 2004

Background

- 1. The Policy Workshop was organized by the United Nations Department of Economic and Social Affairs and hosted by the Government of Namibia, National Planning Commission Secretariat. It was held at Windhoek, Namibia.
- 2. The purpose of the workshop was to bring together representatives of governments and non-governmental organizations as well as academic experts and practitioners from various countries in southern Africa to discuss the impact of HIV/AIDS on families in the region, to consider how families and communities are coping with the disease, and to contribute to the development of a strategic policy framework to assist Governments to strengthen the capacity of families and family networks to cope. In order to compare experience across regions, a participant from Eastern Europe was also invited to the workshop.
- 3. The workshop was organized in the light of the outcomes of recently-held international conferences, in particular the special sessions of the United Nations General Assembly on HIV/AIDS (New York, 25-27 June 2001) and on social development (Geneva, 26 June-1 July 2000). The workshop promoted as well the achievement of the development goals of the United Nations Millennium Declaration: Goal # 6 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.
- 4. In addition to participants from the host country, Namibia, international participants came from Lesotho, Mozambique, South Africa, Swaziland, Ukraine, Zambia and Zimbabwe.
- 5. During the Workshop, discussions focused on:
 - a) Exploring the effects of HIV/AIDS on family and family networks, changing generational roles, and related social integration issues;
 - b) Identifying coping mechanisms at different societal levels to mitigate the impact of HIV/AIDS on the family;
 - c) Reviewing existing policies and programmes to determine how they respond to the needs of families affected by HIV/AIDS at different stages of impact;

- d) Suggesting a policy framework and recommendations for addressing family issues and changing intergenerational roles in HIV/AIDS policies and strategies;
- e) Identifying further capacity-building needs and knowledge gaps for follow-up activities.

Opening of the Workshop

- 6. Mr. Samuel Gôagoseb, Permanent Secretary of the National Planning Commission Secretariat, addressed the workshop and welcomed the participants to Namibia. He stated that Namibia recognized it faced a dreadful threat from the HIV/AIDS pandemic in terms of its development efforts, future plans and its vision of political, social and economic stability. As a result, the Government had made efforts to combat HIV/AIDS a critical part of its Second National Development Plan. In its future vision for Namibia, Vision 2030, the Government's main focus will be on the well-being of all people and the strengthening of family units. He expressed confidence that the workshop would make a significant contribution by assisting Governments to incorporate useful international policy experience into national efforts to combat the disease.
- 7. A statement was given by Mr. Bob Huber of the Division for Social Policy and Development, UNDESA. He referred to the observance during 2004 of the tenth anniversary of the International Year of the Family, and quoted the Secretary-General of the United Nations, Mr. Kofi Annan, "while families have always been the essential social unit in all societies, the observance of the International Year of the Family drew worldwide attention to the issue as a fundamental issue of policy. Ten years later, it is time to take stock, and to determine whether the situation of families has improved, and to consider what more can be done on issues of direct concern to families, such as poverty, the spread of HIV/AIDS, migration and the ageing of societies." Mr. Huber expressed appreciation to the Government of Namibia for its generosity in agreeing to host the workshop, and thanked the participants for their contribution to what promised to be very fruitful and interesting discussions concerning the impact of the epidemic on families in the region, its effect on their ability to support and care for all their individual members, and the policies and programmes that Governments and their partners in civil society can implement to help families to cope better with the challenges they face.
- 8. Mr. Kemal Mustafa of the United Nations Fund for Population Activities, addressed the opening session on behalf of the United Nations Namibia Country Team. He stated that HIV/AIDS was more than just a health issue it was an issue of development, of economics, of security, and of human rights. The effects of HIV/AIDS were diverse and overlapping. These included wiping away gains in life expectancy, depletion of workforces and loss of earnings. HIV/AIDS affects the productive capacity of families, reduces labour productivity, and depletes farm household resources. It severely affects family structure and functions, as parent die and children are sent to live with relatives, often grandparents. Roles within the household are reversed, and become confused. Households suffer greatly from stigma, discrimination and economic

insecurity. Young people are particularly vulnerable: it is estimated that half of all new adult infections, around 6,000 daily, occur among youth. Older persons are also greatly affected by HIV/AIDS: as family structures change due to deaths of young parents, grandparents must provide economic and psychological support to orphaned children. This workshop would mitigate the negative effects of HIV/AIDS, through encouraging and assisting governments and civil society to develop, and implement, policies and programmes to support and protect families and family networks.

Policy Framework

- 9. The United Nations General Assembly Special Session on HIV/AIDS (New York, 25-27 June 2001) called upon Governments to develop or strengthen strategies, policies and programmes which recognize the importance of the family in reducing vulnerability and coping with the impact of the disease. The policy framework set out here is designed for policy makers and practitioners working to stop the spread of HIV/AIDS and to mitigate its impact on families, communities and societies. The framework is a practical tool for stakeholders to review and analyze existing policies and programmes, in order to determine whether or not they support family care-giving functions and strengthen families and communities to cope with the impact of the disease.
- 10. The framework will contribute to the development of a policy approach that recognizes the centrality of family in combating HIV/AIDS. Many policies and programmes are designed to meet the specific needs of individual family members without giving due attention to the family context. Effective policies and programmes must consider the effect they have on the ability of families to retain and strengthen their care-giving functions. This framework was developed by the workshop participants and represents the outcome of active and detailed discussions on the issues among policymakers and practitioners in southern Africa.
- 11. The framework proposes seven desired *outcomes* of policies to combat HIV/AIDS. An overarching *principle*, or basis for action, is suggested for each of these outcomes, followed by a series of *recommended actions* and *proposals for research* to provide additional evidence-based and policy-relevant information. A degree of overlapping among the seven outcomes and the many recommended actions will be noted and is to be expected. Some recommended actions or research proposals will apply to more than one desired outcome. The reader is encouraged to consider this framework as a "work in progress" and is invited to provide feedback and propose additions or alterations to the United Nations Department of Economic and Social Affairs, Division for Social Policy and Development.
- 12. While recommending a wide-ranging series of actions to promote family well being, the frame work does not identify specific actors or stakeholders responsible for each action or activity. Because of differences in national and local circumstances, traditions and structures, the identification of responsibilities for action should result from a process of consultation among national policy makers, practitioners and all stakeholders.

- 13. To promote family well being it is essential to encourage healthy family relationships based on mutual support, shared responsibilities and gender equality. In their Millennium Declaration (September 2000), heads of state and government promised to promote gender equality and the empowerment of women as effective ways to combat poverty, hunger and disease and to stimulate development that is truly sustainable. Achieving gender equality and the empowerment of women are fundamental for reducing the vulnerability of women and girls to HIV/AIDS as well as for strengthening the abilities of families to cope with the disease.
- 14. Appropriate policies and programmes to support families must also promote the full realization of human rights and fundamental freedoms for all persons infected with or affected by HIV/AIDS, including in the areas of prevention, care, support and treatment. The participation of persons living with HIV/AIDS in the definition of issues and problems, and in the development and implementation of policies and programmes, is essential.

Policy recommendations and topics for research

TARGET 1: Reduced risk for and prevented spread of HIV/AIDS

Principle

All family members should have access to information and resources (testing, counselling, protection) to protect themselves against HIV infection and to prevent the spread of the infection.

Recommendations

- (a) Review existing HIV/AIDS awareness and prevention promotional materials (information, education and communication materials) and tools (knowledge and skills) to ensure that all family members are targeted appropriately.
- (b) Develop and disseminate messages which promote sexual behaviour change among family members to prevent the spread of HIV/AIDS.
- (c) Encourage dialogue within families on sexual relationships, with an aim to reduce risk-taking behaviour and encourage responsible sexual behaviour.
- (d) Develop and conduct public information campaigns to break down taboos, refute myths, combat superstitions and eliminate sexual abuse and exploitation.
- (e) Enact legislation and strengthen legal efforts to eliminate sexual abuse and domestic violence.
- (f) Provide accurate information on HIV/AIDS and how it is spread to traditional healers, traditional leaders and faith based organizations.
- (g) Encourage the media and the entertainment industry to undertake awareness campaigns and to promote responsible sexual behaviour.

- (h) Provide information, counselling, support and life skills training to empower families and to strengthen intra-family relations.
- (i) Promote voluntary counselling and testing (VCT) for individuals and couples.
- (j) Provide more information on the non-sexual transmission of HIV and ensure access to essential supplies, including sterile injecting equipment, for all family members, to ensure against non-sexual transmission of HIV.
- (k) Discourage practices and beliefs which further the spread of HIV.

Research topics

- (a) Analysis of the impact of HIV prevention information and dissemination strategies, including whether the strategies are achieving their goals and whether awareness and prevention information strategies are reaching all generations.
- (b) Assessment of the incorporation of traditional beliefs and practices in HIV/AIDS prevention efforts.
- (c) Comparison of different techniques and evaluation of best practices for HIV/AIDS prevention and information campaigns.
- (d) Analysis of whether current approaches to prevent the spread of HIV/AIDS are accessible and appropriate for families living in poverty.
- (e) HIV/AIDS knowledge, attitude and practice (KAP) studies, including impact on changes in sexual behaviour.
- (f) Analysis of the role and impact of the media in promoting awareness and behaviour change for HIV/AIDS prevention.

TARGET 2: Avoided stigma and discrimination

Principle

Stigmatization of, and discrimination against, HIV-positive persons and persons and families affected by HIV/AIDS, should be eradicated.

Recommendations

- (a) Forge political commitment to, and support of, destignatization and anti-discrimination efforts.
- (b) Review and revise legislation that is discriminatory against persons living with HIV/AIDS.
- (c) Review, enact and apply legislation to ensure a workplace free of discrimination against people living with HIV/AIDS (PLWHAs).

- (d) Promote dialogue about HIV/AIDS in society and families, to counter ignorance and prejudice.
- (e) Review the requirements of confidentiality and discretion in testing and treating HIV-positive persons, and assess whether the requirements contribute to stigma and discrimination.
- (f) Promote destigmatization of HIV/AIDS within families by targeting information campaigns to, and providing counselling for, all family members.
- (g) Empower HIV-positive persons to lead anti-discrimination and destigmatization efforts.
- (h) Promote the social acceptance and involvement in self-help efforts of persons living with HIV/AIDS.
- (i) Offer support group assistance to HIV-positive persons.

Research topics

- (a) Identification of factors which contribute to HIV/AIDS stigma and discrimination.
- (b) Analysis of the definition and nature of HIV/AIDS stigma and its effects in different communities.
- (c) Assessment of the social impact of medical approaches to discretion and confidentiality regarding HIV infection and testing.
- (d) Analysis of family attitudes to HIV-positive family members and responses to disclosure of their status.
- (e) Review of positive and negative roles played by traditional healers and traditional leaders in the destigmatization of HIV/AIDS.
- (f) Analysis of attitudes of religious leaders and the role of religion in reinforcing or reducing HIV/AIDS stigma.
- (g) Review of legislation to determine whether it discriminates against persons living with HIV/AIDS (PLWHAs).
- (h) Exploration of individual decisions relating to voluntary counselling and testing (VCT) for HIV infection and disclosure of HIV status.

TARGET 3: Supportive family and community networks

Principle

Families affected by HIV/AIDS must be supported to help them to cope with its impact, with recognition given to the special needs of family members of different generations.

Recommendations

- (a) Ensure that interventions to support families and community networks recognize generational interdependence and promote intergenerational interaction and healthy intra-family relationships.
- (b) Promote strong community mobilization to support families affected by HIV/AIDS in appropriate ways.
- (c) Assist communities to support families affected by HIV/AIDS, including identification of community strengths and needs.
- (d) Coordinate community support efforts to target families as a whole, while recognizing the specific needs of members of different generations.
- (e) Expand community home-based care and build capacity among community health workers in home-based care and information dissemination.
- (f) Provide psychosocial support to families and individual family members.
- (g) Provide support for couples affected by HIV/AIDS, including counselling, to accept and adjust to the impact of HIV/AIDS.

Research topics

- (a) Comparative studies of positive and negative coping mechanisms of families affected by HIV/AIDS in different communities, including traditional ways of coping and solving problems.
- (b) Analysis of the relationships between family coping mechanisms and community support practices.
- (c) Review of interventions that assist and support affected families, and identification of specific needs of different generations.
- (d) Identification, evaluation, dissemination and replication of best practices in community and family care and support.
- (e) Identification of harmful and helpful traditional practices.
- (f) Assessment of the role of traditional medicine as a complementary therapy for HIV/AIDS.
- (g) Evaluation of how families, including family members of different generations, perceive their needs for assistance, and the extent to which communities can meet these needs.

TARGET 4: Diminished economic vulnerability

Principle

Families affected by HIV/AIDS should be empowered to sustain economic viability.

Recommendations

- (a) Ensure HIV-positive persons and affected families retain entitlements to benefits and services.
- (b) Improve access to social grants for eligible family members, including child support grants, foster care grants, disability grants and old age pensions.
- (c) Strengthen efforts to reduce the costs of medicines, especially anti-retroviral treatments, and provide subsidies for these treatments.
- (d) Ensure the implementation of laws and practices that protect the rights of HIV-positive persons in the workplace.
- (e) Promote community solutions to reduce economic vulnerability, through community-based cooperative arrangements and schemes to reduce costs and enable savings, including rotating credit schemes, burial societies and mutual aid societies. Provide education to ensure transparency and honesty in the operation of the schemes.
- (f) Provide non-cash inputs to cooperative agricultural projects, e.g. seeds, fertilizers.
- (g) Ensure that families affected by HIV/AIDS retain legal ownership of their land.
- (h) Educate and assist individuals to write wills to protect their dependants' inheritance.
- (i) Assist individuals and families to start and sustain income generation projects, e.g., crop sharing, livestock sharing, land sharing, petty trading, hawking and food gardening.
- (j) Educate people in financial management, e.g., prudent budgeting, savings and income consumption, and provide financial advice.
- (k) Discourage expenditure on expensive rituals that deplete family and community resources, such as lavish funerals.
- (l) Provide incentives for families affected by HIV/AIDS to keep their children in school, especially girls. Assist families to continue to school their children through reductions in school-related expenses, e.g., school fees and the cost of uniforms.

- (a) Assessment of whether income-generation projects assist families affected by HIV/AIDS to sustain economic viability.
- (b) Review of factors and mechanisms which contribute to the impoverishment of families affected by HIV/AIDS.
- (c) Assessment of the effectiveness of various economic empowerment programmes for families affected by HIV/AIDS.

- (d) Assessment of the extent to which Government poverty reduction strategies sustain and benefit families affected by HIV/AIDS.
- (e) Review of experience and practices in writing wills to safeguard family inheritance.

TARGET 5: Improved care and service provision to support family functions

Principle

Provision of care and services to persons infected with or affected by HIV/AIDS should address family needs in an integrated way.

Recommendations

- (a) Ensure provision is made in Government departmental budgets for programmes to help families affected by HIV/AIDS to cope.
- (b) Provide service packages to support families affected by HIV/AIDS, which meet the needs of all family members.
- (c) Provide more child care facilities to mitigate or alleviate the burden of child care on families affected by HIV/AIDS.
- (d) Provide food parcels and nutritional advice to HIV-positive persons and their families.
- (e) Simplify procedures to access grants and services.
- (f) Compile and maintain a directory of information and services, including rights and entitlements, to facilitate families' access to these resources.
- (g) Develop, expand, implement and monitor home-based care services.
- (h) Assist communities to prioritize their needs, to enable them to respond to the support needs of families affected by HIV/AIDS.
- (i) Strengthen and support the capacity of families and volunteers to render home-based care.
- (j) Promote volunteering and mobilize groups of volunteers to provide services, and provide support for their work, including where possible, provision of stipends.
- (k) Promote greater involvement of men in care and service provision.

- (a) Analysis of the needs of families affected by HIV/AIDS for integrated service provision.
- (b) Identification of existing and potential service providers and evaluation of services provided.

- (c) Comparative analysis and evaluation, including cost-effectiveness, of the implementation of different approaches to service provision, such as:
 - Different forms of home-based care:
 - Centralized versus de-centralized service provision;
 - Generationally-targeted services versus integrated services targeted at families.
- (d) Evaluation of support and assistance provided to caregivers.

TARGET 6: Mitigated effects of a "generation of orphans"

Principle

Comprehensive responses to the needs of families affected by HIV/AIDS will enable them to provide care, support and skills to children orphaned by AIDS.

Recommendations

- (a) Policies and programmes for children orphaned by AIDS should support family caregiving as a first resort.
- (b) Encourage foster care and adoption as alternative placement solutions for vulnerable children and orphans. Provide institutional care as a last resort and work to improve the quality of such care.
- (c) Clarify the legal status and protect the rights of children placed in foster care.
- (d) Ensure that institutions maintain family contacts for children in their care.
- (e) Consider temporary placement solutions for children in distress and to offer respite to caregivers.
- (f) Build capacity among, and provide life skills training for, vulnerable and orphaned children and youth, with particular attention paid to the special needs of street children and youth

- (a) Demographic and situational profiles of children orphaned by AIDS, including their needs and available services.
- (b) Analysis of the situation and needs of child-headed families.
- (c) Comparative analysis of the costs and benefits of different strategies to care for orphans and vulnerable children, including institutionalization, foster care and other forms of residential and support care.
- (d) Evaluation of the long-term effects of alternative forms of care on the individual development of children orphaned by AIDS.

TARGET 7: Intergenerational cohesion

Principle

Healthy intergenerational family relationships should be promoted in policies and programmes addressing HIV/AIDS.

Recommendations

- (a) Review policies and programmes to determine their impact on intergenerational family relationships and the ability of affected families to cope with HIV/AIDS, and revise policies and programmes as necessary.
- (b) Ensure service programmes that target individual family members infected with or affected by HIV/AIDS contribute to strengthening family integration.
- (c) Ensure that policies and programmes that support children affected by HIV/AIDS promote a strong sense of family.
- (d) Ensure that polices and programmes for families affected by HIV/AIDS encourage fathers and grandfathers to support and sustain their families.
- (e) Share information about programmes which address the needs of families affected by HIV/AIDS in an integrated way.

- (a) Analysis of the dynamics of intergenerational relations within families affected by HIV/AIDS.
- (b) Analysis of the impact of HIV/AIDS on family structures and family generational roles.
- (c) Review of new parenting roles and styles: children's reactions, confusion and adjustment.
- (d) Study of the effects of the loss of role models for children affected by HIV/AIDS.
- (e) Analysis of grandparents' feelings towards caring for grandchildren affected by HIV/AIDS.