

United Nations Department of Economic and Social Affairs
Division for Social Policy and Development

**United Nations Economic and Social Commission for
Asia and the Pacific**
Emerging Social Issues Division

**Policy Workshop on HIV/AIDS
and Family Well-being in
South and Southeast Asia**

**Bangkok, Thailand
6 – 9 December 2005**



United Nations
New York, 2006

Department of Economic and Social Affairs

The Department of Economic and Social Affairs of the United Nations Secretariat is a vital interface between global policies in the economic, social and environmental spheres and national action. The Department works in three main interlinked areas: (i) it compiles, generates and analyses a wide range of economic, social and environmental data and information on which Member States of the United Nations draw to review common problems and to take stock of policy options; (ii) it facilitates the negotiations of Member States in many intergovernmental bodies on joint courses of action to address ongoing or emerging global challenges; and (iii) it advises interested Governments on the ways and means of translating policy frameworks developed in United Nations conferences and summits into programmes at the country level and, through technical assistance, helps build national capacities.

Note

This report reflects the collective views of workshop participants and does not imply the expression of any opinion on the part of the United Nations Secretariat concerning the legal status of any country, territory, city or area of its authorities, or concerning the delimitation of its frontiers or boundaries.

The report is reproduced without formal United Nations editing.

TABLE OF CONTENTS

	<i>Page</i>
Background	5
Opening of the Workshop.....	6
Situational and Policy Analysis.....	7
Policy Framework	8
Policy Recommendations and Topics for Research	10
Proposals for Country Follow-up Activities and Action	22
List of Participants	27
Annex I: The Changing Family Institution in Asia: Some Notable Features...	31
Annex II: The Impact of AIDS in Older Aged Parents Evidence from Thailand (and some early results for Cambodia)	35
Annex III: AIDS and the Family: The Concept of Family Capital as a Basis for Policy Options.....	53

Policy Workshop on HIV/AIDS
and Family Well-being in
South and Southeast Asia
Bangkok, Thailand
6 – 9 December 2005

Background

1. This policy workshop was organized by the United Nations Department of Economic and Social Affairs in collaboration with the Emerging Social Issues Division, United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP). It was hosted by UNESCAP in Bangkok, Thailand and included participants from countries of South and Southeast Asia. The workshop was the second in a series, following a similar workshop held in Windhoek, Namibia in January 2004, with participation of countries from southern Africa. The workshops were organized to draw attention to the situation of families in the regions, in connection with the observance of the tenth anniversary of the International Year of the Family, and to promote integration of a family perspective into policies and programmes at local and national levels.

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 South and Southeast Asia to discuss the changing situation of families in the region, consider how families and communities are coping with the impact of HIV/AIDS, and contribute to the further 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, the framework developed at the Windhoek meeting was considered as a basis for reflection and discussion.

3. The workshop was organized in the light of 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 also promoted the achievement of the development goals of the United Nations Millennium Declaration, of which Goal Six relates to combating HIV/AIDS, malaria and other diseases, with Target 7 under Goal Six stating: *“By 2015, to have halted and begun to reverse the spread of HIV/AIDS”*. HIV/AIDS is seriously affecting progress toward reaching the other Millennium Development Goals (MDGs), including the goals to reduce income poverty, reach universal primary education, achieve gender equality, reduce hunger and improve child health.

4. Participants in the workshop came from Bangladesh, Cambodia, China, India, Indonesia, Malaysia, Pakistan, Philippines, Thailand and Vietnam.

5. During the workshop, discussions focused on:
 - a) Major trends affecting families in South and Southeast Asia;
 - b) Existing HIV/AIDS policies and analysis of their responsiveness to the needs of families and communities;
 - c) Key issues related to the impact of HIV/AIDS on generational roles and intergenerational relationships within the family;
 - d) Discussion of the policy framework for addressing the impact of HIV/AIDS on family well-being, including recommendations for strengthening families' abilities to cope, and its applicability to the ESCAP region;
 - e) Policy-oriented research priorities in developing policy responses to the impact of HIV/AIDS on the family unit and family networks; and
 - f) Key areas for further capacity-building of policy makers and programme managers in developing policy responses.

Opening of the Workshop

6. A welcome statement was given by Mr. Bob Huber of the Division for Social Policy and Development, UNDESA. He emphasized that there were many reasons that make the topic of the workshop of interest and worthwhile. According to recent information from UNAIDS, in 2005, 8.3 million people in Asia were living with HIV, including 1.1 million people who became newly infected in the past year. AIDS claimed 520,000 lives in 2005. This is taking place at a time when Asian families are experiencing tremendous change and confronting new pressures. Consequently – and despite the enormous resilience that Asian families have displayed in the face of hardship – there has been a progressive disintegration of families in the region. And yet, in many places there is no real, day-to-day alternative to the caring and support functions played by families.

7. Mr. Huber also referred to the observance of the tenth anniversary of the International Year of the Family in 2004, 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”. Countries in Asia and the Pacific make up 60 per cent of the world’s population, so the policies that Governments adopt would have far-reaching effects on efforts to stop the global epidemic and could provide a model for the rest of the world to emulate.

8. A welcome statement was also given by Ms. Keiko Osaki Tomita, who addressed the opening session on behalf of the Emerging Social Issues Division of UNESCAP. She remarked that it has been stated that the institution of the family in

Asia is at a crossroads, faced with unprecedented challenges as Asian societies undergo profound changes and transformation. With globalization, changing demographic features and technological progress, the role of the family in the region is in great transition. Globalization is having an effect on the traditional life-style, attitudes towards marriage and family, and labour force participation. In addition, greater rural-urban migration and the growing importance of remittances in the daily lives of rural families are having an effect on the ways they perceive the role of the contemporary family. The traditional Asian family, where all members, including grandparents, lived under one roof, is coping with a rapid transformation the likes of which their ancestors never experienced.

9. With respect to HIV/AIDS, Ms. Osaki Tomita stated that in Asia and the Pacific some 8.3 million people are living with HIV, and is the region with the second number of infections after Africa. However, being home to 60 per cent of the world's population, any small increase in HIV prevalence in the region translates into a large number of infections, putting the already stretched health and social services infrastructure under strain and contributing to vulnerability in society. And unfortunately, after many years of progress in fighting HIV/AIDS, the disease is nonetheless gathering momentum in some areas of Asia. While the HIV/AIDS epidemic has an impact on every strata and level of society, its impact on the family, as the fundamental minimum social unit, is direct and enormous.

Situational and Policy Analysis

10. Participants in the workshop considered situational and policy analyses, in order to consider the impact of HIV/AIDS on families. The analyses explored demographic, economic and social transitions under way in the Asian region, which include modernization and urbanization, and resulting changes to the structures and functioning of families. The workshop did not undertake a specific, in-depth analysis of existing policies on HIV/AIDS on a country-by-country basis, but rather considered approaches to policies on HIV/AIDS based on work done internationally and studies conducted in the region.

11. The changes that families are experiencing affect their resiliency and ability to respond to the various impacts of HIV/AIDS. There is little doubt that the traditional, extended Asian family structure is changing. Families in Asia are getting smaller. Changing expectations about filial piety, support for extended and older family members, and mutual obligations and responsibilities affect the willingness of individual family members to care for one another. Migration has sometimes weakened family ties further. At the same time, economic development has increased expectations, promoted consumerism and raised expectations about the provision of support and services by others outside the immediate family. Implications of these changes are diminished kin support available to families rendered vulnerable by HIV/AIDS. (Reports prepared for the policy workshop give comprehensive situational analyses and are annexed to this document.)

12. Policy approaches tend to be sectoral, treating individuals with little consideration for family context. Exposure to HIV/AIDS in the region is often related to particular situations or types of behaviour, which may or may not be subject to the control of the individuals concerned. Therefore, policies to respond to the epidemic must be developed within the context of larger socio-economic issues and concerns, including migration, intravenous drug use, and prostitution and sex tourism.

13. Policies and programmes that address HIV/AIDS in a piecemeal way or as a purely medical concern were considered to be less ineffective. It is important to complement policy interventions focusing on the effects of the epidemic on individuals with those addressing the situations and conditions that cause those individuals, and their families, to engage in behaviour that puts them at risk. A major goal should be to shift to a holistic approach to policies and programmes, an approach which takes into account individual, family and community needs and expectations, as well as the challenges posed by modernization and economic development. Intergenerational family cohesion should be supported, for even in the face of changing family structures strong family ties continue to be evident. Thus, programmes to mitigate the effects of HIV/AIDS should target individuals and their families, in order to sustain family structures and rebuild family capital, while assisting families to care for members and to continue their support and socialization functions.

Policy Framework

14. 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 in the region of Asia and the Pacific. This regional framework is a practical tool for stakeholders to review and analyze existing policies and programmes, in order to determine whether they support family care-giving functions and strengthen families and communities to cope with the impact of the disease.

15. The framework is based on work completed at a workshop held in Windhoek, Namibia in January 2004, which established the key components and approaches. Participants at the Bangkok workshop used the Windhoek framework as a point of departure for their consideration of policies and programmes in the Asian region. The framework they developed represents the outcome of their active and detailed discussions on the issues that are relevant in this region, and should 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 should help families to retain and strengthen their care-giving functions.

16. Participants in the workshop recognized the vast differences that exist within and among countries of the region. There are different cultures, traditions, expectations and practices that affect the way people view issues of human sexuality and personal behaviour and, consequently, how they respond to infection with HIV. There are different levels of awareness about HIV and AIDS, how it is transmitted, what it means for persons who are infected and families that are affected, and availability of treatment. There are different political systems, degrees of involvement by civil society, and levels of economic development that all impact on how countries respond to the disease. As a result, the regional framework that is proposed is, by necessity, general in nature and should be adapted to individual national – and sometimes sub-national – circumstances.

17. The framework proposes eight desired *targets, or 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 *topics for research* to provide additional evidence-based and policy-relevant information. A degree of overlap among the eight outcomes and the recommended actions will be noted and is to be expected. Some recommended actions and research topics 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 or to the United Nations Economic and Social Commission for Asia and the Pacific, Emerging Social Issues Division.

18. While recommending a wide-ranging series of actions to promote family well being, the framework 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.

19. 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.

20. 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 appropriate and complete information and resources (testing, counseling, 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 culturally appropriate messages (appropriate to different age groups), which promote gender awareness and safe sexual behavior among family members to prevent the spread of HIV/AIDS.
- c) Encourage dialogue within families on healthy relationships, with an aim to reduce risk-taking behavior (sexual behaviour and drug abuse) and encourage responsible social behavior.
- d) Develop and disseminate appropriate information and messages to target groups whose situation or behavior places them at higher risk for infection (MSM, drug users, pregnant women and migrant workers, etc.)
- e) Enact legislation and strengthen legal efforts to eliminate trafficking in persons, sexual exploitation, sexual abuse, drug 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 gender equality and responsible sexual behaviour.
- h) Provide appropriate information, counseling, support and life and parenting skills training to empower families and to strengthen intra-family relations.
- i) Promote a peer approach to information, counseling and training.
- j) Discourage practices and behaviors which reinforce gender inequalities and further the spread of HIV.
- k) Prevent non-licensed medical practice, particularly that involving drug injection.

- l) Introduce and enforce measures to prevent the reuse of syringes for medical and commercial (re-sale) purposes.

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) Analysis of whether current approaches to prevent the spread of HIV/AIDS are accessible and appropriate for families living in poverty.
- c) HIV/AIDS knowledge, attitude and practice (KAP) studies, including impact on changes in sexual behaviour and gender perspectives and longitudinal studies where it is appropriate.
- d) Analysis of the role and impact of the media in promoting awareness and behaviour change for HIV/AIDS prevention.
- e) Assessment of the incorporation of traditional beliefs and practices in HIV/AIDS prevention efforts.
- f) Evaluation of public and private health provision facilities regarding their practices of (re)using medical equipment, particularly disposable equipment.

Target 2: **Eliminated stigma and discrimination**

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

Recommendations:

- a) Forge political commitment to, and support of, destigmatization and anti-discrimination efforts.
- b) Review, revise and amend 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/community 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 counseling for, all family members.
- g) Empower HIV-positive persons to lead information and advocacy campaigns, including anti-discrimination and destigmatization efforts.
- h) Promote the social acceptance and involvement in self-help efforts of persons living with HIV/AIDS
- i) Offer group support assistance to HIV-positive persons.
- j) Encourage and engage the media and the entertainment industry to incorporate appropriate anti-discriminatory and destigmatizing images and messages.

Research topics:

- a) Analysis of the definition, nature and factors which contribute to HIV/AIDS stigma and discrimination. There is a need to review available research studies on this, particularly those done by the Asia Pacific Network for Tolerance (APNT).
- b) Analysis of family attitudes to HIV positive family members and responses to disclosure of their status, including people living with HIV/AIDS (PLWHA).
- c) Analysis of attitudes of communities, traditional healers and leaders, and religious leaders in reinforcing or reducing HIV/AIDS stigma.
- d) Review of legislation to determine whether it discriminates against persons living HIV/AIDS.
- e) Exploration of individual decision relating to voluntary counselling and testing (VCT) for HIV infection and disclosure of HIV status.
- f) Assessment of the social impact of medical approaches to discretion and confidentiality regarding HIV infection.

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) Mobilize to increase the resilience of families affected by HIV/AIDS in appropriate ways.
- c) Assist communities (religious, peer and community-based organizations, etc.) 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 and social workers and volunteers 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.
- h) Provide respite support to care givers.

Research topics:

- a) Comparative studies of positive and negative coping mechanism of families affected by HIV/AIDS in different countries, including traditional ways of coping and solving problems.
- b) Study of communities' attitudes towards families affected with HIV/AIDS and drug users, also including an inventory of community support services.

- c) Review and evaluate interventions that support the individually affected families and determine the perceived needs of assistance for different generations.

Target 4: Diminished economic vulnerability of families

Principle A: Families and individuals 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 as well as to legal ownership of their land.
- b) Introduce additional benefits as necessary for economic viability of individuals and families affected by HIV/AIDS.
- c) Improve access to social grants for eligible family members, as well as individuals without family, including child support grants, foster care grants, disability grants, old age pensions, etc.
- d) Strengthen efforts to reduce the costs of medicines, especially anti-retroviral treatments, overcoming political, economic and other barriers, as appropriate, and provide subsidies for these treatments according to need or income level.
- e) Ensure the implementation of laws and practices that protect the rights of HIV-positive persons in the workplace.
- f) Promote community solutions to reduce economic vulnerability, through community-based cooperative arrangements and schemes to reduce costs and enable savings.
- g) Ensure access to credit facilities to enable persons who are HIV-positive and their family members and families to maintain their income.
- h) Provide incentives for families affected by HIV/AIDS to keep their children in school, especially girls. Assist families to continue sending their children to school through reductions in school-related expenses, e.g., school fees and the cost of uniforms.

- i) Assist families and individuals without family to start and sustain income generation projects.
- j) Enhance the abilities of families and communities to manage their assets, including financial resources, e.g., through prudent budgeting, savings and income consumption, and provide financial advice.
- k) Discourage expenditures on expensive rituals that deplete family and community resources, such as lavish funerals, marriages and dowry.

Principle B: Recognizing that individuals and families who are economically precarious are at greater risk for infection, they should be assisted to strengthen their economic viability.

Recommendations:

- a) Ensure access of poor families of migrant workers, drug dependents, victims of commercial sexual exploitation and trafficking, etc., to credit facilities and training in order to sustain their families.
- b) Ensure access of migrant workers to information on HIV/AIDS and their rights in order to protect themselves.

Research topics:

- a) Assessment of relevance and impact of national economic, financial and social protection laws and policies on families affected by HIV/AIDS, including a study of the impact of HIV/AIDS and loss of employment.
- b) Assessment, including impact assessment, of programmes and projects aimed at assisting families affected by HIV/AIDS to sustain economic viability.
- c) Assessment of the effectiveness of various economic empowerment programmes for families affected by HIV/AIDS.
- d) Review of factors and mechanisms which contribute to the impoverishment of families affected by HIV/AIDS.

- e) Assessment of the extent to which the formulation and implementation of Government poverty reduction strategies sustain and benefit families affected by HIV/AIDS.
- f) Review of customary laws, traditions and practices to safeguard family inheritance by members of affected families.
- g) Assessment of the nature of expenditures and the allocation of resources of families affected by HIV/AIDS.

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 information about the appropriate use of medication to ensure its effectiveness.
- c) Ensure that available programmes to support families affected by HIV/AIDS meet the needs of all family members.
- d) Consider programmes to address the special needs, including social and psychological needs, of children from families affected by HIV/AIDS.
- e) Ensure access to community-based child care facilities to mitigate or alleviate the burden of child care on families affected by HIV/AIDS.
- f) Ensure that vaccination programmes are available to children from affected families.
- g) Prevent malnutrition of people living with HIV/AIDS and their families through nutritional advice and provision of a safe diet to the babies of affected mothers.

- h) Simplify procedures for people living with HIV/AIDS and their families to access grants and services.
- i) Provide access to information and services, including rights and entitlements, to facilitate families' access to these resources.
- j) Develop, expand, implement and monitor home-based care services through the active involvement of affected families and volunteers.
- k) Assist communities to prioritize their needs, to enable them to respond to support the needs of families affected by HIV/AIDS.
- l) Strengthen and support the capacity of families and volunteers to render home-based care.
- m) Promote volunteering and mobilize and train groups of volunteers to support affected families, including, where possible, provision of stipends.
- n) Promote greater involvement of men in care and service provision.

Research topics:

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

Target 6: Minimize the impact on children affected by HIV/AIDS.

Principles: Enact and implement comprehensive responses to the needs of children affected by HIV/AIDS to enable their families and caregivers to provide them with the necessary care, support and skills in consonance with the provisions of the Convention on the Rights of the Child.

Recommendations:

- a) Responses to the needs of children affected by HIV/AIDS should utilize the Convention on the Rights of the Child (CRC) as the overriding framework for the development of policies and programmes.
- b) Policies and programmes for children affected by HIV/AIDS should support family caregiving as the best/first choice. When necessary, alternatives to family care, such as foster care and adoption, should be developed and strengthened. Institutional care should only be considered when family or alternative families are not available, and Governments have the responsibility to oversee this care and ensure that it serves in the best interest of the child, and any familial and community bonds should be respected, ensured and maintained.
- c) Policies and programmes should include temporary placement options and solutions for children and families in distress to provide respite to children/families and caregivers.
- d) All legal rights of children affected by HIV/AIDS should be protected.
- e) Build capacity among, and provide life skills training for, children and youth affected by HIV/AIDS.
- f) Policies and programmes should ensure the comprehensive medical treatment of HIV-positive children, including the adequate provision of arts.

Research topics:

- 1) Develop demographic information data and situational profiles of children affected by HIV/AIDS, including available services for analysis of their needs.

- 2) Tools for gathering information on, and analyzing the situation and needs of, children affected by HIV/AIDS need to be researched and developed. They should be nationally appropriate and child-friendly, integrating Convention on the Rights of the Child (CRC) principles and guidelines.
- 3) Conduct comparative analysis of the costs and benefits of different strategies to care for children affected by HIV/AIDS, including family care and alternatives to family care, such as foster care, adoption and institutional care.
- 4) Conduct Country-specific research and evaluation of the long-term effects of alternative forms of care on the individual development of children affected by HIV/AIDS.

Target 7: Promote healthy intergenerational family relationships

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

Recommendations:

- a) Policy and programme stakeholders should review together policies and programmes to determine their impact on intergenerational family relationships and their effectiveness in assisting affected families to cope with HIV/AIDS, and revise them to improve their promotion of healthy intergenerational family relationships.
- b) Service programmes should be developed and implemented in relation to the entire family so as to improve their effectiveness and enrich the care and support provided to individuals infected by HIV.
- c) Ensure service programmes that target individual family members infected with, or affected by, HIV/AIDS contribute to strengthening family integration.
- d) Ensure that policies and programmes that support children affected by HIV/AIDS promote healthy family relationships.
- e) Ensure that policies and programmes for families affected by HIV/AIDS encourage male members to support and sustain their families.
- f) Share information about programmes which address the needs of families affected by HIV/AIDS in an integrated way.

- g) Encourage Government to develop policies and support programme for older parents who have lost their children to AIDS.

Research topics:

- 1) Research and analyze the dynamics of intergenerational relations within families affected by HIV/AIDS.
- 2) Research and analyze the impact of HIV/AIDS on family structures and family generational roles.
- 3) Research new and evolving parenting roles and styles in affected families and their impact on children and their development.
- 4) Study the long-term effects of loss on families, including on children and grandparents, affected by HIV/AIDS.

Target 8: **Reduced vulnerability of families affected by drug abuse**

Principle: Vulnerability of families to HIV/AIDS should be reduced by preventive and rehabilitative measures targeted towards family members abusing drugs.

Recommendations:

- a) Promote dialogue and communication within the family on issues related to drug abuse and HIV/AIDS.
- b) Prevent easy access, especially by young people, to prescription and non-prescription narcotic drugs.
- c) 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.
- d) Assist families to rehabilitate the family member affected by drug abuse.
- e) Organize public campaigns to raise awareness about harm reduction and the high risk involved in the sharing of needles.
- f) Educate, including through life skills programs, adolescents and young people about measures to prevent their involvement in drug abuse.

- g) Introduce peer counseling and implement programmes for alternative engagement to support and rehabilitate younger people involved in drug abuse.

Research topics:

1. Economic, social, cultural and other factors of drug addiction and abuse in the region.
2. Role of drug abuse in regional patterns of HIV/AIDS epidemic. Prevailing methods of transmission of HIV related to drug abuse.
3. Identification of the prevailing trafficking trajectories (paths) and consumption patterns of injecting and non-injecting narcotic drugs.
4. Assessment of rehabilitative measures for drug abusers and measures to prevent drug abuse among family members appropriate for the different countries of the region.
5. Impact assessment of life skills programmes to prevent the involvement of adolescents in drug abuse.

Proposals for Country Follow-up Activities and Action

The proposals that follow were submitted by the workshop participants as areas of follow-up and action upon their return to their respective countries.

Policy and programme formulation, assessment and analysis:

- Review the existing related programmes of our respective institutions to identify if these programmes are family-based and care-focused.
- There is a need to pay much attention to children influenced by HIV/AIDS. It is urgent to develop policies or launch programs focusing on these children.
- Make existing HIV/AIDS and related policies informed by the targeted people.
- Revisit the programme and projects of the National AIDS Council members and relate it to the family framework.
- Propose a work plan to the National Committee on HIV/AIDS (which consists of all concerned ministries, e.g., the Ministry of Public Health, Ministry of Education, Ministry of Labour, Ministry of Social Development and Human Security, concerned GO/NGOs, etc.) in order to make sure that the work plan be integrated into national policy.
- Undertake an assessment of the effectiveness of existing policies and programmes on families affected by HIV/AIDS.
- Undertake an assessment of the existing model of orphan care and care for people living with HIV/AIDS.

Information dissemination, capacity building and training:

- Capacity building of NGO staff, target groups and the different layers of stakeholders on people living with HIV/AIDS (PLWHA) and the role of family, community and society:
 - awareness campaign and educational programme to share concepts on PLWHA;
 - develop MIS (management information system) for managing information and caregiving.
- There is a need to train family members to care for AIDS patients. Training centers should be set up at the village level, if possible.

- Share the HIV/AIDS family approach framework with:
 - the national AIDS authority, which consist of 26 line ministries;
 - health networks in place at provincial levels in every quarter;
 - a regional workshop on women and HIV/AIDS, which will take place in March 2006.

- Hold a seminar about how to reduce the risk of HIV transmission to specific groups that are at higher risk of infection, such as men who have sex with men, drug users, pregnant women, migrant workers and medical professionals.
 - Partners: NGOs, Government Department of Health, Department of Social Welfare and Development Federation of Family Planning Association, National Aids Commission, etc.

- Hold a seminar about how to encourage parents' involvement in healthy communication.

Partners: Religious leaders, Union of Family Welfare (sub-district level).

- Support the existing vocational courses promoting income-generation for families affected by HIV/AIDS.

Partners: Government and NGOs.

- Share the family framework with the National Aids Council and relate it to the National Plan on HIV/AIDS.

- Conduct a follow-up roundtable forum among GOs, NGOs and PLWHA organizations focusing on children in affected families (to be sponsored jointly between governments and NGOs).

- Encourage governmental support for vocational training programmes for HIV/AIDS affected persons/families:
 - sustainable vocational training programs;
 - marketing plans for the products.

- Promote community education on how to take care of and live with HIV/AIDS infected persons and their families through the Family Development Centers.

- Educate people, especially young people, on the prevention of HIV/AIDS.

- Eliminate negative social attitudes towards HIV/AIDS affected persons and families.

- Promote correct knowledge on HIV/AIDS, especially for people in rural areas.
- Promote education for mothers infected with HIV/AIDS, especially pregnant or breast-feeding mothers, in order to prevent mother-to-child transmission, as well as educating them on how to take care of themselves and children, such as through appropriate dietary substitution.
- Promote a peer approach to information, counseling and training:
 - Approach high school and college students in order to reduce risk and prevent the spread of HIV/AIDS. Train students, make them aware about the information on HIV/AIDS, demonstration of condoms, etc. and further expect them to train other peer friends. Initially such a process can be started with a seminar.
- Sensitization workshop for media reporters and editors.
- Youth Summit – sharing the concept of HIV/AIDS and family.

Research:

- Situational analysis of PLWHA.
- Conduct surveys to be sure to have valid data.
- Assess the needs of families affected by HIV/AIDS. Conduct a survey if it is possible.
- Conduct a research study on the impact of HIV/AIDS on the family.
- Study female-headed households to identify the problems they face and how they can be assisted.
- Review laws that discriminate against PLWHAs – including the lack of laws to protect the rights of PLWHAs.
- Situational analysis of affected family needs and unmet needs.
- Longitudinal study in cooperation with Ministry of Development, health system, social security, and education.

Advocacy:

- Advocacy at grass roots, local and national levels (including schools/pre-university students/media/management policy makers, media journalists)
- Advocacy with decision makers.
- Continue to advocate the government about HIV/AIDS and encourage and reinforce the political will necessary to respond to the needs of care, support and treatment.

Partners: Government, religious leaders, NGOs, etc.

- Advocate government to provide knowledge and institutional care for HIV-positive children.
- Advocate for greater awareness on the affect of HIV/AIDS on families.
- Advocate/campaign to promote “pure love” or sexual abstinence as a way to prevent HIV/AIDS transmission among primary and secondary school students, and review school materials regarding sex education to promote correct knowledge and positive social attitudes towards HIV/AIDS affected persons and families.
- Advocacy workshop with parliamentarians, sharing recommendations and outcomes of workshop with National Aids Control Program.
- Advocate enterprise-level policies to safeguard the interests of families of workers vis-à-vis HIV/AIDS.

Collaboration:

- Investigate and implement means to increase collaboration, networking and skill development.
- Community networks and volunteers have their own capabilities and potential and they play a very important role in supporting and helping affected families.
- Promote cooperation and collaboration among these organizations:
 - Government department charged with HIV/AIDS prevention and control;
 - Commission on population, family and children;
 - Institute of Social Sciences;
 - Ministry of Labour and Social Affairs;
 - Women’s organizations.

Service support and support systems:

- Promote and provide care services both family-based and institutional
- Inventory and mobilization of country based organizations in strengthening family support systems.
- Create more support groups for HIV-positive people. This will not only be a platform for them to share their emotions and problems, but as a group they could also start up ventures which could be based on an income-generation activity.
- Assistance schemes to be started by the government for the health needs of families affected by HIV/AIDS, just like we have other social grants, such as pension schemes or widow assistance schemes.

Other:

- Selection of a target from among the eight framework targets to be applied in a pilot project.
- So far, our country's ministry has developed a policy on women, children and HIV/AIDS. In this policy, there were several points similar to those we have discussed in this family framework, and which can be continued, according to the donors' budget.
- Building management information systems on families affected by HIV/AIDS
- Support groups can start their own banks by contributing a minimum amount of money on a regular monthly basis which can be lent to any of the contributing members in case of an emergency due to health or any kind of disaster. This money at the time of the emergency will help them to cope. This money can also be utilized for some kind of income-generation activity as well.

Easy access to credit for HIV-positive people who are willing to start up their own business in order to make them self-sustaining.

List of Participants

Bangladesh

Ms. Hasina Chaklader
Director
MIS & Operations Research
Bangladesh Women's Health Coalition
Dhaka

Cambodia

Ms. Hou Nirmita
Ministry of Women's Affairs
#3, Preach Norodom Blvd.
Wat Phnom, Khan Don Penh

Mr. Pok Socheat
Buddhist for Development
Wat Phnom, Khan Don Penh

China

Ms. Li Xiaolin
Program Officer
China Population Welfare Foundation
Beijing

Ms. Mo Lixia
Division Chief
Information, Education and
Communication Department
National Population and Family
Planning Commission
Beijing

Mr. Xiao Yuanhong
Project Officer
Marie Stopes China
Beijing

India

Ms. Kritika Jhalani
Naz Foundation India Trust
New Delhi

Indonesia

Dr. Niken Tri Utami
Banjar Barm District Hospital
South Kalimantan

Ms. Sri Daryanti
Pangjalan Jati
East Jakarta

Ms. Caroline Thomas
Spiritia Foundation
Jakarta

Malaysia

Dr. Huang Soo Lee
Honorary Secretary-General
Federation of Family Planning
Association, Malaysia, and
Member of International Planned
Parenthood Federation
Subang Jaya, Selangor

Mr. Mohammad. Mizal Bin Bin
Mohamed. Noor
Sarawak State Director
Lembaga Penduduk dan Pembangunan
Keluarga Negara (LPPKN)
(National Population and Family
Development Board)
Ministry of Women, Family and
Community Development
Sarawak

Pakistan

Mr. Saleemullah Baig
Senior Executive
Reproductive Health Initiative for
Youth in Asia , SACHET
Islamabad

Philippines

Ms. Alicia R. Bala
Undersecretary for Policy and
Programs
Department of Social Welfare and
Development
Quezon City

Ms. Lorraine Anderson
Executive Director
Precious Jewels Ministry
Metro Manila

Thailand

Ms. Kanjana Emdist
Social Worker
Bureau of Social Welfare Service
Department of Social
Development and Welfare
Ministry of Social Development
and Human Security
Bangkok

Ms. Jitiya Purksametanan
Social Development Worker
Office of Women's Affairs and
Family Development
Ministry of Social Development
and Human Security
Bangkok

Mr. Wanchai Sonchaisakul
Secretary General
FFWPU-Thailand
Bangkok

Vietnam

Ms. Nguyen Thi Ngan Hoa
Center for Gender and Family Studies
Southern Institute of Social Sciences
Ho Chi Minh City

Mr. Tran Van Chien
Director
Scientific Institute for Population,
Family and Children Committee for
Population, Family and Children
Hanoi

United Nations Economic and Social Commission for Asia and the Pacific (ESCAP)

Ms. Keiko Osaki
Population and Social Integration
Section
Emerging Social Issues Division
Bangkok

Ms. Nguyen Thi Kim Xuan
Population and Social Integration
Section
Emerging Social Issues Division
Bangkok

United Nations regional team

Ms. Nwe Nwe Aye
UNAIDS
Partnerships Development &
Mobilisation Advisor
Regional Support Team, Asia Pacific
Bangkok

Ms. Motoko Seko
Programme Specialist
Gender and HIV/AIDS
United Nations Development Fund for
Women (UNIFEM)
East & Southeast Asia Regional Office
Bangkok

Mr. Karl Spence
Coordinator of the Regional
Consultation on Children and AIDS
UNICEF Regional Office for East Asia
and the Pacific

**United Nations Department of
Economic and Social Affairs (DESA)**

Mr. Bob Huber
Chief, Generational Issues and
Integration Section
Division for Social Policy and
Development
New York

Mr. John Knodel
Professor
Population Studies Center
University of Michigan
Ana Arbor, Michigan
United States

Mr. Alexandre Sidorenko
Focal Point on Ageing
Division for Social Policy and
Development
New York

Mr. Eric Olson
Focal Point on the Family
Division for Social Policy and
Development
New York

Annex I:

The Changing Family Institution in Asia: Some Notable Features

Presentation by Ms. Keiko Osaki and Ms. Kim Xuan Nguyen
Emerging Social Issues Division, UN ESCAP

The HIV/AIDS epidemic has exerted tremendous impacts on the family, both socially and economically. Often, the epidemic significantly increases the burden of care for a member infected with HIV/AIDS. The death of adult family members with HIV/AIDS may lead to the dislocation or dissolution of the family, thus weakening its function. Community attitudes towards the HIV/AIDS-affected family are also likely to be negative. There are a number of economic impacts of HIV/AIDS on families as well as medical expenditures increase, placing a heavy financial burden on those families affected by the epidemic. The absenteeism or loss of family members, especially a breadwinner, may result in the loss of income and the impoverishment of the family.

The resilience of the family to such adverse impacts of the epidemic depends on its characteristics and the functions that it performs. As a basic social institution, the family provides emotional, financial and material support which is essential to its members, and bears most of the burden of the disease as an individual copes with the disease. Hence, any changes in the features of the family could either increase or mitigate the vulnerability of the family affected by HIV/AIDS. It is within this context that the overview of the changing family institution in Asia is discussed.

Over the past decades, the family or household in Asia has gone through tremendous changes in the face of rapid modernization and globalization. From a demographic perspective, one of the most visible changes in the family institution is its declining size. Except for the sub-regions of South and South-Western Asia, the average size of the household continues to decrease in most countries in Asia, implying the weakening capacity of care provision by its members. Today, in the developed countries of Asia, households average less than three persons. Continued declines in fertility and, to a lesser extent, the tendency among adults to live in separate residences have contributed to the general trend towards smaller family size.

The family in Asia is also changing in terms of its composition and structure. Because of declining fertility and increasing longevity, the presence of young people in families is declining. In turn, the relative proportion of elderly people who will require care and protection is destined to grow. While the extended family structure is still very common in much of Asia, gradually the nuclear family type of living arrangements has gained popularity. Furthermore, many countries in the region have witnessed increases in single-person households or female-headed households, as a result of increased dissolution of marriage as well as population ageing.

Families in Asia are also affected by the dynamics of societies to which they are exposed. With growing economic opportunities outside the community of residence, young members of families are more likely to move out of parental homes to seek employment or career opportunities. Asia is also a region which has seen a growing volume and an expanding scale of international labour migration, generating a non-negligible number of transnational families which are emotionally tied cross national borders.

It has been noted that social attitudes towards family issues have gone through changes in the region. The 2001 survey conducted by the Government of Singapore to examine changes in social attitudes in the country over time indicates that while there is a fairly positive attitude towards marriage and having children, there are significant differences between the attitudes of various groups, a strong negative correlation between family size and the education level of females, and more liberal attitudes among younger Singaporeans towards other family arrangements and practices such as cohabitation, unmarried persons with children, divorce and homosexual relationship.

The structural changes occurring in the labour market, partly due to the process of globalization and partly due to the changing patterns in competitiveness of the countries in the region, have increased the role of the family in the production and growth dynamics of the region. With the rise in sub-contracting and home-based work, the family is becoming an important unit in the production, distribution and marketing chains. In this changing environment, women (mostly housewives) and children (mostly girl children) are playing a dominant role in sustaining family incomes and consumption levels. On many occasions, they work in poor conditions with wages that are significantly below their productivity.

One of the most important changes faced by families in Asia is the growing participation of women in the labour market. In countries like Bangladesh and Nepal, more than 50 per cent of women of working age join the active labour force (ILO, 2005). While this has been viewed as a welcome change in improving living standards and alleviating poverty, it has also meant that young women have tended to postpone marriage, thereby having an effect on the demographic patterns, as well as how the role of family is being perceived by young generations. Another related feature is the high unemployment rate among youth in Asia, with Southeast Asia reaching rates of 16.7 percent for males and 17.6 per cent for females, followed by South Asia with corresponding rates of 13 per cent and 15.9 per cent (ILO, *Labour and Social Trends in Asia and the Pacific*, 2005). While this situation may be the result of the youth population making up a large percentage of the total population, and the incapacity to absorb new entrants into labour markets, it does signal a source of concern to families and societies at large, including the burden of continuing support to be provided by families to jobless youth and the need to address the social implications of youth unemployment, which may also include social exclusion, violence, crime, and drug abuse.

The traditional role of the family as a care provider is being challenged in many parts of Asia with increasing labour force participation, especially that of women,

migration, population ageing, and epidemics such as HIV/AIDS. For families affected by HIV/AIDS, a missing link is often the result whereby grandparents take care of adult children and grandchildren, and young people drop out of school to look after HIV/AIDS infected parents. The HIV/AIDS epidemic has taken a heavy toll on the care-giving capacity of families.

In Asia, the family has functioned as a steady provider of informal social protection. In lower-income countries with inadequate formal protection, the family provides the first line of defense and self-organized protection against risks, including life cycle risks such as illness and old age, economic risks such as unemployment, as well as social and environmental risks. However, this informal support mechanism is showing signs of weakening as a result of profound social changes, including migration, urbanization, and changing attitudes. The Asian financial crisis in the late 1990s dramatically illustrated the need for preserving the family as the basic social and economic unit. Many people who became unemployed in the wake of the crisis had to fall back on their families for economic and social support. On most occasions, the burden fell on women who had to combine their daily household responsibilities with the provision of these services to their family members.

In conclusion, family issues such as marriage and procreation are highly personal choices, driven by one's attitudes and values that may not be easily influenced. Yet, such choices have broader social, economic and societal impacts. Understanding family issues provides a basis for proactive and effective policy responses to possible shifts in family-related attitudes, choices and values over time. As the basic unit of society, the family in Asia remains resilient. Appropriate policies are needed that provide requisite support and resources for the family institution to fulfill its developmental and societal functions.

Annex II:

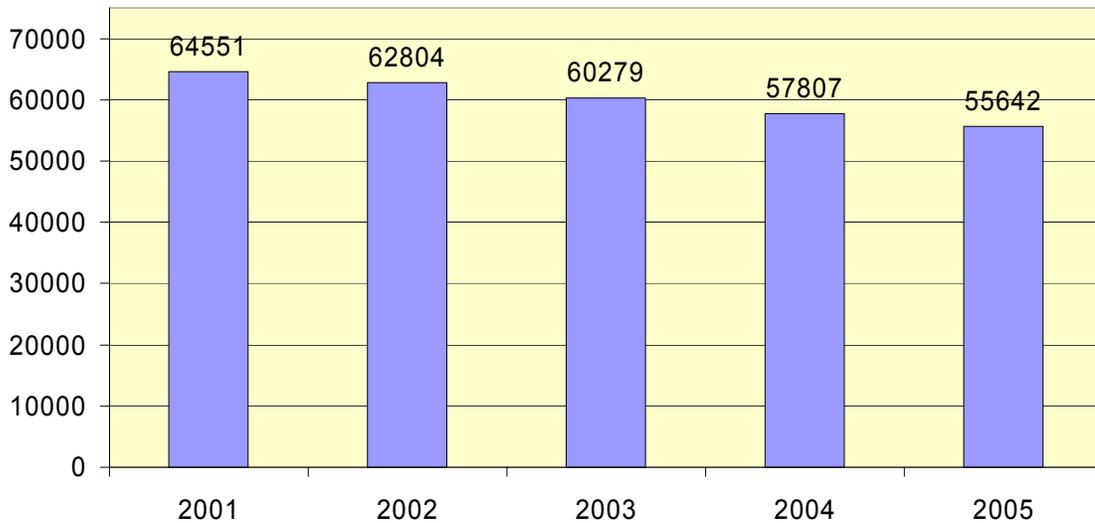
**The Impact of AIDS on Older Aged Parents
Evidence from Thailand (and some early results for Cambodia)**

Presentation by Professor John Knodel
Population Studies Center, University of Michigan

Introduction

One universal and tragic feature of the HIV/AIDS epidemic is that large numbers of older persons lose an adult son or daughter to AIDS. In Thailand (see fig.1), most adults who die of AIDS have living parents: over 90% of adult Thais who die of AIDS have at least one parent alive and over half have both alive. Thus most AIDS deaths leave behind one or two parents. Since most who die of AIDS are aged 20-44, most AIDS parents are of older age, in their 50s, 60s, or 70s at the time their child dies.

Fig. 1 Number of persons age 50+ who experienced the death of an adult son or daughter to AIDS, Thailand, 2001-2005



A variety of potential pathways exist through which older persons as parents of adult sons and daughters with HIV/AIDS can be affected by this disease. *Emotional distress* over the adult child's suffering during illness and grief following the child's death are surely universal. Parents may also experience *economic, health* and *social* consequences. These include *financial difficulties* emerging from a son or daughter's illness, especially if the parents help with medical costs and living expenses, curtail

their economic activity to give care, pay funeral costs, or take responsibility for orphaned grand children. The loss of current or future support from the child can leave the parents in financial difficulty. The health of older-aged parents could suffer through physical strains from caregiving, extra work taken on to pay expenses, or potential exposure to TB or other opportunistic diseases that persons with AIDS often contract. Stigma may lead parents to withdraw from normal community life or cause others to avoid socializing with them or patronizing any local shop or business they may run.

Thai and Cambodian Settings: Differences and similarities

There are both important differences (see table 1) and similarities between Thai and Cambodian settings, which are important for obtaining and interpreting the results of this study.

Table 1: Thai and Cambodian Settings: Differences

Thailand	Cambodia
33% live on under \$2 a day	78% live on under \$2 a day
Rapid fertility decline from high levels in 1960s to low levels currently - Thus current reproductive age adult generation have few children but their older age parents have many.	Mostly high fertility with only modest decline since 1990s so both current reproductive age adult generation and their older age parents have many children.
An extensive public health system; basic health insurance; welfare measures targeted at persons with AIDS.	Poorly developed public health system and few social welfare measures at all.

Similarities between Thai and Cambodia settings include pervasive filial support for older parents since a large majority of older parents live with or adjacent to an adult child. In addition, a large majority of older persons receive material support from adult children including remittances from children living outside their household.

There are also some similarities and differences in HIV/AIDS epidemic in Thailand and Cambodia, as highlighted in table 2.

Table 2: Similarities and differences in HIV/AIDS epidemic in Thailand and Cambodia

Thailand	Cambodia
Began in the late 1980s	Began in the early 1990s
2nd highest HIV prevalence in Asia but declining	Highest HIV prevalence in Asia but declining
Peaked at about 2% and now 1.5%	Peaked at 3.3 % now 2.5%
Large pool of infected adults remains to die	Large pool of infected adults remains to die
Mostly heterosexually spread	Mostly heterosexually spread
Public is reasonably well informed about AIDS	Public is reasonably well informed about AIDS
Government open and active re fighting AIDS	Government open and active re fighting AIDS

Data collection methods used in the study

Thailand:

- 1) Case information for over 900 individual AIDS cases provided by interviews with mainly local health staff in 85 sites around the country in 1998-99
- 2) A survey directly interviewing AIDS and non-AIDS parents (almost 400 interviews in each group) in 2000.

Cambodia:

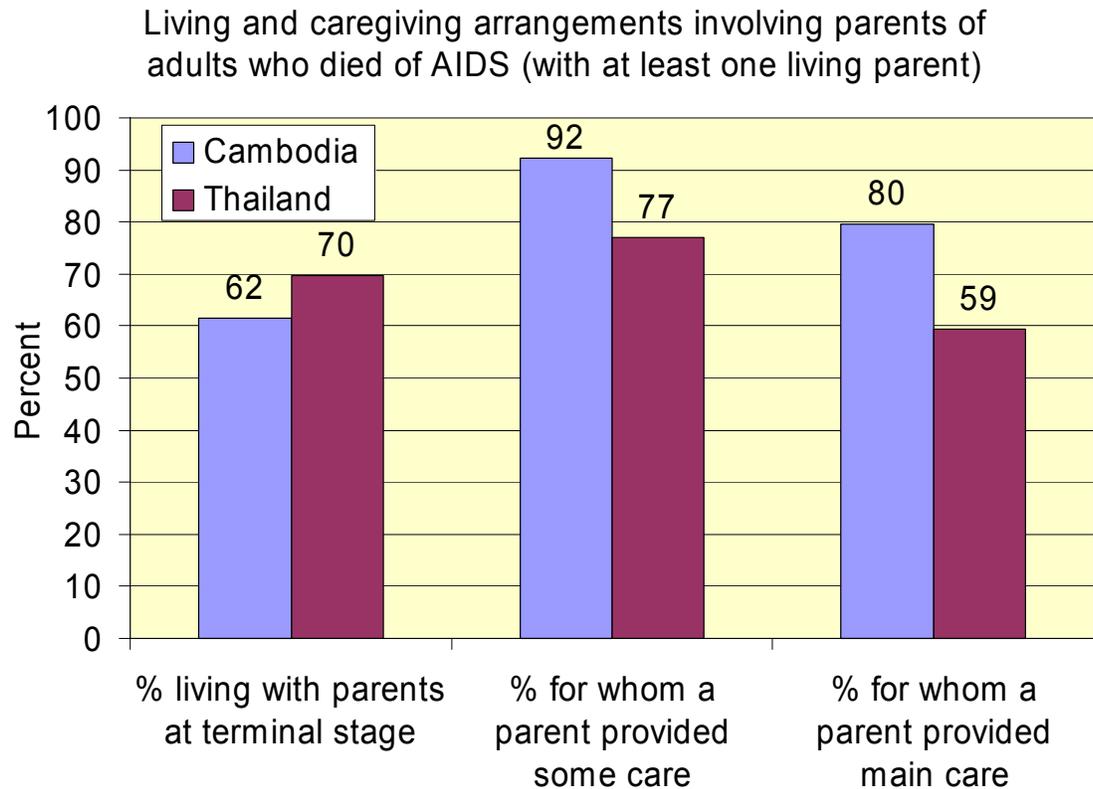
A general representative survey of persons 60+ in 2004 and a supplemental sample in 2005 of about 100 persons age 50+ who recently had an adult child die.

Key findings

1. Parents commonly live with and/or give care to adult sons and daughters with HIV/AIDS at the terminal stage of the disease.

The results of our research clearly show that Thai and Cambodian parents are intensively and extensively involved with their infected adult children through both living and caregiving arrangements (fig.2).

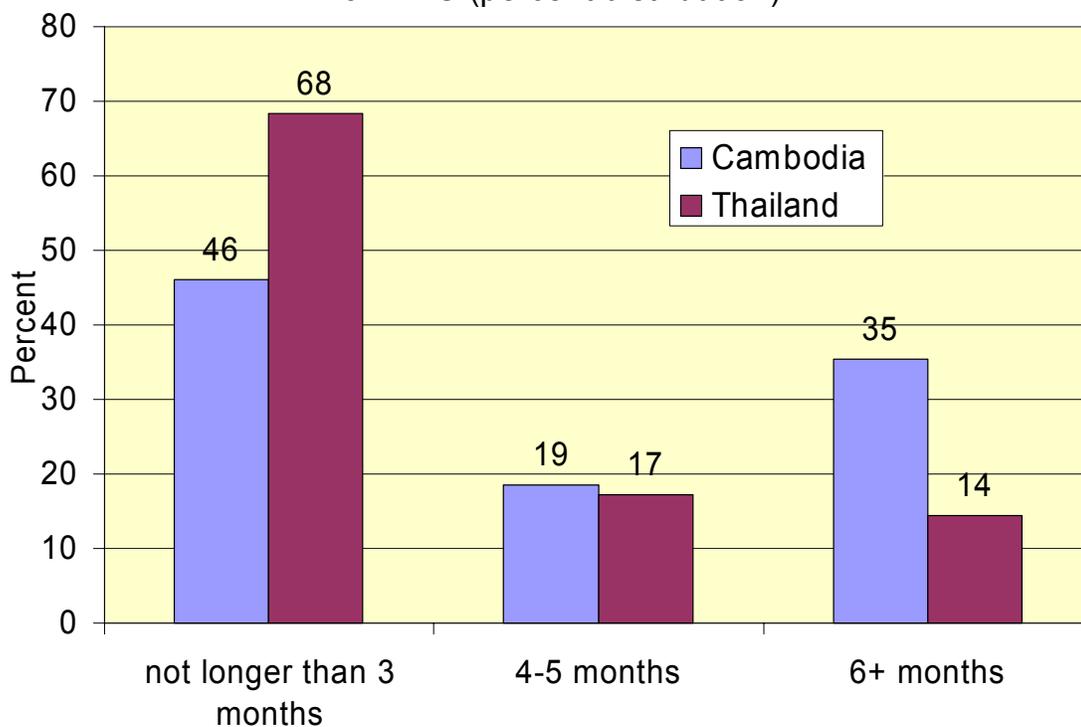
Fig.2



2. Parental caregiving is usually of short duration, but because it occurs at the terminal stage of illness it is typically physically and emotionally intense.

Parental caregiving usually occurs only when their HIV infected children become seriously ill and can no longer take care of themselves. Thus the typical duration is short (fig. 3). However, it occurs during the most disabling stage of the illness and thus is particularly time consuming and difficult for many parents.

Fig.3 Duration of parental caregiving to adult children who died of AIDS (percent distribution)



To understand the extent to which parents are involved in the living and caregiving arrangements of adults with AIDS, it is useful to recognize that there are three basic routes that lead adult sons and daughters with AIDS to be with parents at the terminal stage of illness. First, about half of adult children in Thailand normally live with or nearby their parents. Such normal residential proximity facilitates parental involvement when a son or daughter falls ill and is the most common route accounting for well over half of parental caregiving. Second, the adult child may live elsewhere before becoming ill but move back to stay with parents after becoming seriously ill. Return migration of adult child accounts for about a third of parental caregiving. This is particularly likely when the ill adult child is unmarried and has no spouse to provide care and support. Many who return do so at an advanced stage of the illness. Finally in

a much smaller percentage of cases, the child lives elsewhere and does not return, but the parent goes to where the ill child lives to provide care.

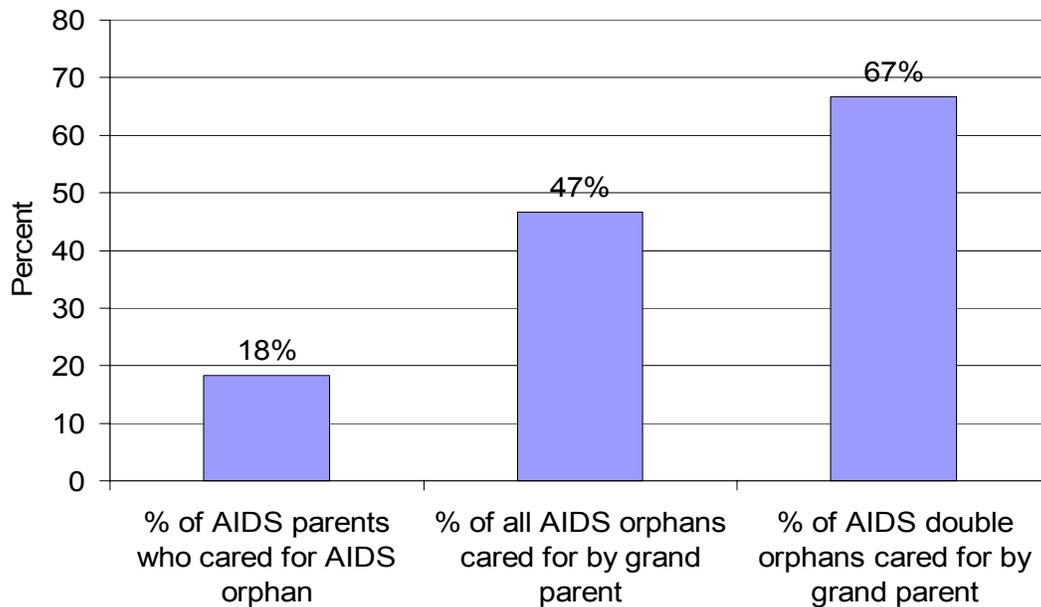
3. Only a minority of AIDS parents in Thailand are involved in caring for or supporting AIDS orphans, far less than were involved in caring for an adult child ill with AIDS. Still orphans often will end up with grandparents.

Although grandparents fostering AIDS orphans has received considerable public attention, it is by no means the most common impact of the epidemic for older persons in Thailand. AIDS parents are far more likely to give care to an ill adult son or daughter than to foster an AIDS orphan.

According to our research, only 18 percent of AIDS parents had cared for an AIDS orphan (fig. 4). From the perspective of the orphaned children, however, almost half were under the care of a grandparent. Moreover, among double orphans, that are those who lost both parents, two thirds were cared for by grandparents. Our open-ended interviews with AIDS parents revealed considerable diversity in the situations of those who fostered AIDS orphans. For some, the responsibility was clearly a burden but others viewed it positively as a source of emotional gratification.

Fig.4

Care of AIDS Orphans
Source: Key Informant Study

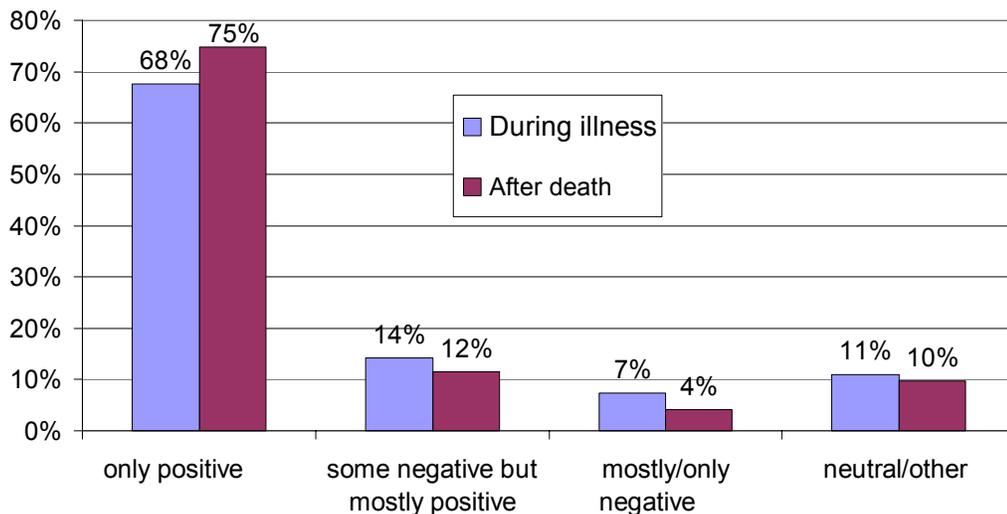


There are several reasons why most AIDS parents are not caring for AIDS orphans in Thailand. First, almost 60% of adult children who died had no children themselves, either because they were still single or had married but had not yet had children at the time of death. Second, adults with children who died typically left behind two sets of parents, among whom at most only one set would foster the orphaned grandchild. Finally, at the time of data collection, many orphans left behind when the first parent died were still being cared for by the surviving parent, typically their mother; however, if the surviving parent is infected with HIV herself, and dies in the future, the orphan may eventually end up with the grandparents. That this is a likely outcome is reflected in the high percentage of double orphans being fostered by grandparents.

4. Community reaction to AIDS parents is much more likely to be positive than negative, especially in areas where the epidemic has a longer history and is more widespread.

AIDS is virtually always portrayed as a highly stigmatized disease throughout much of the world. Stigma is also typically assumed to extend beyond the infected persons to those closely associated with them, especially those who are providing personal care. The nature, degree, and consequences of stigma, however, are likely to vary considerably across settings and over time. Yet remarkably little systematic assessment of community reaction has been carried out in Thailand or elsewhere. Our research indicates that in Thailand by the late 1990s, most community reaction experienced by AIDS parents at least was relatively sympathetic to their situation although negative experiences continue to affect some (fig. 5).

Fig.5 Community reaction to AIDS parents during the illness and after the death of their adult child -- percent distribution
(Source: AIDS Parents Survey)

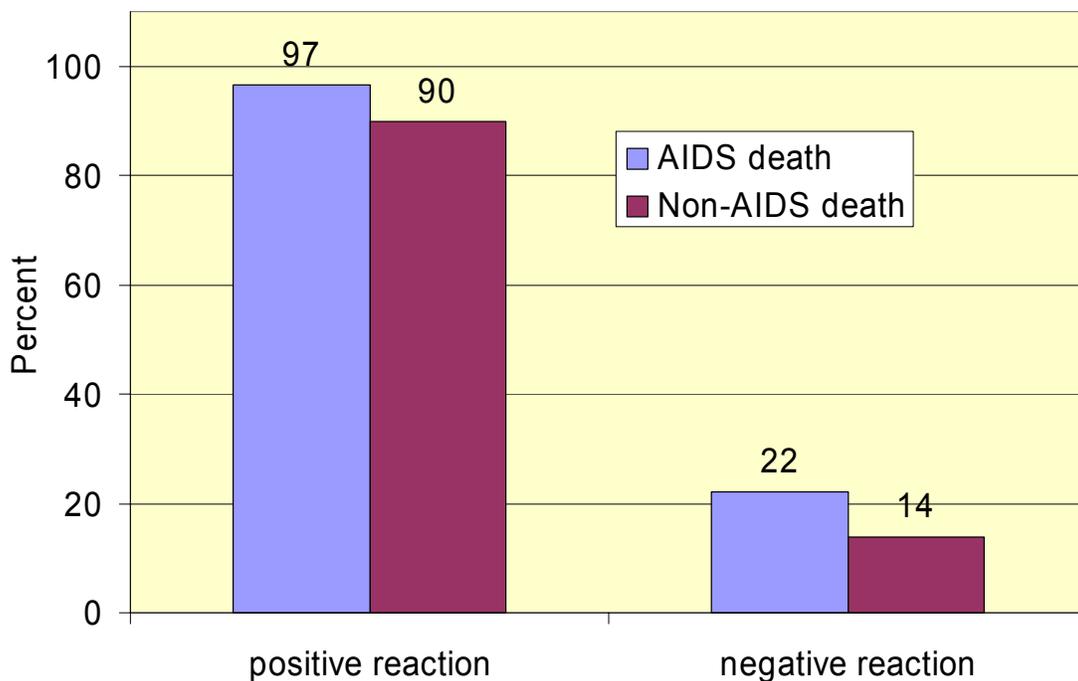


Fully two thirds of respondents in our survey of AIDS parents reported that they only experienced positive reactions such as expressions of sympathy or offers of help, during the time their adult child was ill. Reactions following the child's death were even more likely to be only positive. Moreover among those who reported experiences with negative reaction, most indicated that their experience was of a mixed nature. For only a relatively small minority was the reaction solely or mainly negative.

Most of the negative reactions reported in our open-ended interviews appeared to be out of fear of possible contagion. Rarely did negative reactions carry a moral overtone. The relative tolerance of commercial sex patronage, a main risk behavior underlying AIDS in Thailand, likely helps account for the general lack of moral disapproval that we found. Also most Thais are now aware that the disease is not transmitted through casual contact. These factors may help explain why stigmatization of AIDS parents is not more widespread at the time of our research. We note however that virtually all key informants said that initially there was far more fear of persons with AIDS earlier in the epidemic than now.

Even higher level of positive reaction was noted in Cambodia (fig. 6).

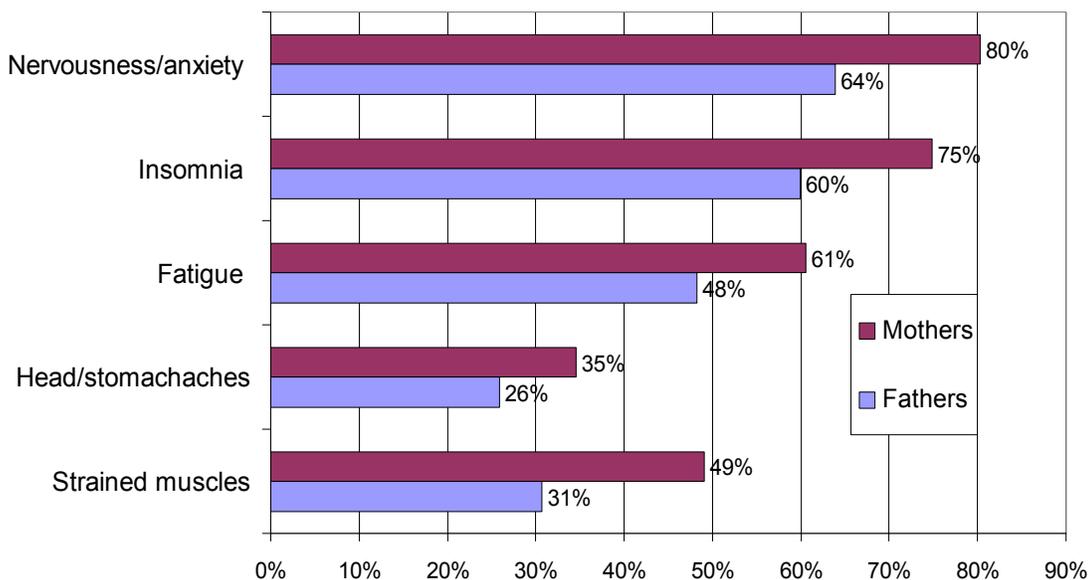
Fig. 6 % of parents reporting positive and negative community reactions by cause of death of their adult child - Cambodia



5. Parental care giving is associated with numerous psychological and physical symptoms; undoubtedly worst of all is the lasting grief suffered by many who lose an adult son or daughter to AIDS.

The older-age of many AIDS parents makes them particularly vulnerable to physical strains of caregiving. According to our survey of AIDS parents, more than half who cared for their ill adult child experienced fatigue, insomnia, and anxiety. Substantial minorities also experienced strained muscles, headaches, or stomachaches (fig.7). Among parents who gave personal care, mothers were more likely than fathers to suffer each of these symptoms.

Fig. 7 **Health problems experienced during caregiving by parents who gave care to an adult child with AIDS**
(Source:AIDS Parents Survey)



6. Parents often incur financial costs when an adult child becomes ill and dies of AIDS.

Illness and death of an adult child from AIDS can have numerous economic repercussions for older-age parents. Some are *immediate* and *temporary* while others can be *delayed*, or *long term*. The most immediate effects are likely to stem from expenses the parents incur associated with treatment, caregiving and funeral costs. When the adult child dies, funeral costs can be considerable. During their adult child's illness, parents may also take time away from economic activities for caregiving, and thus incur a temporary loss of income. Parents may also deplete their savings, sell possessions or property, and go into debt to cover caregiving or funeral expenses. If parents foster orphaned grandchildren, school, health care, and daily living expenses

for the orphans and opportunity costs associated with childcare can continue for years. If the parents were dependent on their deceased son or daughter for support or help in economic activities, a sustained reduction in household income could result. Finally, the parents are deprived of any old-age filial support that the adult child would have provided.

Our research indicates that parents often incurred expenses as a result of an adult child getting AIDS. However, in Thailand government health insurance and to a lesser extent welfare helped reduce the financial burden this created. In addition, other family members sometimes helped with expenses. Also membership in funeral societies and customary contributions by persons attending the funeral reduced funeral costs for many parents.

According to the information collected from key informants, parents helped pay for medical expenses for their children just over half of the time (figs. 8 & 9). The share doing so was considerably higher when a parent was a main caregiver.

Fig. 8 Parental involvement in paying medical expenses, among cases with a living parent

Source: Key informant study

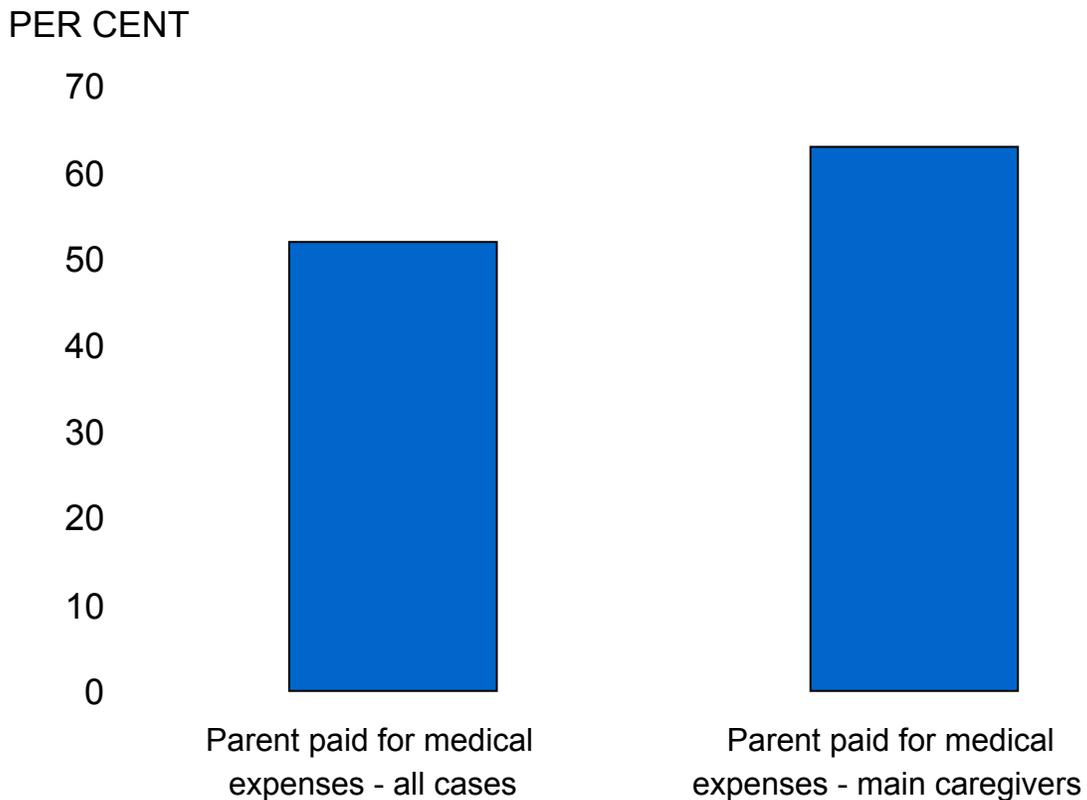
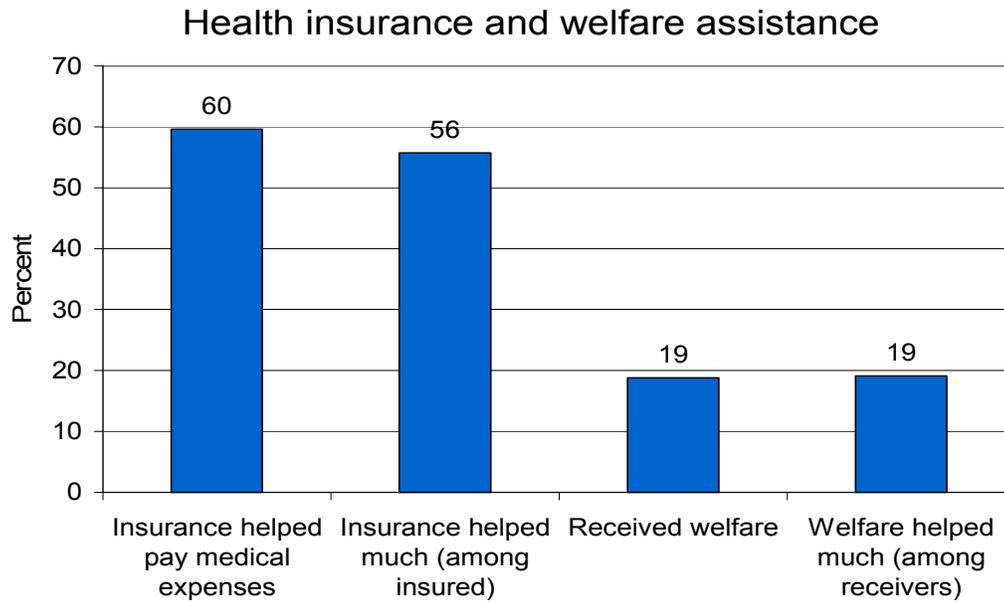
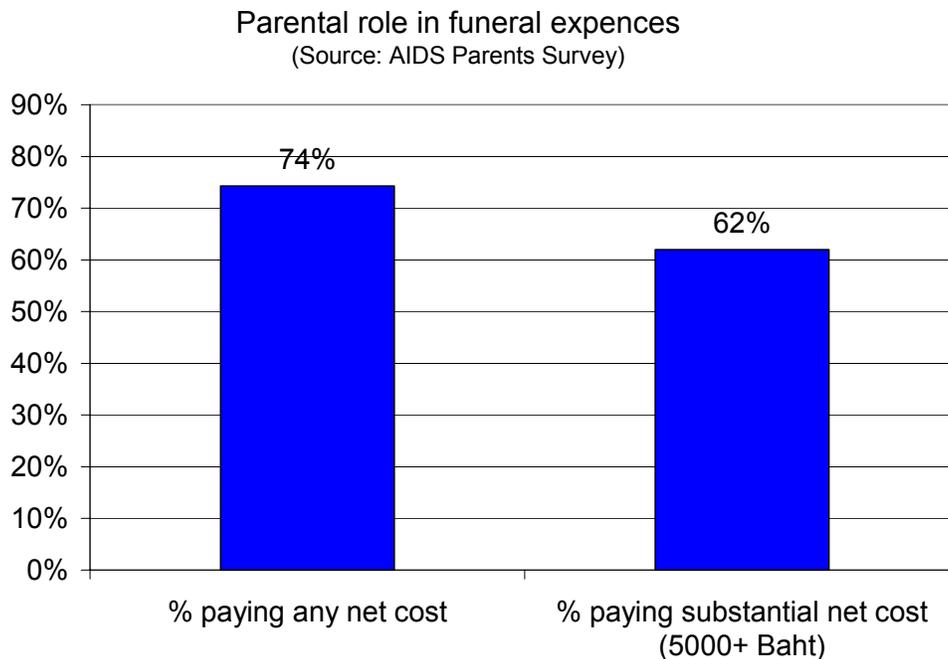


Fig.9



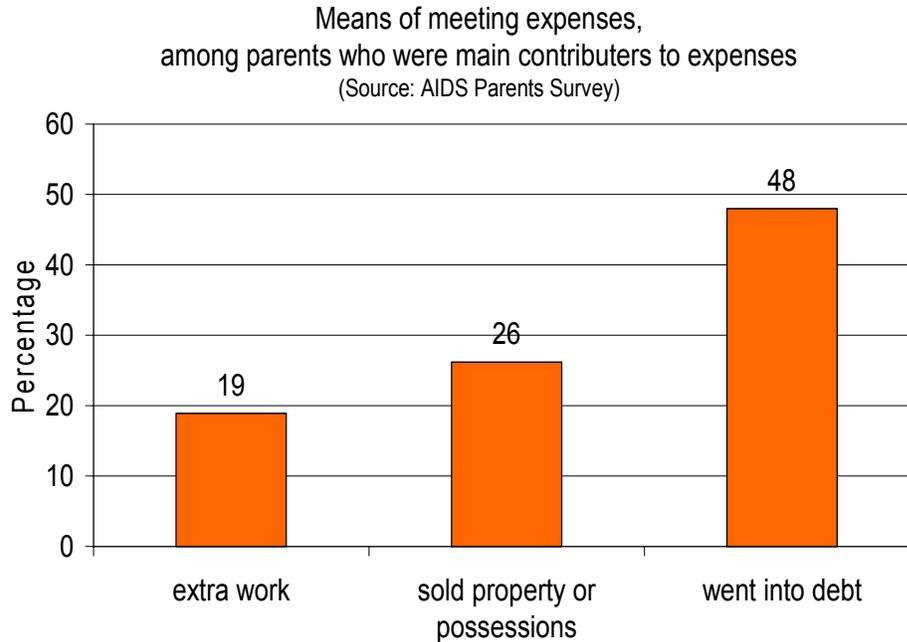
According to the AIDS parents survey in Thailand, parents also typically help pay for the funeral (fig. 10). However, community insurance schemes and contributions by those attending helped defray expenses reducing the share which had a substantial cost.

Fig.10



Thai parents resorted various other measures they took to meet the expenses associated with their son's or daughter's illness and death if they did not have sufficient savings (fig. 11). According to the AIDS parents survey, among parents who were main contributors to expenses, a fifth took on extra work, over a fourth sold property or possessions, and almost half went into debt. Most however had paid off the debt by the time of the survey.

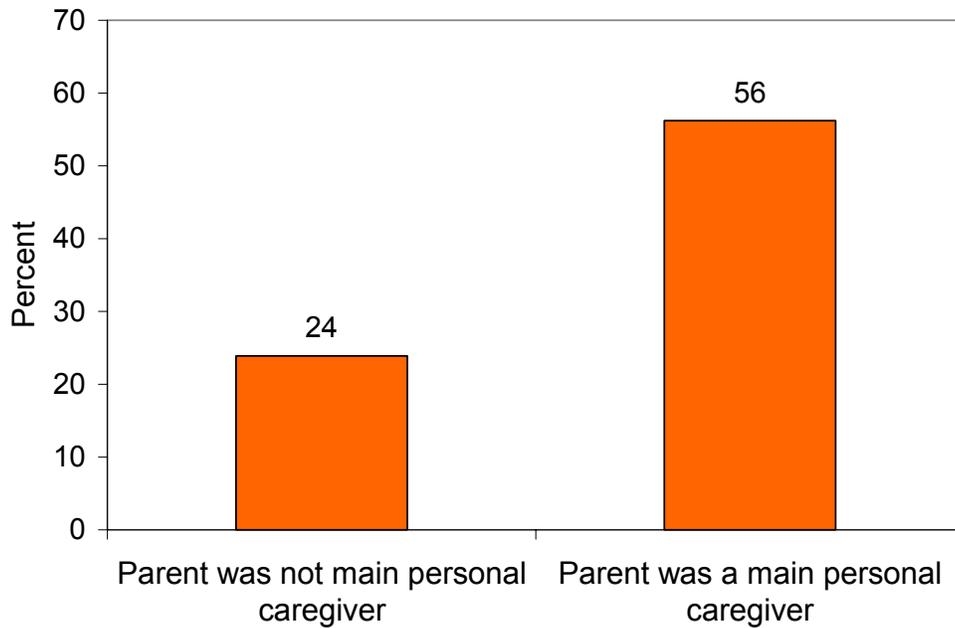
Fig. 11



7. Parental caregiving often disrupts economic activity.

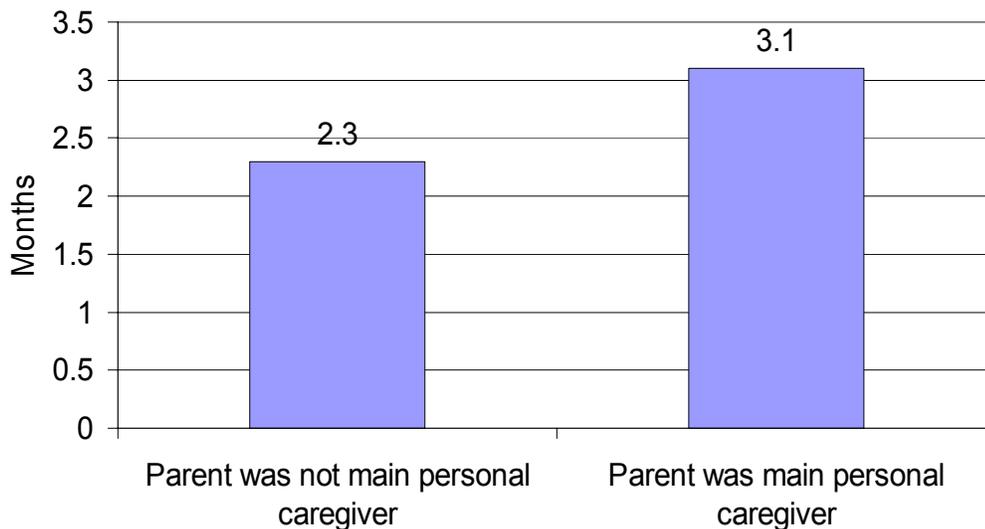
Parental caregiving often disrupted economic activity. However, since the duration of caregiving was not long, the burden created by these opportunity costs was often not severe except for poorer parents. In over half of the cases where a parent was a main caregiver, one or both parents had to interrupt their economic activities according to the AIDS parents survey. Even when parents did not assume the main responsibility for caregiving, a fourth had to curtail their work. (fig. 12).

Fig. 12 Percent of cases in which economic activities of parent was disrupted by caregiving



Given that the duration of caregiving was typically short, the mean duration of the interruption of economic activity was usually only a few months. Even for parents who were main caregivers, the interruption averaged only about 3 months (fig. 13).

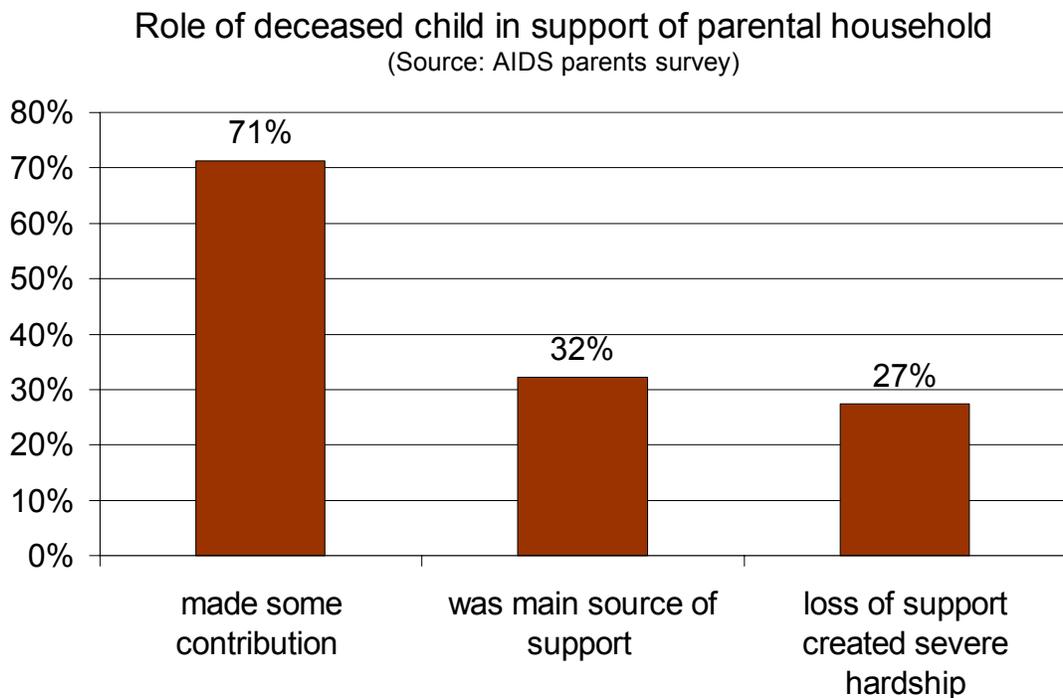
Fig. 13 Mean duration of work curtailment among parents who curtailed economic activity
(Source: AIDS Parents Survey)



8. Most deceased children had contributed financially to the parental household before becoming ill.

The illness and death of an adult child also means that any current or future support from the child is lost. In Thailand most adult children make at least nominal contribution to older-aged parents material support. This was also true of the deceased adult children of the AIDS parents we surveyed. However in most cases the deceased child was not the main source of support although the impact of the loss of support was far greater for poor parents than those better off (fig.14).

Fig. 14

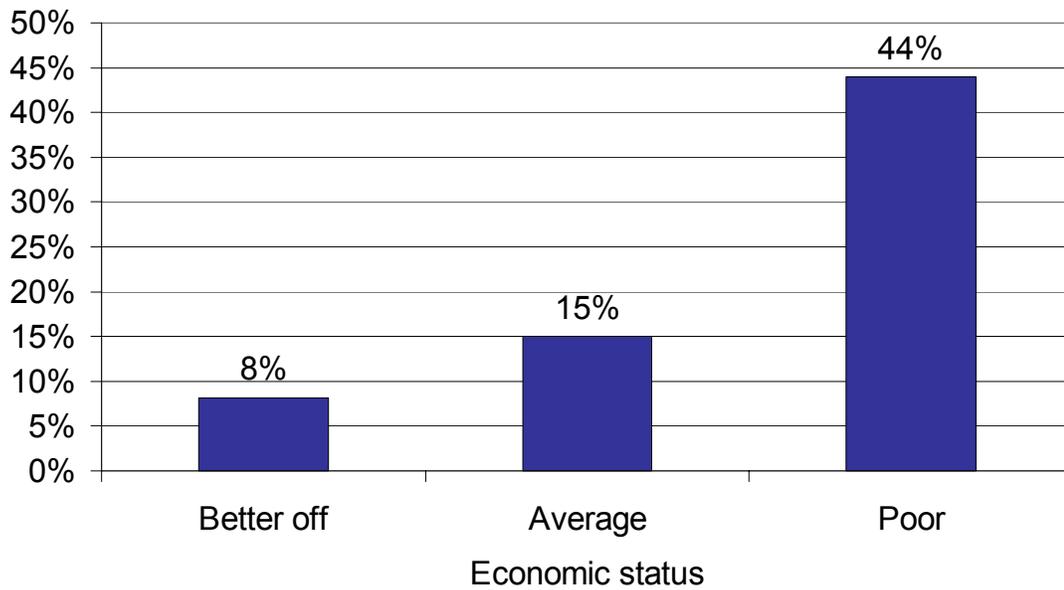


Again, however, the impact of lost support was far worse for poorer than better off families. Over 40% of poorer parents reported the loss to be a severe hardship compared to much smaller fractions of those who were average or relatively well off economically (fig.15).

Fig.15

Percent for whom loss support from deceased child created severe hardship

(Source: AIDS parents survey)

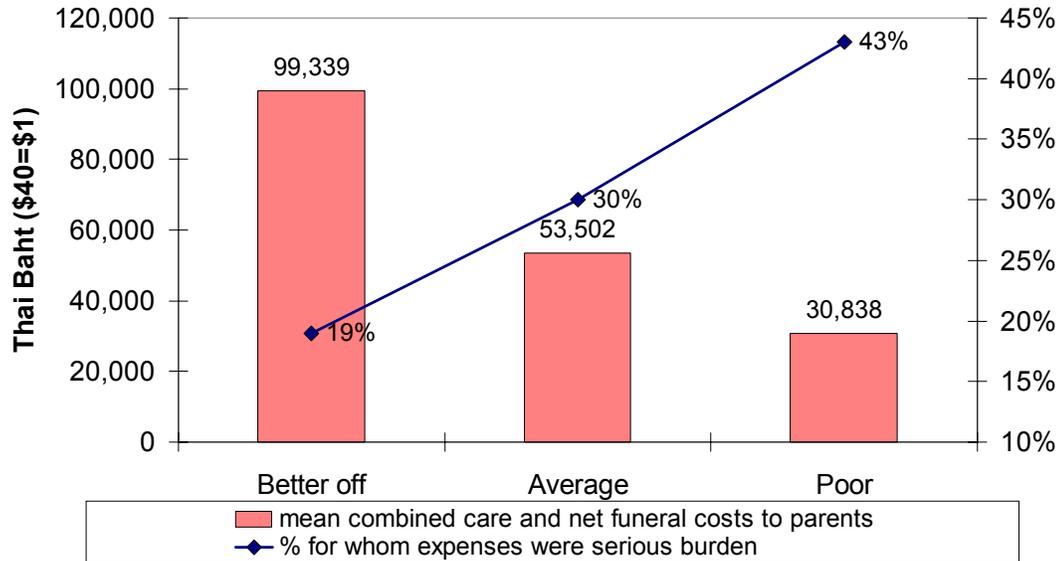


9. Poorer parents spend much less than better off parents on expenses. But the burden created by expenses is far greater for poorer than better off parents.

Both the total amount of expenses incurred by parents and the resulting burden are related to economic status in Thailand, but in opposite directions. Lower economic status is associated with far lower amounts spent but with far higher percentages who report that the costs were a serious burden (fig.16).

Fig. 16

Mean combined care and net funeral costs to parents and percent for whom costs were a serious burden, by economic status
Source: AIDS Parents Survey



Conclusions

Large numbers of older persons in Thailand and anywhere else where the AIDS epidemic is occurring lose adult children to the disease. Our research shows that older age parents frequently play a central role in caregiving for their ill adult sons daughters with AIDS. Not surprisingly, the emotional impact of losing an adult child to AIDS is devastating for virtually all AIDS parents. Severe economic hardship resulting from losing of an adult child to AIDS, however, is largely limited to poorer parents. Programs are needed to provide emotional support and caregiving training and assistance. Such programs should be directed at the full spectrum of AIDS parents. Programs are also needed to address economic consequences but should focus on parents who are particularly susceptible to hardship.

Older parents have shouldered much of the burden of caregiving, financial strain, sorrow, and child fostering that have resulted from the AIDS epidemic. The general lack of recognition of their situation by organizations and governments responsible for dealing with the epidemic is a major oversight that needs to be remedied.

Notes

1. Research team for the study included

Thailand:

Wassana Im-em, Mahidol University

Jiraporn Kespichayawattana, Chulalongkorn University

John Knodel, University of Michigan

Chanpen Saengtienchai, Independent researcher

Mark VanLandingham, Tulane University

Cambodia:

Souvan Kiry Kim, Royal University of Phnom Penh

John Knodel, University of Michigan

Sina Puch, Royal University of Phnom Penh

Zachary Zimmer, Population Council

2. Funding institutions:

Thailand Research

Primary: National Institutes of Aging (US)

Secondary: Fogarty International Center (US)

Cambodia Research

Primary: National Institutes on Aging (US),

Secondary: UNFPA, Cambodia

3. Detailed references and reports are available at: <http://aidseld.psc.isr.umich.edu>

Annex III:

AIDS and the Family: The Concept of Family Capital as a Basis for Policy Options

Presentation by Mr. Eric Olson,
United Nations Department of Economic and Social Affairs

This presentation is based upon a forthcoming 2005 publication of the United Nations Department of Economic and Social Affairs. The publication is entitled *AIDS and the Family: Policy Options for a Crisis in Family Capital*. It is authored by Dr. Mark Belsey, M.D., a retired staff member of the World Health Organization (WHO).*

In his publication, Dr. Belsey refers to three different global HIV/AIDS epidemics, which are non-sequential, characterized by various degrees of overlap, and which have occurred at different times in the affected countries and regions. The first is the HIV infection that progressed silently for more than a decade; the second is the epidemic of AIDS and of AIDS-related illnesses; and the third is the epidemic of fears, perhaps more accurately described as the epidemic of fear and silence, which includes, but is not limited to, fear of rejection and silence on sexual issues and HIV-positive status.

HIV/AIDS is a family disease. It has profound impacts on family structure, functioning and well-being. Infections can, and often do, occur in the context of the family through sexual relationships and through mother-to-child transmission. The family is also where prevention can take place, and is the context in which infected and sick individuals receive care-giving and primary support. The family also shares the burden of any stigmatization, discrimination and social exclusion associated with a family member being HIV positive or contracting AIDS.

The concept of family capital is introduced by Dr. Belsey as a new conceptual tool to achieve a better understanding of the relationship between AIDS and the family. The concept is comprised of three major components – relationships, resources and resilience. These components have been clearly identified as factors affecting the ability of families to cope with the three HIV/AIDS epidemics. Because there is also some interaction between relationships, resources and resilience in the family's response to HIV/AIDS, family capital is believed to provide a unifying conceptual framework.

The three major components of family capital – the “three R’s” – are relationships and the family network; resources of the family, such as knowledge, skills and material resources; and resilience and the ability to cope with adversity while supporting the family and keeping it functioning and unified.

* *AIDS and the Family: Policy Option for a Crisis in Family Capital* may be obtained from Mr. Eric Olson, Focal Point, United Nations Programme on the Family, E-mail: olsone@un.org, Tel.: (212)963-0013, Fax: 212-963-3062.

These three components of family capital can be analyzed from a perspective of assets and liabilities. The assets of family relationships include the nuclear and extended family and kinship networks; a sense of belonging and self-esteem; family duties, obligations, rights and expectations; and communication. The liabilities of family relationships can include a lack of communication and sharing; arbitrary decision-making; separation; domestic violence or substance abuse.

Similarly, with respect to the resources component of family capital, the assets include food and income; housing; land; tools; knowledge; education; skills; insurance; and planning and management capabilities. On the other hand, resource liabilities can include unemployment; food insecurity; gender discrimination in education; debt and usury; poor or unsafe working conditions; and environmental degradation.

The assets of the third component, resilience, include security; social capital; integration into community, institutions and schools; and a religious/moral point of reference. Liabilities can include vulnerability; insecurity; social exclusion, discrimination and isolation; forced migration; family separation, particularly women and children; and civil conflict and war.

The impact of HIV/AIDS can be looked at from the perspective of family capital. In terms of relationships, HIV/AIDS can impact families via intra-familial conflict; rejection and/or isolation; loss of parents, the “middle generation” between parents and grandparents; and can lead to a change of structure and roles of both children and adults, including grandparents.

Regarding resources, HIV/AIDS can lead to loss of labour, income, remittances, food security and education. It can also mean increased time and costs for medical care and funerals, and a decrease in the family stock of knowledge, skills and education.

HIV/AIDS impacts family capital resilience through demoralization, loss of dignity, and loss of security. In addition, there is a loss of social network links as well as links to community institutions. HIV/AIDS can also lead to reduced family resilience if, as a result, countries or communities adopt discriminatory legislation and regulations.

Using family capital as the conceptual tool for understanding the relationship between HIV/AIDS and the family, Dr. Belsey also proposes using it as the basis for family policy. In this context, the objective of family policy is to promote, protect and support the integrity and functioning of the family by ensuring that family capital, reflected by family relationships, resources and resilience, is accumulated and strengthened. This requires the adoption of policies that reinforce healthy family relationships; protect and increase family resources; and strengthen the resilience of families in an ever-changing environment.

Policy and programme responses must also consider the different stages of impact of HIV/AIDS on the family. There are several stages, and they do not occur at the same time for affected families and may also overlap. The first or initial stage is before any family member is infected. Another stage is where the family is vulnerable to HIV, such as due to high risk behaviors or exploitation or abuse. A further stage is when an asymptomatic HIV-positive family member informs the family of his or her status. The next stage is when an HIV-positive family member becomes symptomatic with AIDS or an AIDS-related illness. And lastly, the final stage of impact is when the family experiences an AIDS or AIDS-related death.

Policy and programme responses should be conceived and implemented taking these different stages into account. At the initial stage, before any family member is infected, the main policy/programme response should be prevention. In terms of family capital and its three components of relationships, resources and resilience, relationships should be strengthened through communication, particularly through the encouragement and awareness-raising of effective, culturally sensitive and respectful intra-familial communication on sexuality and HIV/AIDS. The family resource of knowledge should be targeted by policies and programmes, through the development of culturally sensitive and relevant, age-appropriate educational curricula and materials. Family resilience should be promoted via social networks and the education of health workers, teachers, political, community and religious leaders and the general public. Increased resilience should also be achieved through reducing vulnerability, particularly through the elimination of discrimination against women in education and healthcare.

For those families at the stage where a family member is vulnerable to HIV infection, policies and programmes need to focus on reducing risks. In the area of relationships, policies should be developed and implemented to prevent intra-familial exploitation and to promote the equity of women. Family capital resources should be expanded through the promotion of voluntary counseling and HIV testing. Family resilience should be strengthened through awareness raising of HIV risk behaviours, exploitation and abuse, and through reducing vulnerability through policies to eliminate exploitation and abuse, such as commercial sexual exploitation of women and children and human trafficking.

When an HIV-positive family member informs their family, policies and programmes should be in place so that, with respect to family relationships, to assist families to minimize the intrafamily transmission of HIV, including mother-to-child transmission. In the area of family resources, assistance should be given to prolong the productive life of the person living with HIV through food security and adequate nutrition, access to health care and availability of antiretroviral treatment. Family resilience for families in this situation should be promoted through the elimination of discriminatory legislation, regulation and any harmful traditional practices involving HIV-positive persons and their families.

At the stage when an HIV-positive family member becomes ill with AIDS, at the family relationship level the policy/programme response should include respite

arrangements for care-givers. In terms of family resources, policies and programmes should have the objective of providing assistance to the family for planning for the future, including covering school fees and ensuring food security; ensuring efforts to delay the progression of AIDS, such as through subsidized therapy; and improving the training and work conditions of healthcare workers. In terms of family resilience, family policies and programmes should provide community-based support for the families affected by HIV/AIDS.

At the last stage, when a family experiences an AIDS death, the policy/programme response should be to maintain the integrity of family relationships and the family to the extent possible. Family resources may be severely affected, and they need to be enhanced through ensuring the access of affected families to limited resources such as labour, land and capital, facilitating the creation of income-generating activities to improve the economic situation of affected families, and empowering affected groups such as child-headed households, widows, grandparents, youth and orphans. Family resilience should be enhanced through policies and programmes that provide community support, ensure that the needs of the affected family are met without discrimination or violation of the rights of the family, and protect the rights of surviving members, such as inheritance rights.

To conclude, there is a quotation that Dr. Belsey includes in the publication on AIDS and the family that makes one reflect upon the relationship between family and society. While everyone may not agree that the quotation is necessarily or always true, it nonetheless is thought-provoking. The quote is by Claude Levi-Strauss, in his book *A History of the Family*, and the quote is: “There would be no society without families, but equally there would be no families without society.”