

Children and AIDS - Towards a Social Welfare Policy

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The only effective way of managing the problem of children affected by AIDS is for health and welfare workers to join forces with the community. In this article the complex issues involved in formulating a humane and effective social welfare policy for dealing with children who are HIV-positive or have full blown AIDS are discussed. The ideal scenarios are considered against the obstacles we face in attaining such ideals.

1. Partnership Issues

The impact that HIV (Human Immunodeficiency Virus - the virus that can give a person AIDS) will have on almost all aspects of human existence, demands an effective response involving inter-disciplinary co-operation on an unprecedented scale. As health care and social service practitioners, we should be on the front line of preventing the spread of the virus and dealing with its consequences. While the health and social service disciplines have moved towards a much closer partnership on a number of fronts in recent years, our present challenge is to find an even greater level of co-operation. AIDS which targets the already marginalised in our society, demands that we combine skills in health care, human relationships and social development in new ways.

2. Models and Mindsets

If we concern ourselves with the expressed needs of people with AIDS, our services should be structured in a manner which includes a model of empowerment. This means programmes whereby:

- uninfected people are equipped with the knowledge and skills to protect themselves from the virus;

- those who have the virus are helped to live with it productively, with dignity, and as far as possible cared for within their own homes when illness takes hold;
- persons, families and communities are enabled to overcome ignorance and fear, and in terms of their capacities, are enabled to support those around them who are infected;
- families and friends of people with AIDS are offered support in dealing with loss and grief; and
- a strong advocacy approach is taken to counter discrimination against people with HIV, including children, and those in contact with them (CWLA, 1988; Ryan and Rowe, 1988).

2.1 Community Care: an alternative to closed institutions

We should not underestimate the obstacles we face. The usual response of the government and mainstream private welfare sector has been to set up institutions in which to house people in need, regardless of particular needs. The effect is to deprive people of assistance in functioning fully as members of their communities. Government financing systems for institutional care greatly outweighs those for community based care. However, a start is being made against placing affected people in institutions and thereby, marginalising them. We have to counter any temptation to prematurely hospitalise HIV positive patients by single-mindedly developing community care systems.

2.1.1. How are we doing so far?

On a recent broadcast of "Agenda", Natal doctors cited some horrifying facts about mounting numbers of destitute children, some 10 % of whom have tested HIV-positive, and have been kept in hospital for as long as 2.5 years in hospital. This is done at great cost. For instance, doctors at Johannesburg Hospital, where a similar problem is developing, have mentioned R300-R350 per day for the cost of a bed alone. Many more such children are being cared for in large institutions and state places of safety. For a fraction of the cost involved, we could be placing these children in specially recruited and well-supported substitute families; or better still, helping their own mothers to care for them. To do so we have to free ourselves of our strong attachment to institutions. We need to break from our *health and welfare compartments and undertake joint planning of services*. If we continue to operate as we presently do, the desperately under-financed state of our family support services and our foster care system will cripple our efforts to address the AIDS crisis.

3. Target Groups

Children for whom we are called on to plan services include the following:

- those whose parents require education in order to prevent contracting the virus;
- those whose parents or other care givers are ill with or have died from AIDS;
- infants without care givers who are testing HIV positive;
- older children who test positive or who are ill with AIDS (these may include, for example, child sex abuse victims and sexually active adolescents);
- special risk groups such as street children;
- those not at special risk but requiring age-appropriate life skills education, including AIDS related information (that is, the broad population of children).

Our starting point for approaching all these target groups, is that these services should be provided primarily within the family and community, with hospitals and residential care facilities serving, as far as possible, as inter-disciplinary resource centres and as bases for supportive services.



It must be made clear that HIV positive children pose no risk of infection to others in normal daily contact. *Photo: Cedric Nunn*

3.1 Creation of a positive climate

We need to be assertive in creating a social climate in which people are accommodating to those with HIV who pose no risk of infection to others or to themselves. School, pre-school educare facilities and family service organisations need to be provided with the necessary knowledge and understanding to forestall any tendency to discriminate. These institutions need to become outreach and education resource centres in their own right. It must be clear that HIV infected people pose no risk of infection to others in normal daily contact.

3.2 Support for people with AIDS and their children

Programmes combining medical care, education, counselling, comfort and financial aid (White, 1990) can go far to improving the quality of life for children and families affected by AIDS. We have a lot to learn from programmes elsewhere in Africa such as those run by The AIDS Support Organisation (TASO) in Uganda, which provides information, counselling and support to infected people and their families, with HIV positive people serving as an integral part of the organisation's work force (Hampton, 1990). The organisation assists families as far as possible to care for their own sick with full access to medical services and to hospitalisation when necessary. Where children stand to be orphaned, the organisation assists parents plan for their care. The organisation also helps parents identify relatives or friends who will care for their children when they pass away. TASO provides information to potential foster parents so as to overcome the fears and stigma associated with AIDS, and provides material and financial help to them once they have taken the children into their homes.

3.2.1 Programmes of support for women and HIV infected babies

Support for women with HIV and for mothers and their babies is a key aspect of a family support approach. Women's support groups have proved themselves to be most resourceful. (Taylor, 1990). Existing pre- and post-natal care facilities, with the necessary expansions and adaptations, are a natural base for preventive education and for information and support for infected mothers and their children. Active outreach and practical help including financial aid to vulnerable groups of women, such as teenagers and those who are homeless or destitute, could help

contain growing incidence of abandoned infants, enabling more mothers to care for their own children if they are sufficiently healthy to do so.

3.3 Formal foster care or adoptive placement

A network of well supported foster homes for children with special needs - children with HIV, children whose parents are incapacitated and children who are abandoned or orphaned is needed. This would involve substantial financial investment in active outreach and education. It would also involve locating, preparing and supporting people with the ability to deal with the pain of not knowing for months or even years whether or not a baby is actually carrying the virus, to face the prospect of terminal illness in infected children, to deal in their own homes with the difficult features of paediatric AIDS, and to cope with grief. The churches and religious groupings are likely to be in touch with such people. Religious groupings also offer a sense of meaning for sickness, suffering, and death, and a support system for providers of care. In the USA the health care professions have also shown themselves to be an important source of foster families for children with the virus.

3.4 Home-based employment for child care workers

Allied to and overlapping with traditional models of substitute family care is the concept of salaried persons who in their own homes provide therapeutic care for children with special needs, which could include children with HIV. The concept has many precedents in specialist foster family programmes which operate successfully in various parts of the world. A major ingredient promoting success in these schemes is provision for respite care - families who become well known to all children in a particular network of people providing care will take in a child for a brief period while the family acting as the main provider of care takes a much-needed break. Such programmes combine the advantages of hospital and children's home care (team support, training and time off for staff) with those of life in a normal family environment. They do, however, require more financial input than conventional foster care but considerably less than hospitals or children's homes, and could provide much needed employment.

3.5 Residential care issues

It is important that admission policies to residential care do not discriminate



There is a need to encourage the placing of HIV positive children in a normal community and environment, and not isolating them in hospitals. *Photo: Cedric Nunn*

against those carrying the virus, especially in the case of children who cannot be cared for by their own or substitute families and for whom the placement of choice is residential care. High-risk behaviour needs to be identified for what it is to avoid paranoia developing and children's homes being perceived as a source of infection. Encouraging behaviour which counters victim blaming and dealing with the impact on all concerned when a child becomes ill or dies, are among the challenges facing staff and volunteers. In dealing with infected children who use intravenous drugs or are sexually active and whose behaviour cannot be effectively controlled, we may in the long term have to consider providing, preferably on a very limited basis, some specialised residential facilities (Wilson, 1990).

4. Some Problematic Areas

4.1 Testing

For child welfare organisations testing of certain categories of children, for the purposes of appropriate planning for their future and dealing with prospective adoptive and foster families is important. The most clear-cut category in this

respect comprise children under 3 years who have been abandoned or formally released for non-disclosure adoption. (Non-disclosure adoption when a mother signs papers giving up her child for adoption without knowing who the adoptive parents are. A disclosed adoption, on the other hand, occurs when a mother consents to her child being adopted by parents she knows). Other categories are not so clear. A positive diagnosis in a situation of compulsory testing often introduces many problems with which we may not be able to help the children concerned effectively, but consideration has to be given to the possible risks to non-infected children including those who are in care against their own wishes and those of their parents.

4.2 Confidentiality

Although there must be strict rules of confidentiality, there is considerable difficulty as regards securing support systems for foster and adoptive families. Thus, were we to succeed in recruiting foster families or home-based child care workers for infected children, community support will be the life-blood of such arrangements. We have to walk a tight-rope between using firm measures to protect privacy while building in the support of selected people who can reasonably handle information, and make all-out efforts of removing the stigma of the disease. We must aim for a situation in which a child's HIV status is no more of a confidentiality problem than his having chicken-pox. We must move as far along that route as we are able.

4.3 Infection control procedures

The Johannesburg Child Welfare Society has set out to educate staff and foster parents in infection control procedures based on those propagated by the Centre for Disease Control in the USA (CWLA, 1988). This should enable staff to feel secure in the knowledge, that even the minute chances of contracting HIV in the course of giving care and contact with infected colleagues, would be eliminated. At present, we find the measures difficult to implement because:

a) their use is expensive, requiring a very large scale disposable gloves (experts suggest that plastic ones are unreliable and that the expensive latex type should be used). The cost of household bleach is also a problem. Whereas large agencies could manage these costs, we wonder if attempts at propagating these measures among impoverished parents, and pensioners who form the majority of foster care providers in our townships, are realistic.

b) emphasis on these measures to prevent the theoretically possible but extremely

unlikely transmission of HIV via, for example, through cleaning up a grazed knee or a bleeding nose may in fact create more fear than security, and detract from the messages about how one is really likely to contract the disease.

Perhaps we would have to find the money for the materials, or health workers could assist in developing effective guidelines. Guidelines which are affordable and easy to implement in the South African context.

5. Developing and Supporting Providers of Care

Every strategy we use in designing services for families and children must include plans for equipping management, staff and community providers of care with the knowledge and skill they will require. The provision of support systems needed by those who will daily face the crises arising from positive testings, and the emotional tasks involved in confronting sickness, disability, death and grief is vital. In all these processes we will need each other's skills, insights and support.

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