# THE IMPACT OF HIV/AIDS ON CHILDREN AND YOUNG PEOPLE

REVIEWING RESEARCH CONDUCTED AND DISTILLING IMPLICATIONS FOR THE EDUCATION SECTOR IN ASIA

## HIV/AIDS & EDUCATION



Discussion Paper No. I

## THE IMPACT OF HIV/AIDS ON CHILDREN AND YOUNG PEOPLE

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### HIV/AIDS & EDUCATION





This paper was prepared by Jan Wijngaarden and Sheldon Shaeffer and originally presented in a December 2002 workshop on "Anticipating the Impact of AIDS on the Education Sector in South-East Asia."

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he AIDS epidemic in Asia and the Pacific is considered to be only in its infancy. In South and South-East Asia, the number of new infections in 2004 was 800,000. This brought the total number of HIV-infected people in South and South-East Asia to 7.1 million. HIV prevalence among the adult population is estimated at 0.6% – much lower than the prevalence seen in some sub-Saharan countries (UNAIDS 2004).

However, looking at the picture from a macro-level disguises situations in specific population groups or regions, where the epidemic has caused heavier tolls. Already in 1993, the epidemic had peaked among Thai military recruits at over 4% (MOPH and CDC 2000); in a group of female sex workers in Cambodia a prevalence exceeding 28% was found (WHO 2005) and a more than 2% prevalence of HIV among pregnant women has been recorded in Myanmar, Cambodia, Thailand, and certain areas of India and China (UNAIDS 2002). In some provinces of Thailand, HIV prevalence has even exceeded 3.5% (UNDP 2004). An infection rate of more than 1% in pregnant women nationwide is one of the criteria for UNAIDS to classify an epidemic as 'generalized' rather than 'concentrated.' (UNAIDS and WHO 2000).

UNAIDS estimates suggest that over half of new HIV infections are occurring among young people (15-24 year olds) – or over 7,000 new infections a day worldwide (UNAIDS 2004). The impact on children and young people is growing (Summers, Kates and Murphy 2002). The USAID/UNAIDS/UNICEF report, *Children on the Brink 2004*, estimates that there were 15 million children orphaned by AIDS at the end of 2003. Wattana Janjaroen and Suwanee Khamman (2002) quote official sources as saying that in Thailand, over 4,000 children are newly infected by HIV each year, and they quote an estimate that 63,000 children were infected with HIV by the end of 2000. They note that the number of new infections through mother-to-child transmission in Thailand increased from 0% in 1987 to 14% in 2000 (MOPH, 2001). In Cambodia, the number of children and young people orphaned by AIDS was estimated at 30,000 in 2005 (UNICEF 2005). In India, according to the Human Rights Watch (2004), there were 1.2 million children under age fifteen orphaned by AIDS.

This paper takes a closer look at the impact of the epidemic on children (0-18 years old) by reviewing and synthesizing several research studies that have been conducted in the Asia-Pacific region over the years. Since no specific studies about AIDS' impact on education have been conducted in the Asia-Pacific region, this paper will then look at the implications of the existing research for the education sector – looking at access to education for children affected by the epidemic, but also looking at the demand- and supply-side, the quality of education and planning, and management issues. In the final section of the paper, we will identify gaps in our knowledge and understanding of the impact of AIDS on the education sector by outlining a number of questions for future research.

#### Education and Its Role in Responding to AIDS

The relationship between education and AIDS is complex:

As a major actor in the development of human resources – through the teaching of literacy and numeracy, the transmission of basic knowledge and skills for survival, and the delivery of vocational, tertiary and professional training – the education system bears both a special burden in terms of being affected by AIDS and special responsibilities for responding to its impact (Shaeffer 1994, p. 8).

Shaeffer identifies three issues for discussion: first, changes needed in the education system in order to effectively deliver messages about the epidemic; second, the question of how to deal with the immediate impact of AIDS on the education system, itself, and third, the longer-term response of the education system to such impact (Shaeffer 1994, p. 9).

In the worst affected areas, especially sub-Saharan Africa, the impact of the AIDS epidemic on the education sector has been severe. This impact can be analyzed at different levels:

First, there is an impact on the *access* to education. Children may be denied access to school due to fears and stigmatization in the community (Malikaew 2002; Hunter 2005; Human Rights Watch 2004). This seems to be the case particularly when a community experiences the first impact of the epidemic, when community members increasingly fall ill and fear/discrimination are on the rise. This impact is likely to decrease when AIDS as a disease and cause of death becomes more common. With more and more families affected, AIDS becomes less of an exception and, therefore, less of a moral stigma.

Second, there is an impact on *demand* for education. Children may be pulled out of school by their families to care for sick family members, or may be demotivated to go to school. This impact becomes stronger as the number of AIDS cases in the community increases.

Third, there is an impact on the supply of education. As teachers and administrators fall sick and die, often not enough new teachers and administrators can be trained in time to replace them.

Fourth, there is an impact on the *quality* of education. Teachers and students may be traumatized and demotivated to teach or to learn; the curriculum may not be relevant for the students; and the teaching-learning process in classrooms becomes disrupted due to AIDS.

Fifth, the *role* of education in the community changes, as more and different demands are put on it (Shaeffer 1994; Kelly 2000; Coombe 2001; IIEP 2001). Finally, when the epidemic advances, there is an impact on the funds available for education, for aid agencies' involvement in it, and on the management and planning of education (Shaeffer 1994; Kelly 2000; Coombe 2001).

All studies on which the conceptual framework outlined in the above are based were conducted in Africa. No studies specifically on the impact of AIDS on education in Asia have been undertaken, thus far. The few impact studies in Asia that exist focus mainly on changes to the economy at the macro-level (Bunna and Myers 1999; Bloom and Godwin 1997; Godwin 1997; Viravaidya et al. 1992). The main purpose of these studies seems to be to support advocacy efforts intended to convince policy makers to put AIDS on their agendas. However, some studies have examined the impact of AIDS at the micro-level – most of them by NGOs. We review these studies, focusing on the impact on children and young people, in the next section.<sup>1</sup>

1 For practical reasons, this review is limited to English-language studies and documents only.

#### The Impact of AIDS on Children and Young People in Asia: An Overview of Study Results

In February 2002, Wattana Janjaroen and Suwanee Khamman authored *The Long-term Socio-Economic Impact of HIV/AIDS on Children and Policy Response in Thailand*. The study describes different impacts from AIDS on children, as well as on pregnant women and infected mothers. The authors quote a study that discusses 'emotional deprivation' among children infected with AIDS, leading to depression and lack of interest in the surrounding environment (Acharakup 1992, in: Pitayanon et al 1996). The authors describe the process of children being taken out of school to take care of ill or dying parents, and link the lack of schooling for girls as a potential risk factor for their possible entry into the country's sex industry, 'indirectly exacerbating the spread of HIV/AIDS' (p. 25). Yoktri, in an excellent review of the situation facing children affected by AIDS that has been translated from Thai into English by Prue Borthwick of UNICEF, also makes the link between disruption of education especially for girls, and the increased likelihood of their entry into sex work (Yoktri 1999, p.7).

Janjaroen and Khamman quote a Chiang Mai-based study on the economic impact of AIDS on households. The researchers noted that in 48% of the 116 households studied where a death due to AIDS had occurred, the person ill with AIDS suffered 'significant community discrimination' before succumbing to illness. In 15% of the families, family members were also subject to discrimination. The researchers found that in 20% of the AIDS-affected families with children, these children were ostracized by playmates. In several cases, they were forced to leave school (Pitayanond et al 1996). The same problem is described by Yoktri (Yoktri 1999). In Viet Nam, HIV-infected children are allowed to enroll. However, often times teachers express their concerns or worries about the risks of HIV being transmitted to other children (Hong, Van Anh and Ogden 2004).

Janjaroen and Khamman also note that often the fear of AIDS in the community can be traced to the initial government campaigns of the early 1990s, which tried to scare the population with pictures of emaciated AIDS patients, and linked the disease to prostitution, drug use and what the authors characterize as 'marginal behavior.' Indeed, during focus group discussions held in Phayao, Kon Kaen and Bangkok, the issue of discrimination and stigma related to AIDS in the school setting was mentioned several times (pp. 52-53).

Sean Devine has conducted several studies on the psycho-social impact of the epidemic on children in families affected by AIDS. He describes Thai families where parents physically distance themselves from their children upon hearing that they are infected with HIV, apparently in a mistaken fear of infecting their children. More often than not, parents do not disclose their HIV-positive status to their offspring, leading to feelings of rejection and being unloved among children affected by AIDS. After a death occurs in the family, children and other family members get little chance for proper mourning. Due to the stigma and shame attached to AIDS, people tend to tell children to ignore and forget what happened as soon as possible, leading to psychological problems later in life (Devine 2001).

The study, *Small Dreams Beyond Reach: The Lives of Migrant Children and Youth Along the Borders of China, Myanmar and Thailand*, was conducted by Save the Children Federation United Kingdom (SCF-UK) as "participatory action research" in 2002. The study objectives were to gather insight into the lives of migrant children and youth, as well as to pilot a new participatory research approach. Not surprisingly, the work confirms that migrant children are a vulnerable group in need of holistic interventions – including improving access to literacy training, both non-formal and formal education, and health and other services in their own language. Impoverishment due to weak health is mentioned on several occasions. In addition, trafficking and child labor are main problems for the children and young people in the study. No findings related to the impact of HIV/AIDS on education are reported.

A second SCF-UK publication, Young People and HIV/AIDS: Responding to the New Asian Crisis (2001), gives an overview of SCF-UK's work in Nepal, China, Myanmar, Pakistan, Lao PDR, Cambodia, Sri Lanka

and India. Similar to the study described above, it concludes that holistic approaches are needed for HIV/ AIDS prevention and impact alleviation, taking into account all the areas in which the epidemic has a possibly detrimental impact on fulfilling children's different needs. The authors further mention that it is essential to link NGO work with government efforts to ensure sustainability. They plead for culturally appropriate approaches in order to ensure effectiveness of interventions. Again, no findings in this study deal with the impact of AIDS on the education sector.

The pioneering study, *Household Resources Allocation and Responses Toward AIDS-Related Illnesses* (Im-Em and Phuangsaichai, 1999), aims to determine key parameters for more extensive research related to AIDS' impact on households in northern Thailand – research that is currently ongoing. It describes a disproportionate burden to women, since the husband usually contracts HIV first, gets ill first and dies first – often using all family resources in paying for several treatments. Also 75%-80% of the people with HIV/AIDS (PLWA) in the study had children under the age of 18 – which are often taken care of by the mother. Families of PLWA end up using all their savings and selling land (often initially intended to pay for their children's future education) in order to take care of the sick family member (usually the husband). Interestingly, fewer than 10% of the additional burden fell on the spouse and other (adult) family members. This could be explained by the fact that most households researched were experiencing their first AIDS case. It is likely that in families where the second parent is ill and dying, the burden on their children will be much heavier.

Im Em also found that marital problems resulting from HIV often lead to separation and divorce – resulting in the break-up of families even before AIDS related death(s) occur. Women usually move back to their parents' home, taking their children along. Yoktri also describes the psychological and emotional strains the marital relationship (and, indirectly, the relationship between parents and children) must endure after one or both of them are diagnosed with HIV (Yoktri 1999, 8-10). Some of the women who divorce their husbands remarry, mainly for economic reasons, even though their HIV status often remains unclear. In terms of stigma and discrimination, Im Em found that "villagers and relatives of PLWA said that the level of social acceptance was dependent on the behavior of the person before becoming ill. Those that had acceptable behavior would receive more understanding and support from the community and family." (p. vi) A similar reaction was observed in Viet Nam (Hong, Van Anh and Odgen 2004).

The Khmer HIV/AIDS NGO Alliance (KHANA) published *Children Affected by HIV/AIDS: Appraisal of Needs and Resources in Cambodia* in 2000. The study used Cambodian NGO staff as researchers in a capacity-building exercise, which led to a less solid research process and, thus, less accurate and/or complete research data than would be expected from professional researchers. However, it still manages to convincingly describe the process of impoverishment in families affected by AIDS.

Whereas the adult key informants in the study thought orphanages were a suitable solution to the problem of AIDS orphans, those children interviewed in orphanages disagreed, saying they would prefer to live in foster families or communities. Adding to the argument against orphanages and in favor of community-based solutions, the USAID/UNAIDS/UNICEF report *Children on the Brink 2002* quotes studies conducted in Africa showing orphanages to be at least 14 times more expensive per child than community-based solutions (USAID, UNAIDS and UNICEF 2002, p. 12).

The KHANA report further describes a lack of general services in the field of counseling and support, and a total absence in specialized services for children. To decrease stigma and discrimination experienced by children and their families affected by AIDS, the report suggests widespread community education on HIV transmission to increase understanding of the disease. However, it does not address the often moralistic causes of stigma and discrimination, which are much more difficult to tackle, as Yoktri points out (Yoktri 1999).

Save the Children (UK) in Phnom Penh developed an internal document called *A Situation and Response Analysis of Children Affected by HIV/AIDS in Cambodia* in 2001-2002. Major recommendations are that preventive peer and outreach programmes for young people should include support for children and young people affected by AIDS; IEC materials for illiterate and less literate audiences must be developed; and a rights-based approach for children should be used, which includes children's participation in decision-making, planning, project implementation and advocacy on behalf of children affected by AIDS.

Mike Merrigan and Lim Yi conducted a small qualitative research in the northwestern Cambodian province of Banteay Meanchey to study the way families affected by AIDS sell off their assets in their struggle for treatments. They found that lack of knowledge among families affected by AIDS made them vulnerable to unscrupulous healers who promised to cure them of AIDS in exchange for big sums of money or land. Interestingly, in the only reference to education they note that:

The 3 female PLWA interviewed were in a [...] situation with less support. F2 was living in her brother's house, but had to take her daughter out of school so the daughter could care for her. F1 was living in her own house and also relying on her daughter for support, while F5 had no place of residence, except hospital. (Merrigan and Yi 2001, p. 4)

UNICEF's report, A Multi-sectoral Approach to Planning Services for AIDS Orphans in Sanpatong District, Chiang Mai, focuses on several inter-twined and inter-related projects aimed at providing a model for a multisectoral response at the community level. The report describes involvement by the government, several NGOs, foundations and community groups. Some successes in decreasing stigma and discrimination of persons and families affected by AIDS were reported, as well as an improvement in the quality of life of so-called AIDS orphans. No antiretroviral treatment is provided to the orphans.

Save the Children-UK also notes successes in combating stigma and discrimination at its project sites in Chiang Mai. The school played an important role in achieving this:

Teachers reported that among the most significant changes that have come about as a result of the project has been the attitude of the local community towards people with HIV/AIDS, which was previously characterized by fear and discrimination. (SCF-UK 2001b)

The school also played a major role in facilitating preventive and awareness-raising education to the community, including adolescents and adults, especially in rural and semi-urban areas.

Mayuree Yoktri, of the Vieng Ping Children's Home in Chiang Mai mentioned several times above, describes the problems of children from AIDS-affected families with regard to education, and the cruelty they often must endure on behalf of some schoolmates. Sometimes this, as well as pressure from parents of presumably HIV-negative children on school administrators to expel children from AIDS-affected families, leads the children in question to take forced blood tests. Rightfully, Yoktri denounces this:

Forcing a child to take an HIV test is an abuse of human rights. Whether or not a child has HIV, they should have the same right to receive an education as other children [...]. They should not be segregated from other children (Yoktri 1999)

Yoktri gives a comprehensive overview of the different psycho-emotional stages parents and children go through when they learn that HIV has entered the family, and the consequences this may have for the child's mental state. She pleads for stronger counseling and socio-psychological support services for children; however, she realizes that children in need of this form of support may be scattered in villages all over the country. Therefore, she recommends establishing networks and organizing seminars/camps to which both children and caregivers can be brought together, or camps for children alone. She also mentions camps for families with members



who have HIV/AIDS, with activities including music and other creative activities, as well as psychotherapy, as possible interventions to improve the social support provided to PLWA and their families (Yoktri 1999).

Susan Hunter, working as a consultant for UNICEF, notes that the socialist Government of Viet Nam ...

[...] finds that institutionalization is a convenient mode of segregating people who succumb to social evils while at the same time effectively quarantining HIV-infected individuals, including children. Institutionalization may be a short-term solution to social problems, but as the number of HIV-affected people increases, many Vietnamese are recognizing that the policy of institutionalization creates more problems than it solves. (Hunter 2002)

In her report for UNICEF in Viet Nam, Hunter notes that due to delayed marriage in the country, elderly people who end up caring for orphaned children and youth face 'greater generational clashes with adopted children.' This problem is also mentioned in Thailand by SCF-UK (SCF-UK 2001, p. 16). Even so, Hunter notes that family and community-based solutions are preferred by the people interviewed for her research, despite the 'popularity of institutional solutions' among government employees. A similar conclusion was reached in Cambodia (KHANA 2000) and Thailand (Yoktri 1999). Hunter recommends more research on what lies behind the so-called social evils – the sexual cultures and gender perceptions of Viet Nam's young – and increased focus on providing proper and youth-friendly voluntary counselling and testing (VCT) and reproductive health services.

In a rare English language document on children and AIDS from China, UNICEF consultant Ionita (2002) gives an overview of the AIDS epidemic and its impact on children in the Chinese province of Yunnan, which borders Myanmar, Lao PDR and Viet Nam. The report mentions that:

Ethnographic and anecdotal evidence indicates people being shunned, dismissed from their jobs, evicted from their homes, and chased out of town when it became known that they were infected with HIV. (Ionita et al 2002, p. 8)

The report also notes high levels of fear due to misconceptions and lack of knowledge about HIV/AIDS in the general population. There is a strong moral judgment linking AIDS with prostitution and, especially, with injecting drug use. By focusing strongly on the sexual behavior of injecting drug users, and stating that "the frequency of extramarital sexual behaviour among drug users was four times the average among non-drug users; condom use was only 2.5% in these sex acts," the authors do little to dispel such prejudices. The report mentions the impoverishment that hits families affected by AIDS and urges more social and medical support services (Ionita et al 2002).

In an unpublished UNESCO report (2002), Jan Wijngaarden describes the project *Baan Gerda* in Lopburi, Thailand, which is supported by the Children's Rights Foundation. The idea behind this small German-supported NGO is to improve the social and psychological condition of orphaned children with AIDS through the creation of small pseudo-family units with caring surrogate parents (also persons living with AIDS), and to improve their physical condition by providing them antiretroviral treatment. With the existing antiretroviral treatment, the children in *Baan Gerda*, many of whom were dying when they first entered the project, are likely to live a normal life for many years to come. *Baan Gerda* is giving children infected by HIV a chance to live – to give them what they rightfully deserve in this world: a good and happy childhood, including shelter, medical care, clothes, food, love, understanding and a proper education. It is one of only a few projects in Thailand where ARV drugs are provided to keep orphans with AIDS alive. Examples of other projects include the Vieng Ping Foundation in Chiang Mai, providing treatment to 24 orphans (SCF-UK 2001), and the ACCESS project in Chiang Rai, providing ARV treatment to nine orphans. In both *Baan Gerda* and the Vieng Ping Foundation, the children go to state schools. The ACCESS project is setting up psycho-social support systems for orphans in the community in a number of districts in Chiang Rai, with the aim of making these permanent and self-

supporting. Medecins Sans Frontieres also supports treatment of children with ARV in the region (Medecins Sans Frontieres 2004).

UNICEF consultants Anne-Sophie Dybdal and Gary Daigle, with the Cambodian Ministry of Social Affairs, Labour, Vocational Training and Youth Rehabilitation, conducted a survey of alternative care providers for children. An interesting focus of their research is the testing of two hypotheses that "the way [alternative care-providing] staff describe and understand the children's situation is closely knit with their understanding of their own role" and that "children may have different needs in the staff-child relationship from what adults think." In fact, it appeared that the second hypothesis was not true. They further found that street children are extremely sensitive to discrimination and stigma. They recommend that children should be more involved in developing interventions, and that further research should be conducted to find out whether this is consistent with Cambodian child-rearing practices (MoSALVY 2001, p. 26).

Athipat Cleesuntorn of the Policy and Planning Bureau of the Thai Ministry of Education reported in 2000 on his country's situation of Thailand during a workshop to examine the impact of AIDS on education. He mentioned that extended families and religious institutions in Thailand had so far absorbed the initial need for child care services, but he acknowledged that the numbers of children were still increasing. He pleaded for 'Living with AIDS' to become a 'national agenda,' and advocated using information and education campaigns to implement child-friendly school policies 'with a focus on children affected by AIDS' (Cleesuntorn 2000).

In a UNICEF-supported study on the commercial sexual exploitation of children in Lao PDR conducted by that country's Ministry of Labour and Social Welfare (MOLSW), it was found that 43% of the young people interviewed had no knowledge about HIV/AIDS, and self-reported consistent condom use of only 72%. Most of the interviewees were introduced to the sex trade by friends. Many said they did so for economic reasons; others had lost their virginity to a boyfriend, destroying their chances for marriage (MOLSW and UNICEF 2001).

In summary, the main impact of HIV/AIDS on children found in the studies described in this section can be divided into three main areas – psycho-emotional impact, social impact and material impact:

- 1. Loss of social / family support, or 'psycho-emotional impact.' Possibly the most important direct consequence of AIDS for children and young people is the loss of their family unit, and with it their natural economic, social and emotional 'safety net.' Apart from the problem of HIV-positive mothers abandoning their newborns out of despair, this usually means grown-up children in families affected by AIDS have to put up with living in a foster family or in either state or religious institutions. This may lead them to be less well-supervised than would be the case in a nuclear family situation, which could result in dropping out from school or attachment to unfavorable role models (gang leaders), or even entry into the sex industry or into crime. All this is based on the severe consequences to children's psychological well-being and self esteem that result from the loss of their parents to AIDS.
- 2. Stigma and discrimination, or 'social impact.' Stigma and discrimination are caused by ignorance and fear of AIDS in the community and the moralistic and often judgmental views community members (including many people with AIDS, themselves) have about AIDS equaling 'bad' with HIV-positive and 'good' with HIV-negative. Addressing these misconceptions not only would tackle one of the heaviest burdens on the well-being of persons with AIDS, but also would make sense from a prevention perspective. After all, people often make judgments about the need to use condoms based on a similar moralistic argument for example, "this person is 'good' so there is no need to use a condom," or "this person is a sex worker, therefore 'bad', so we'd better use a condom."
- 3. Decreased access to education, health care and social services, or 'material impact.' As a consequence of losing the family unit, as well as of stigma and discrimination, children and young people end up having less

access to education, health care and social services. In many instances, they are shunned by community members and are actively discriminated against – this is called 'enacted stigma.' The saddest examples of this are community members forcing head masters of local schools to expel children from families affected by AIDS from the school.

More often than that, and strongly related to the moralistic prejudices surrounding AIDS mentioned above, people affected by AIDS *feel* shunned by community members, and this 'perceived stigma' leads to similar, be it self-imposed, barriers to seeking access to services or allowing children to go to school. [See examples of felt and enacted stigma among AIDS patients in Thailand (Ngamvithayapong 2000) and in Cambodia (Wijngaarden 2001, p. 30)]. Merrigan and Yi, in their study on landlessness related to AIDS in northwestern Cambodia, describe what they call 'self-stigmatization' as "occurring when a PLWA treats him or herself in a manner consistent with stigmatization, making their lives more difficult than is necessary, because they are afraid of the effect they may have on others" (Merrigan and Yi 2001, p. 16). Illness in the family also leads families to take children – especially girls – out of schools to function as caregivers. A worse scenario is experienced by disabled AIDS orphans who are usually ignored because they often require extra care vis a vis more expensive facilities (Groce 2004).

#### Distilling Implications of the Studies Reviewed for the Education Sector

We look at the implications of the above for the education sector using the framework for impact of AIDS on the education sector described by Michael Kelly (2000).

Looking at the implications for access to education, it is obvious that the loss of the family unit and the existence of discrimination and stigma in the community have a detrimental impact on the accessibility of education services for children and young people affected by AIDS. It is imperative that proper policies protecting the fundamental right of children and young people to education, even if (or we should perhaps say 'especially if') they are affected by AIDS, are developed in each country. More importantly, it is of the utmost importance that these policies are widely disseminated and that supportive training activities for teachers and school administrators are conducted, since it is they who will have to act as catalysts for decreasing stigma and fearrelated barriers to education for children and young people affected by AIDS.

Policies should not focus merely on punishing stigma and discrimination, but take a more positive approach in promoting compassion and care for adults, children and young people infected and affected by AIDS. Yoktri seems pessimistic about the possibilities for stigma reduction, saying that, "No one has been able to solve the problem of rejection of people with AIDS and turn it into acceptance and sympathy" (Yoktri 1999, p. 7). Fortunately, later studies by SCF-UK and UNICEF describe projects that claim to have done just that (Devine 2001; SCF-UK 2001a). However, Yoktri hopes that by promoting understanding among the community, mainly through educational and participatory discussion activities, this can be achieved in the future. She also notes a need for better coordination between providers of different services – Yoktri suggests the establishment of community 'networks' using teachers and village committees as leaders as a way to improve access and reduce barriers to education for children affected by AIDS.

Looking at the implications for education *demand*, it is likely that a mechanism similar to that found in Africa will occur in Asia – demand will decrease due to a reduction of the number of children of school age caused by AIDS illnesses and deaths (at least compared to estimated demand without HIV/AIDS), due to felt stigma, due to fewer children being able to afford education and due to demands on children as caregivers in the household (Shaeffer 1994; Kelly 2000). Indications that similar processes will lead to a reduction in the demand for education in Asia are rife in many of the studies described in this paper. It is important that education ministries work together with social welfare ministries and NGOs to make sure support systems are designed to tackle stigma and some of the financial factors reducing demand for education among children.

Looking at the implications for the *supply* of education in Asia in the coming years, it is unlikely that AIDS will cause a similar demographic disaster as that found in sub-Saharan Africa (i.e. over 40% of the adult population sick and dying). Teacher mortality and absence due to AIDS-related illness will occur, but not to the extent that replacements can not be found or that schools will have to be closed.

In terms of *quality/content* of education provided, one of the issues that Kelly mentions may actually be a significant impact – that of teacher stress due to AIDS-related problems in the community. Often teachers are looked upon as role models or as advisors by members of the community. Increasing demands on teachers in this field, and a perceived inability to deal with these demands, may decrease teacher motivation and productivity, leading to a decline in the quality of education (Kelly 2000, p. 69).

In terms of content, there remains a pressing need for effective preventive education in schools. Integrating HIV preventive education (including sex education) into core subjects of the curriculum is essential, but often meets resistance by parents or religious authorities. Provision of well-tested and evaluated preventive education across the education system will be the most effective long-term basis for reducing the number of children affected by AIDS and, therefore, the impact of AIDS on children and young people. Apart from preventive education in the school setting, there is a strong need for effective and creative approaches to preventive education for out-of-school youth (for example, for youth in juvenile detention centers and migrant youth) (Save the Children-UK 2001b).

It is also important that the curriculum and learning process take the situation of children and young people affected by AIDS into account, making school more responsive to their needs and, therefore, more relevant. The mere presence of PLWA in the classroom will have an impact on the teaching and learning process. To deal with this, it is important that children (both affected and not affected by HIV/AIDS) are given the opportunity to actively participate in the development of interventions and curricula (Dybdal and Gaigle 2001). Basic marketing theory has taught us that demand can be stimulated by making the product more 'desirable' in the eyes of the 'consumers.' Doing so may help stop a decline in demand for education described above.

The *role* of education – especially of the school at the community level – is also likely to change dramatically as a consequence of the AIDS epidemic. UNICEF and SCF-UK studies describing schools as centers to disseminate messages related to AIDS prevention, as well as to promote compassionate and caring attitudes toward people living with AIDS, point clearly in this direction. New demands will be put on schools: They will be more involved as counselors and advisors to members of the community; they could be strong advocates and agents for change in attitudes towards people living with AIDS, and they could reinforce the need for openness and discussion in relation to sexuality-related issues in order to achieve safer sexual behaviors in the community, in addition to their traditional role as an institution for educating children. Yoktri and others have pointed out that the role of schools could be strengthened, especially when part of a multi-sectoral network also involving religious institutions, government and NGO social welfare organizations.

In terms of *planning and management*, the above analysis already points out that the Ministries of Education in the region need to take an open and constructive approach to the AIDS problem – first and foremost by developing their own ministerial response. The establishment of an interdepartmental committee to deal with HIV/AIDS within the Ministry, as well as the development and adoption of a strategic plan for responding to HIV/AIDS, are important first steps. It is also important that the Ministry links up with outside agencies in order to further and strengthen its response to HIV/AIDS. These agencies could include the Ministry of Health, Ministry of Social Welfare, Ministry of Information, and the national AIDS programme (if there is any), but also specialized agencies in the UN or NGOs (for example, UNAIDS, UNESCO, UNICEF, Save the Children, and Family Health International).



At the local level, multi-sectoral partnerships are also needed. Guidance from the central level is often essential to promote active participation of a state or provincial Department of Education. For this reason, it is important that the ministerial strategic plan, but also policies related to preventive education and stigma and discrimination reduction, are well disseminated and accompanied by training and awareness workshops for provincial/state education department-level staff.

#### Discussion and Conclusions: A Rights-based Approach and the Need for Additional Research

In working towards lessening the impact of AIDS on children and youth, especially with regard to education, it is important to adopt a rights-based approach. This means that children – HIV-positive or negative, from AIDS affected households or not – have certain basic rights that governments in most countries of the world have promised to uphold or fulfill in numerous declarations, treaties and commitments. UNAIDS puts the importance of a 'rights-based approach' as follows:

An environment in which human rights are respected ensures that vulnerability to HIV/AIDS is reduced, those infected with and affected by HIV/AIDS live a life of dignity without discrimination, and the personal and societal impact of HIV infection is alleviated. (UNAIDS 1998, p. 5 in Kelly 2000b, p. 32)

In this final section, we will review these basic rights.

First, all children and youth have the right to receive an education (Convention of the Rights of the Child 1948; The Dakar Framework for Action 2000). Children and young people must be given the opportunity to basic education – whether they are from AIDS-affected households or not.

Second, children and young people, in general, have the right to appropriate information on the HIV/AIDS situation in their country or region, and they have the right to information on how to protect themselves from HIV. Human Rights Watch, speaking about the situation of children in Africa, puts it as follows:

One of the most frequent AIDS-related rights violations suffered by children worldwide was that of their right to information on HIV/AIDS, a matter of life and death for children where the epidemic has a foothold (Human Rights Watch 2002)

Since Ministries of Education are responsible for the education of (as well as the provision of appropriate information to) children and young people in their countries, they must work to fulfill this right (Coombe 2002). In doing so, they contribute in a significant way in the struggle against the AIDS epidemic.

Third, children and youth have the right to appropriate social, psychological and medical care. Governments and NGOs must work together to make sure that these rights are upheld for children affected by AIDS in Asia, since the studies reviewed in this paper found that there are barriers related to AIDS that hinder their access to these services. Furthermore, in countries where antiretroviral drugs are unavailable or too expensive, governments – despite this barrier – have a basic responsibility for ensuring the health and well-being of their people. Governments must work actively with private companies, NGOs and pressure groups to achieve ARV treatment for all persons infected with AIDS.

Fourth, children and youth with HIV/AIDS or from AIDS-affected households have the right to protection of their privacy in order to prevent them from being victims of exclusion due to stigma and discrimination. Governments have the duty to make sure their medical services uphold basic principles of confidentiality and privacy.

Fifth, children and young people have the right to protection from exploitation and abuse. Many laws have been adopted by countries in the region in order to ensure this – the problem is that these laws are rarely enforced (Human Rights Watch 2004, Kutcher 2003, Hunter 2005). Even worse, sometimes certain groups are not covered by a country's laws. Such is the case for Thai hill tribes, who are excluded from the protection of Thai law (Physicians for Human Rights, 2004).

Looking at the limited number of studies that we could find for this review, one clear conclusion we reached is that still very little is known about the impact of AIDS on children and young people in Asia, in general, and on the education sector, in particular. We summarize questions for further research that came up while reviewing the studies:

- What will be the specific impact of AIDS on the education sector in Asian countries, looking at access, demand and supply, as well as the quality and content of education in countries affected?
- What makes children and young people vulnerable to HIV/AIDS in the Asian context, and how can we reduce this vulnerability?
- How can we strengthen local social support networks in communities affected by AIDS, with a special focus on the role schools can play in local settings, taking the specific culture of these settings into account?
- What are the needs for children affected by AIDS, especially related to psycho-social care, in different socio-cultural settings?
- What are the needs of children and youth in juvenile detention centers and jails, and for other out-of-school children in Asia?
- How can the preventive education, care and support needs of migrating children and youth be fulfilled?
- How can the promotion of care and compassion for persons affected by AIDS be integrated into prevention interventions and school curricula in Asian countries?
- How can existing legal frameworks that protect children from exploitation and abuse be effectively enforced?

Universities and research institutions in Asia must form strategic partnerships with national AIDS programmes and Ministries of Health, Social Welfare and Education in a concerted effort to answer these and other questions that remain unanswered in many countries around Asia. A first step to take in this regard is to agree on a multi-sectorally developed national research agenda. UNESCO will work with its Government and UN partners in facilitating such a collaboration.

The UN General Assembly Special Session on HIV/AIDS in June 2001 agreed that all countries should work toward implementation by 2005 of comprehensive national programmes to protect and support children affected by AIDS, including

...providing appropriate counseling and psychosocial support, ensuring their enrolment in school and access to shelter . . . and protect[ing] orphans and vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking and loss of inheritance (UNGASS Declaration, 2001)

HIV/AIDS is a deadly disease that spreads in conditions of ignorance and silence. The consequences of it are borne by individuals and communities affected by it, again in silence and shame. Only by shedding more light on the dynamics of vulnerability to the epidemic, by researching appropriate ways of dealing with its impact, and by seriously upscaling human and financial resources available for battling the epidemic can we stand a chance of overcoming a global catastrophe.



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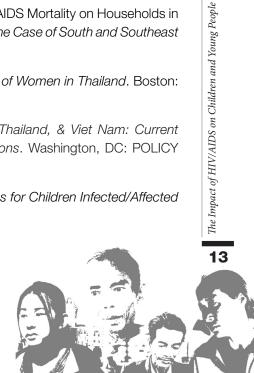
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