The impact of HIV/AIDS on children and young people:

Reviewing research conducted and distilling implications for the education sector in Asia

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Introduction

The AIDS epidemic in Asia and the Pacific is considered to be only in its infancy. In South and Southeast Asia, the number of new infections in 2002 was 700,000. This brought the total number of HIV infected people in South and Southeast Asia to 6 million. HIV prevalence among the adult population was estimated at 0.6% - much lower than the prevalence seen in some Sub-Saharan countries (UNAIDS 2002).

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 peaked among Thai military recruits at over 4% (MOPH 1994); in the group of female sex workers in Cambodia a prevalence exceeding 30% was found (NCHADS 2002) and a prevalence of HIV among pregnant women of more than 2% has been recorded in certain states in India, in areas in China, as well as in Myanmar, Cambodia and Thailand (UNAIDS 2002). An infection rate of more than 1% in pregnant women is one of the criteria for UNAIDS to classify an epidemic as 'generalized' rather than 'concentrated'.

UNAIDS estimates suggest that over half of new infections with HIV are occurring among young people (15-24 years old) – or over 7000 new infections a

day worldwide (UNAIDS 2001). The impact on children and young people is growing (Summers, Kates and Murphy 2002). The USAID/UNAIDS/UNICEF report, '*Children on the Brink 2002*' estimates that there are 1.8 million children orphaned by AIDS at the end of 2001; this number is expected to rise to over 3 million in 2005 (p23 and p26). Wattana Janjaroen and Suwanee Khamman (2002) quote official sources as saying that in Thailand, over 4000 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 and is projected to rise to 17% of all new infections by 2005 (MOPH 2001). In Cambodia the number of children and young people orphaned by AIDS was estimated at 60,000 by the end of 2001 (SCUK 2002).

This paper aims to take 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 over the years in the Asia-Pacific region. Since no specific research studies on the impact of AIDS on education have been conducted in the Asia-Pacific region, it will then look at implications of the findings in these studies 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 lines out three issues for discussion: first, the way the education system must change 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, what should be 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. The impact of AIDS on the education sector 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, see for example Bangkok Post, 17 September 2002). This seems to be the case especially in the beginning of the epidemic, when more and more community members fall ill and fear and 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. Then there is an impact on the *supply* of education (teachers and administrators fall sick and die; 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 de-motivated to teach or to learn; the curriculum may not be relevant for the students; the teaching-learning process in classrooms changes 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 so far. The few impact studies in Asia that exist focus mainly on the impact on the economy at the macro level (Myers and Bunna 2000; Bloom & Godwin 1997; Godwin 1997; Viravaidya et al. 1992). Their main purpose seems to be to back-up advocacy efforts with policy makers, providing 'ammunition' for putting AIDS on their agendas. However, some studies were undertaken on the impact of AIDS on the micro-level – most of them by NGOs. In the next section we will review these studies, focusing on the impact on children and young people[1].

The impact of AIDS on children and young people in Asia: an overview of study results

Wattana Janjaroen and Suwanee Khamman studied the *Long term socio-economic impact of HIV/AIDS on children and policy response in Thailand* in February 2002. The study describes different impacts of AIDS on children as well as on pregnant women and mothers infected with AIDS. 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' (p25).

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

Yoktri, in an excellent review of the situation of 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 of especially girls, and the increased likelihood of their entry into sex work (Yoktri 1999:7)

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).

Janjaroen and Khamman do not fail to mention that much of 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'. 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 psychosocial 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 not loved by the parents 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 try to ignore and forget what happened as soon as possible, leading to psychological problems later in life (Devine 2002).

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 UK (SCUK) as 'Participatory Action Research', probably in 2001. The study objectives are to gather insight into the lives of migrant children and youth, as well as to pilot a new participatory research approach. Not surprisingly, it confirms that migrant children are a vulnerable group in need of holistic interventions – including improving access to literacy training, (non) formal education, and health and other services in their own language. Impoverishment due to weak health is mentioned on several occasions, and 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.

The SCF-UK publication, *Young People and HIV/AIDS: Responding to the new Asian Crisis*, (2001) gives an overview of SCUK'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 mention further that it is essential to link NGO work with Government's efforts to ensure sustainability. They plead for culturally appropriate approaches in order to ensure effectiveness of interventions. Again in this study no findings deal with the impact of AIDS on the education sector.

The pioneering study, *Household resources allocation and responses toward AIDS related illnesses,* by Wassana Im-Em and Sasipen Phuangsaichai, Mahidol University and CARE, Bangkok 1999, aims to determine key parameters for more extensive research on the impact of AIDS on households in Northern

Thailand – research that is currently ongoing. It describes a disproportionate burden of AIDS on women, due to the fact that the husband usually got HIV first, got ill first and died first – often using all family resources in paying for several treatments. Also 75%-80% of the people with HIV/AIDS in the study had children under the age of 18 – which are often taken care of by the mother. Families of PWA ended using up all family 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 siblings of PLWA reported more work or increased burden as a result of their parent(s)'s sickness – most 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 PHA 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)

The Khmer HIV/AIDS NGO Alliance (KHANA) conducted an *Appraisal of needs and resources for children affected by HIV/AIDS in Cambodia* in 2000. The study

used Cambodian NGO staff as researchers as a capacity building exercise, which led to a less solid research process and less accurate and complete research data than could 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, children interviewed in orphanages themselves 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/UNICEF 2002:12).

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 programs 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 there is a need to shift to a rights-based approach for children, 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 on the way families affected by AIDS had to 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 2001:4)

UNICEF's report, *A multi-sectoral approach to planning services for AIDS orphans in Sanpatong District, Chiang Mai*, focuses on several inter-twined and interrelated projects aimed at providing a model for a multi-sectoral response at the community level. The report describes involvement by the Government, several NGOs and 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 in 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* (SCUK 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 (1999) of the Vieng Ping Children's home in Chiang Mai, mentioned several times above, describes the problems of children of AIDS affected families with regards to education, and the cruelty they often must endure on behalf of some schoolmates. Sometimes this, as well as pressure of parents of presumably negative children on school administrators to expel children from AIDS affected families, leads the child in question to take a forced blood test. 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 and camps to which 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 SCUK (SCUK 2001:16). 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 VCT and reproductive health services.

In a rare English language document on children and AIDS from China, UNICEF consultant Ionita et al (2002) give an overview of the situation of the AIDS epidemic and its impact on children in the Chinese province of Yunnan, which borders Myanmar, Lao PDR and Viet Nam. They mention 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 2002:8)

The authors report 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. 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 and 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; another one is the Vieng Ping foundation in Chiang Mai, providing treatment to 24 orphans (SCUK 2001, Wijngaarden 2002). In both *Baan Gerda* and the Vieng Ping foundation, the children go to state schools.

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 providers of alternative care 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 for them, and that further research should be conducted to find out whether this is consistent with Cambodian child-rearing practices (MOSALVY 2001:26)

Athipat Cleesuntorn of the Policy and Planning Bureau of the Thai Ministry of Education reported on the country situation of Thailand during a workshop on the impact of AIDS on education in Paris in 2000. 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 plead for 'Living with AIDS' as a 'national agenda' for the public, advocating for information and education campaigns for the community and the implementation of child friendly school policies 'with focus on children affected by AIDS' (Cleesuntorn 2000).

In a UNICEF-supported study in Lao PDR by the Ministry of Labour and Social Welfare on the commercial sexual exploitation of children in Lao PDR, 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/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 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 their entry into the sex industry or into crime. All this is based on the severe consequences of the loss of their parents to AIDS to their psychological well-being and self esteem.
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 wellbeing 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 the loss of 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 2001:30)). 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 2001:16). Illness in the family also leads families to take children – especially girls – out of schools to function as caregivers.

Distilling implications of the studies reviewed for the education sector

We have tried to 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 fear-related barriers to the access 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 1999:7). Fortunately, later studies by SCFUK and UNICEF describe projects that claim to have done just that (Devine & UNICEF 2001; SCUK 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 the *demand* for education, it is likely that a mechanism similar to that found in Africa will occur in Asia – due to a reduction of the number of children of school age due to illness 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, demand will decrease (Shaeffer 1997; Kelly 2000). Indications that similar processes will lead to a reduction of 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 2000:69)

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) (SCUK 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. Their mere presence 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 in the 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 SCUK's studies describing schools as centers of dissemination of messages related to AIDS prevention as well as promotion of compassionate and caring attitudes toward people living with AIDS in Northern Thailand 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, but also towards the need for openness and discussion in relation to sexuality-related issues in order to achieve safer sexual behaviors in the community. The studies in Northern Thailand confirm the role of schools as educators for adults in the community in addition to their traditional role of an institution for the education of children. Yoktri and others have pointed out that the role of schools could be strengthened, especially when part of a multisectoral network also involving religious institutions and social welfare organizations, both governmental and NGO.

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 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 Program (if there is any), but also specialized agencies in the UN or NGOs (for example, UNAIDS, UNESCO or UNICEF; also Save the Children, Family Health International).

At the local level multisectoral 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 regards 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, which Governments in most countries in 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 1998:5 in Kelly 2000b: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; Dakar Declaration 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) – and in doing so, 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 the health and wellbeing of their people. Governments

must work actively with private companies, NGOs and pressure groups towards achievement of the principle of 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.

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. Below we summarize some of the 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 psychosocial care, in different socio-cultural settings?
- What are the needs of children and youth in juvenile detention centers and jails and for other children out of school 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?

Universities and research institutions in Asia must form strategic partnerships with National AIDS Programs 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 multisectorally 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 agreed that all countries should work toward implementation by 2005 of comprehensive national programs 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 2000)

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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