

Children Affected by HIV/AIDS - What Happened in Bangkok?

By
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Children were not a serious part of the international AIDS agenda in Bangkok. Some people were even annoyed at the repetitive images of wide-eyed pathetic children. Kate Harrison, Senior Program Officer with the International HIV/AIDS Alliance wrote on the CABA list serve about her anger at the way children were represented at the conference. She contended that "while we continue to have images of children as cute, passive and needy, using them as decoration for publicising our programmes, children will not be taken seriously as dynamic actors in community action against AIDS". I was also dismayed during the official ceremonies to have children from institutions brought out to sing and dance for the audience, in what Kate called "a display of manipulation, tokenism and decoration that could be used as examples of how NOT to work with children".

There were very few presentations on the scale and seriousness of the problems affecting children as the people on whom they depend lose jobs, fall deeper into poverty, become demoralised by the burden of their worries, are preoccupied and worn out by the stress of caring for others, fall ill and/or die. It is as if these issues - more serious in their impact on caregiving, and therefore on children's wellbeing, than any world or regional war - are not fully comprehended. "Orphans" is just too simple an extraction from this threat to be useful. In a book entitled Supporting Disadvantaged Children in a World of Poverty, War and HIV/AIDS, which will appear early in 2005, Karsten Hundeide and I argue that there are three priorities in children's care that have to form the core of, and give purpose to, interventions for children affected by AIDS. Firstly, all children must have at least one caregiver devoted to their wellbeing. Without this, external agencies attempt to provide material and psychosocial care, often in unsustainable ways



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that, in any case, do not address the child's primary needs to be in relationship with others. Secondly, these caregivers must receive the support they need to effectively care for the child. This is the key role of government aid and service organizations; and thirdly, the child and caregiver must be helped to be part of the social institutions that make up our communal endeavours. These are families, schools, religious groups, civic associations, and the like. If we don't keep our eyes on these goals, much of what we do is not likely to be effective or sustainable.

At the conference I was on the look out for interventions to support families and communities, programmes to care for AIDS sick children in hospitals including their caregivers and the professionals involved in their treatment, and efforts to include men in children's care and support. In common with many conference goers, I was looking for people who think like me or who, for good reason, don't think like me - and to whose views I better pay attention!

There was very little on programmes to assist the family and kin of children affected by AIDS. Even the term, children affected by AIDS, isolates children from their social environment and creates them as a target for a myriad of individualised programmes, such as play groups and memory projects, delivered by people outside of the extended family. While well-intended, there are pitifully few such interventions that have demonstrated their effect on averting negative, or on promoting positive, outcomes in children. In addition, such one-by-one efforts have no chance of matching the scale and duration of the AIDS epidemic's impact on children.

In 2002 it was estimated that nearly 3 million children were living with AIDS. Several reports in South Africa are that well over half the children in paediatric wards are infected with HIV. During my visits to hospitals I have been extremely disturbed by the distress of everyone involved - children are frequently unable to feed or soothe themselves, caregivers are overwhelmed by their own sorrow and the suffering of their children, and staff lack direction on what to do in a situation that is also agonizing for them. Only one paper at the conference dealt directly with the palliative care of children. The care of sick and dying children is an area urgently needing attention, not only because so

many people are suffering, but because it is important to retain and share our humanity through kindness and respect to those facing the last months or hours of their life.

I was more fortunate on the issue of the involvement of men in the care and support of children. At least in PMTCT programmes, there seems to be growing recognition of the importance of, and success achieved in, involving men from the start of VCT through couple's counselling. There was also a smattering of presentations on the involvement of men in the care of terminally ill, orphaned and vulnerable children. However, an innovative paper by Lorraine Sherr and her colleague filled a gap in focusing also on men's reproductive choices and fatherhood as a component of their HIV testing. They found that men were rarely given reproductive information or advice during testing and more than half said they'd value fertility and fatherhood consultations.

Women carry an unbearable burden in the AIDS epidemic, including for the care of children. However, researchers and practitioners need to do more to assist women and not just their children, and to promote men's involvement in responsibility for, and care of, children affected by the epidemic.

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