Kululeka
grief support for children and youth

How Children are affected by HIV/AIDS

HIV/AIDS affects children in many ways, because HIV/AIDS is in many ways a family disease: it takes some members and leaves the others (children and the old people) to cope. The children affected in one or the other way by HIV/AIDS fall into the following categories:

- *Children with the disease:*
  Between 15 and 20% (other sources claim that it is about one third) of babies born from a mother with HIV/AIDS are themselves infected, mostly shortly before or during the birth. They can be also infected by breast feeding. Infected infants generally develop AIDS symptoms more rapidly than do adults - especially if they have been already infected in early pregnancy.
- *Children whose parents are sick or have died of HIV/AIDS.*
  This rapidly growing category is confronted with a number of problems:
  - Psycho-social: The illness and the loss of the parents is stressing and often traumatic for the child; it is accompanied by deep emotional suffering
  - The loss of consistent nurture and the physical child neglect can produce serious development problems.
  - Loss of guidance: The loss of parental guidance will make it more difficult for children and adolescents to reach maturity and to be successful in the society
  - Education and training: The economic resources of the remaining family may not be enough to allow the children to continue in school or any formal training. Traditional skills (such as agricultural knowledge) may not be passed on.
  - Subsistence: Illness and loss of a parent may reduce the capacity of a rural family to produce crops or an urban family to generate income.
  - Shelter: The loss of income or the inability to repair or maintain the home can result in shelter being lost or deteriorating.
  - Health: Increasing poverty multiplies health risks and reduces ability to obtain health services.
  - The children's psychological (and economic) problems start long before a parent dies of HIV/AIDS: reduction of the family income, growing uncertainty about their own future, experience of a long period of losing their parents, because where one parent is infected with HIV/AIDS the other usually is as well.
- *Children whose siblings, relatives or friends have the disease or have died.*
  These children are confronted essentially with the psychological effects of loss and death.
- *Children whose household is stressed by AIDS orphans coming from relatives etc*.
  There are more and more families who accept five, six, and more children from their already deceased brothers and sisters. This reduces the emotional and economical support, which was given until now to their own children.
- *Children on the street*
  A growing number of orphans have no other way to survive than to work, to beg or to steal in cities and towns. HIV/AIDS is a serious threat to the health and survival of those children. Sexual activity (voluntary, coerced or for money is high among street children putting them at risk of HIV/AIDS infection.)

Although children are in many ways victims of the actual HIV/AIDS disease, children should be presented and viewed not only as 'victims', 'AIDS orphans' etc., but also as social agents, as boys and girls who will act and intervene in this new reality created by the pandemic, developing their own strategies in order to survive and to cope with the new situation.

The "Child Bereavement Study" confirms what we already know from our experience: Many bereaved children are able to adapt to loss without any special intervention at all. But it is also true that all children who lose a parent obviously suffer and have to cope with the loss.

And it is also true that losing a parent constitutes a risk for developing further emotional or behavioural disorders. Addressing certain basic needs in this situation can help to minimize the possibility that children develop more serious problems.

Ben Wolfe once used the picture of the broken glass to help us understand the situation of children who experienced a loss: The story describes a window that is broken and the realization that no matter how hard one tries, after being glued together the glass will never be the same again. Some individuals think they can quickly find all the pieces and glue them back together as they were previously for either themselves, other members of their family or friends. Others learn that part of the window will become blurred.

Youngsters who have experienced the death of a family member, relative or close friend have an entirely different perspective on what the 'glass' looks like today compared to youngsters who never had a similar experience. They are changed because of death".

When children do not have sufficient information, they will make up a story in their fantasy to fill the gap. It is very helpful for children to get clear, comprehensible and age-adapted information about an impending death and about the cause of the death. Worden points out, "a lack of information can make a child feel anxious and less important; and in the worst-case scenario, the child can feel responsible for what is happening to the dying person." Without clear and adequate information the child can develop unrealistic fears about death and disease. Children may wonder "Will it also happen to me? Is the death and the disease contagious?" Helping them to know that "Dad died because of cancer" or "of AIDS" and that they cannot "catch" cancer or AIDS (at least at this age of young children) can somehow reassure especially younger children.

Barbara Monroe, head of the Department of Social Work of the St. Christopher's Hospice in London insists that it is impossible not to communicate with children: "A terminal illness or death in a family causes enormous changes and children quickly sense when something so serious is happening. They pick up the emotions around them, notice changes in the routine, read body language and overhear conversations. However, a child's silence, lack of questions or apparent indifference may be interpreted by adults as a lack of awareness or a state of coping which should not be disturbed. Children want to protect their parents and often attempt to obey family (and cultural) rules even if they are unwritten. If the whole emotional atmosphere of the family and/or the social environment is saying 'don't ask, we don't talk about it' children may try to join in the pretence that nothing is happening, and they may develop fantasies which are sometimes worse than the reality and can be very frightning." *(Interventions with bereaved children, 1995, p. 88)*.

Parents have, of course, good reasons for their reluctance to share information about illness:

- It may be culturally not allowed or practiced.
- They are struggling to maintain some control over themselves in an uncertain situation.
- They can feel overwhelmed by their own raw and confused emotions.
- They may wonder if they themselves may cope with the child's reaction and grief.
- They themselves may try to avoid the truth.
- They may underestimate or be anxious about what their child understands.
- They might be worried that they don't know how to communicate with the child and to say the wrong thing, which may make an already difficult situation worse.

Girls are especially vulnerable!
It was already mentioned that the HIV/AIDS epidemic has apparently a special negative impact on the life-chances of girls. They are more vulnerable than boys in terms of their social status and their economic dependence. Rape of girls has become one of the most common offences appearing before regional magistrates' courts.