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SORROW MAKES CHILDREN OF US ALL: A LITERATURE REVIEW ON THE PSYCHO-SOCIAL IMPACT OF HIV/AIDS ON CHILDREN

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CSSR Working Paper No. 47

ASRU

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Sorrow Makes Children of Us All: A Literature Review on the Psycho-Social Impact of HIV/AIDS on Children

Overview

This review describes the available research literature regarding the impact of HIV/AIDS on children, who are often referred to as OVCs (orphans and vulnerable children). It draws on the academic literature, including both published and unpublished research papers, books and reports regarding children who have a parent living with, or has died of, HIV/AIDS. The review focuses predominantly on African research. Children who are themselves infected with HIV are not covered in this review. Clearly, children with HIV/AIDS have unique needs and challenges which warrant separate consideration.

The review begins by looking at the general academic literature regarding the impact of HIV/AIDS on children. In section one, it is argued that the emphasis on, firstly, orphanhood and, secondly, financial deprivation have both been counter-productive to defining the research agenda regarding OVCs more broadly.

Section two focuses on research findings regarding the psychological impact of (a) living with a parent with AIDS and (b) being orphaned as a result of AIDS. Research findings suggest that if there is any one aspect of HIV/AIDS as a cause of parental death that stands out as the most significant difference in determining its increased psycho-social impact on OVCs, then this is the social stigma attached to the disease.

In section three, empirical evidence regarding the type of adjustment difficulties experienced by OVCs is explored. It is argued that, although the evidence suggests that OVCs, especially orphans, are prone to depression, there is very little research evidence to suggest that OVCs are more prone to delinquent or anti-social behaviours than other children from similar socio-economic backgrounds.

Section four and five of the review focus on issues surrounding disclosure of an HIV positive diagnosis or AIDS-related death to children, and the kinds of

difficulties practitioners may encounter when helping caregivers and children come to terms with HIV/AIDS sickness, death and dying. A clinical overview of children's conception of death and dying is presented, and implications for intervention are briefly outlined.

Section One

The Focus on AIDS Orphanhood and Financial Deprivation

The Focus on AIDS Orphanhood

By far the largest proportion of the published academic research literature on the impact of HIV/AIDS on children relates to orphans. There are numerous reports by large development organisations containing demographic models predicting unprecedented levels of orphanhood in Southern Africa, and containing dire predictions of the long-term consequences of AIDS orphanhood for society as a whole.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) estimates that 13.2 million children under the age of 15, ninety percent of whom live in Sub-Saharan Africa, had lost their mother or both parents as a result of HIV/AIDS (USAID Report to Congress, 2000). A USAID study predicts that, by 2010, there will be 44 million orphans in the 43 countries hardest hit by AIDS. (USAID, 2000). In South Africa, it is estimated that there were 1.5 million orphans in 2001 (UNAIDS 2002) and this number is expected to grow to approximately 3 million maternal orphans under 18 by 2015 (Johnson & Dorrington, 2001).

Clearly, numbers are important. There can be no underestimation of the power of statistics in giving validity to a crisis. But Bray (2003) argues that such epidemiological reports describe the extent of the current and potential orphan 'epidemic' only in generalisations. Such reports span diverse geographical and socio-cultural space and lack comparative or contextual analysis of orphanhood or its consequences. Historical data on trends in orphanhood, non-nuclear household arrangements, and child-care outside the family is usually absent. Despite these limitations, such reports are drawn on uncritically in academic literature.

Apart from the epidemiological research literature, there is also a large amount of international literature on AIDS which describes the impact of HIV/AIDS on household economies and children's well-being in non-statistical terms. These publications often draw from experience and anecdotal evidence as much as from rigorous and systematic empirical research. Emphasis is usually placed on the fact that the illness and death of wage-earning adults leads to acute financial hardship with orphans being at significant risk of malnutrition, inadequate shelter, clothing and schooling (Muller *et al*, 1999; Ntozi *et al*, 1995). Likewise, attention is drawn to the fact that AIDS orphans are particularly vulnerable to exploitation. Financial exploitation includes the use of children as cheap labour, the siphoning off of childcare grants, and the appropriation of inheritance, homes and property by adult relatives (Foster, 1997; Muchiru, 1998; Webb, 1995). AIDS orphans are also reported to suffer increased sexual abuse (UNAIDS 2002). Such exploitation and abuse contributes to an increased likelihood of anti-social behaviour and criminality on the part of OVCs, including becoming involved in commercial sex work (AFXB, 2000; Schonteich, 2000).

Such research generally provides a powerful motivation for increased funding for NGO's involved in the provision of increased support to OVCs, but tends to fall short of advocating large-scale changes to the state welfare system. Loening-Voysey (2002) is one of the few authors drawing attention to the failure of the state to take care of South Africa's OVCs.

Apart from the plethora of research papers calling attention to the orphan crisis, the plight of children affected by HIV/AIDS is reported on repeatedly in the local and international media, and the funding needs of NGO organisations with scarce resources trying to address these children's needs are relatively well-advertised. The failure of government to address the problem of children affected by AIDS adequately is, however, as little discussed in the media as it is in academic literature.

This is despite the fact that, according to USAID, the vast majority of children affected by HIV/AIDS do not receive any government help or support of any kind. A UNICEF study in Zambia (1999) found that only 5% of children affected by AIDS receive any direct support.[1]

Clearly, then, the need to highlight the plight of orphans and vulnerable children has not diminished. Researchers may, however, need to pay more attention to

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[1] No data regarding the number of OVCs receiving direct support from the South African government was available at the time of writing.

strategising the way in which their research findings are used to motivate policy makers to increase funding for relevant service provision (Stein, 2003).

Another problem which emerges from a consideration of academic literature needs to be highlighted. Such literature is predominantly concerned with the threat of massive social dislocation and breakdown posed by high numbers of orphans and the impact this will have on society as a whole. In comparison, the plight of children themselves is of secondary concern. The following quotations provide some examples of the overwhelming concern being expressed regarding orphans as a problem for society:

> 'We are talking about unsocialised, uneducated, and in many instances unloved children struggling to adulthood. The costs to them remain unmeasured. The costs to the wider society are potentially enormous and are already being seen and felt.' (Barnett & Whiteside, 2002, cited in Bray, 2003: 210).

> 'Children orphaned by AIDS will have no role models in the future and they will resort to crime to survive.' (Grimwood, 2001, cited in Schonteich, 2001: 3)

> '…they are juvenile delinquents, potential rebels. What future do they have? What future do we have?' (Hunter, 1990, p683, cited in Bray, 2003:683).

Rachel Bray (2003) points out that most of these generalised findings and 'apocalyptic predictions' are based on dubious evidence and that they are not only unfounded but ill-considered. She argues that the misrepresentation of the problems faced by children distracts attention from the very real traumas children experience and precludes analysis of the consequences of orphanhood that matter most to children themselves. It also has negative unintended consequences for the way in which the crisis of AIDS orphanhood is conceptualised and investigated. Rather than *addressing* stigma, the labelling of AIDS orphans as delinquents and criminals by professional researchers and policy makers merely serves to reinforce and perpetuate the stigma experienced by children at community level. These sorts of perceptions are like self-fulfilling prophecies, in that they create an inherently exclusionary society in an attempt to dominate and control a group of children regarded as a potential threat. Bray uses research with street children in different contexts to show that children without an obvious care-giver or role-model are not more prone to violent behaviour – *unless* they live in communities that exclude, abuse, condemn and abandon them. She extrapolates from this data and suggests that it is not the fact of orphanhood which constitutes a threat but, rather, the way society constructs

and deals with the 'problem' of parentless children. Bray's work makes an important intervention. It re-locates the emphasis of responsibility for outcomes away from children themselves and onto society as a whole.

The emphasis on orphanhood in academic literature and popular media has been counterproductive for other reasons as well. Firstly, it tends to exclude the fact that children living with caregivers who have HIV/AIDS experience many negative changes and can start to suffer neglect, including emotional neglect, long before the death of a parent or caregiver. The focus on AIDS orphans undermines the plight of children whose parents are infected with the virus but are still alive (Fox, 2002; Kelly, 2001; USAID, 2001). The impact of living with HIV/AIDS infected parents is further discussed in a later section of this paper.

The term 'AIDS orphan' contributes substantially to the labelling and stigmatisation of children whose parents have died of AIDS, as opposed to other causes. A USAIDS report to congress, therefore, suggests that programmes should avoid singling out children orphaned by AIDS as it exacerbates the stigma attached to HIV (USAID, 2001). In any event, it is difficult, and indeed inappropriate, to determine eligibility for assistance on the basis of the specific cause of parental death (Foster & Williamson, 2000).

It has also been pointed out that in societies where fostering is prevalent, the focus on the concept of AIDS orphanhood may be reifying the concept of orphanhood and unnecessarily increasing the amount of stigma attached to HIV/AIDS. In African countries, the extended family remains the predominant caring unit for orphans, and fostering by non-relatives is uncommon (Ankrah, 1993; Caldwell, 1997; Ntozi, 1997). However, children who are fostered by relatives are not necessarily orphans. In Tanzania, less than one-quarter of children being fostered by relatives were orphans.

Finally, it remains to be pointed out that, while children with HIV infected parents are especially vulnerable to the impact of HIV/AIDS, there are many other children who are affected by HIV/AIDS, both directly and indirectly. The loss of *any* primary caregiver to HIV/AIDS is equally significant to those many children who are not living with their parents in the first instance. Moreover, as the epidemic takes hold, the services and structures that exist to provide a safety net for all vulnerable children, regardless of the source of vulnerability, are becoming strained and over-whelmed (Foster & Williamson, 2000).

While the stereotypical images of AIDS orphanhood being created and projected evokes strong emotions of pity, they also evoke aversion, fear and moral panic. Bray suggests that the orphan discourse could easily fuel the impulse to segregate and exclude such children. We need to avoid well-intentioned labels

of vulnerability that stand to single out children, position them in a state of abandonment, and influence the course of their lives forever.

The Focus on Financial Deprivation

Research studies exploring the needs of children usually present the material or financial needs of children as the most pressing (Ali, 1998; Gilborn *et al*, 2001; Segu & Wolde-Yohannes, 2000). Indeed, children themselves will tend to identify money to buy food, clothing, etc. as their most urgent need (Kelly, 2001). However, this is not always in case, especially when children are given the time and space to also express their emotional needs:

> 'My sister is 6 years old. I must look after her…. There are no grown-ups living with us. I need a bathroom tap and clothes and shoes. And water also, inside the house. *But especially, someone to tuck me and my sister in at night-time.*' (Apiwe, 13 years old, National Children's Forum on HIV/AIDS, 2001).

It is by now commonly accepted that HIV/AIDS has a disproportionate impact on poor communities (Geballe & Gruendal, 1998; Taylor *et al*, cited in Wild, 2003). AIDS morbidity and mortality also have a significantly greater negative impact on household economies than other terminal illnesses, both during the prolonged course of AIDS illness and when adult bread-winners die. (Bharat, 1999 cited in Verma *et al*, 2002; Muchiru, 1998; Giese *et al*, 2002). Since HIV/AIDS illness is generally prolonged, children are all too often left destitute, and it is for this reason that they are at high risk of abuse and exploitation at the hands of others (Cook, cited in Wild; McKerrow, 1995). While welfare provision in the form of financial grants for those fostering AIDS orphans is an important and vital way to address the needs of orphans, this money does not necessarily reach the orphans for whom it was intended. Indeed, it has been argued that, as a result of welfare provision, orphaned children are increasingly being viewed as an economic asset to be cared for nominally as a means of provisioning households already under financial stress (Loening-Voysey, 2002). The economic abuse of AIDS orphans, such as the theft of their worldly goods and homes, has also been highlighted:

> 'If we do not get to the children within eight hours of them being orphaned, they loose their possessions and homes to neighbours who come in and evict the children…' (Director of a home-based care programme in Mpumalanga, cited in Loening-Voysey, 2002:4).

Given the overwhelming financial crisis most orphans face, the psycho-social impact of HIV/AIDS on children has generally been neglected, and programmes have tended to focus specifically on providing for the material needs of children rather than on counselling or other forms of emotional support (Foster & Williamson, 2000; Fox, 2002).

Family Health International (2001) also describes psycho-social support as one of the most neglected areas of support for OVCs. Certainly, the majority of UNAID-funded activities to reach children which have been implemented thus far (such as the Save the Children/Cope project in Malawi and the CRS Safety Net project in Rwanda) have attempted to distribute food, clothing and school fees (USAID Report to Congress, 15 March 2001).

According to Daniel (2003) the lack of psycho-social support for orphans in Botswana is not just because financial security is of paramount concern. Rather, this is because it is difficult to find workable means to deal with emotional trauma or what she calls 'hidden wounds'. She argues that a selective defining of the situation of OVCs by those around them denies the pain and suffering OVCs experience. As a result, children are not only left wounded by emotional loss, but by the fact that these emotional wounds are ignored and hidden, so that the rest of the community does not have to see them or face the consequences (Daniel, 2003).

Comparative studies on HIV/AIDS orphans and non-orphans do seem to suggest that orphans suffer significantly more hunger than non-orphans (Makame, *et al*, 2002; Manual *et al*, 2002). However, one of the studies which employed a comparative approach conducted by Lucie Cluver (2003) found that orphans are not in fact necessarily more vulnerable or disadvantaged than other children in equivalent contexts. This begs the question of the extent to which AIDS, in and of itself, is or is not the main contributing factor to children's financial vulnerability in situations of endemic poverty. It is suggested that children's vulnerability is rooted in the social and economic dynamics of poverty, regardless of whether they have been directly affected by AIDS or not (Giese *et al*, 2003; Whitehouse, 2002).

Researchers and practitioners need to recognise the substantial role which endemic poverty plays in shaping the experiences of OVCs, rather than laying blame entirely on the HI virus alone. This is of importance for addressing the *psycho-social* as well as the *economic* needs of children. There is a growing literature on the impact of poverty, in and of itself, on children's psychological development (Brooks-Gunn *et al*, 1997; Fitzgerald, Lester & Zuckerman, 1995; Rogers & Ginsberg cited in Dawes & Donald, 1994)**.** This should be brought to

bear on interventions addressing not only the material wellbeing, but also the psychological and emotional needs of OVCs.

Those involved in the psycho-social support of children affected by AIDS need to acknowledge poverty, as well as the fact of orphanhood, as a primary psychological stressor. In addition, psychological support interventions cannot be effective without at the same time lessening the urgent material needs of OVCs.

As mentioned previously, Loening-Voysey (2002) draws attention to the failure of the State to take care of the basic material needs of South Africa's OVCs, and calls for a detailed analysis of state functions. According to Loening-Voysey, children in general, and OVCs in particular, are suffering most from overall budget cuts, despite the fact that President Mandela signed the Convention on the Rights of the Child in 1996. He argues that it is not only poverty, but also inefficient state services, which thwart efforts to manage the plight of children affected by AIDS.

> 'The reference team at the start of the study on approaches to the care of OVCs identified poverty and [lack of] political leadership as being the critical stumbling blocks to quality care for OVCs'. (Loening-Voysey, 2002).

Section Two

Research Regarding the Psycho-Social Impact of HIV/AIDS on Children Affected by HIV/AIDS

Empirical research regarding the psychological *impact* of HIV/AIDS must be distinguished from research regarding the psychological *adjustment* of children affected by AIDS. Before outlining research regarding either of these topics, however, it is necessary to briefly indicate the limitations inherent to empirical research regarding the psycho-social needs of OVCs.

Limitations of Empirical Research Findings

Despite the huge emphasis on AIDS orphans and their potential to create a lost generation of dysfunctional and delinquent South African youth (Bray, 2003;

Burnett, 2000), many authors have noted that the psycho-social adjustment of orphans and other vulnerable children is seldom highlighted as a priority for research and intervention funding (Bray, 2003; Foster, 1997; Geballe & Gruendal, 1995).

There are no published empirical studies on the grief reactions of AIDS orphans prior to 1994 (Siegel & Gorey, 1994). Wild's extensive search found six unpublished studies which appeared from 1995 onwards investigating children whose parents are HIV positive, have AIDS, or have died of the disease. However, only one of these studies was conducted in Uganda, Africa, with the rest in the USA. Other published studies described in Wild's review include some discussion of psycho-social issues, as part of a broader investigation of the circumstances and experiences of AIDS orphans, but have not been devoted to this area of study.

The vast majority of existing research is cross-sectional, with only one study by Forehand *et al* (1999) adopting a longitudinal approach assessing children over time. Most studies have lacked a control (comparison) group comparing the adjustment of children affected by AIDS with that of unaffected children from the same community. The need for control groups cannot be overemphasised. AIDS orphans may exhibit levels of psychological difficulty which on first appearance seem high but, on further investigation, are in fact standard for non-orphaned children living in equivalent socio-historical contexts.

Clearly, those research findings from first world contexts (such as the USA) which do exist cannot be generalised to the African context. This review will therefore focus on African research. It must be noted, however, that there is a danger in assuming that findings from studies conducted in Africa are relevant in all African contexts. Clearly, this is not the case. There are different cultural, social and economic contexts within cities, as well as across countries or continents. Equally importantly, the fact that research is conducted in an African setting does not mean that it is not designed using Western psychological norms. The appropriateness of many of the standardised psychological scales used in most of the studies under review remains to be assessed.

It is difficult to compare findings across the available research, given the variety of methods used – from ethnographic interviews to quantitative psychological assessment measures. Wild therefore concludes that 'at present, knowledge about the psycho-social adjustment of AIDS orphans is based on an intermingling of sound data, less reliable data and clinical observation, and is therefore somewhat less secure than might appear at first glance' (Wild, 1993:8).

Despite methodological limitations, there is nonetheless sufficient data available to give us a fairly good picture of some of the major stressors facing children affected by HIV/AIDS. Perhaps the most disappointing aspect of available empirical research is how little it tells us that are not obvious to anyone with experience working in the field.

Psycho-Social Stressors on Children Affected by HIV/AIDS

> 'When the mother dies, the children struggle. They begin to suffer. They don't become teachers, nurses, or doctors. They just become dead men walking on the streets.' (Boitumelo, 9 years old, National Children's Forum on HIV/AIDS, 2001).

The sickness and death of a parent is clearly a major trauma for any child. There has been limited attention given by empirical social science researchers to children's experience of parental illness and death in general (Lewis, Hammond & Woods, 1993; Roy, 1990), let alone with regard to HIV/AIDS more specifically. Altschuler (1997) points out that the belief that childhood should be a safe-haven makes adults unwilling to recognise pain and confusion in children. He argues that this is as true of researchers as it is of anyone else (cf. also Daniel, 2003).

Elisabeth Lewis's (2001) book on the needs and views of young people living with HIV/AIDS in supported housing in London is particularly commendable for the attention given to research methodology. Gaining informed consent to do research from young people is an important ethical concern in research of this kind, and Lewis provides useful examples of the verbal explanations given to children before interviews. The children's interview guide takes the form of interactive games designed to focus conversation on a series of topics in a non-obtrusive way.

 If the process of living with HIV/AIDS and grieving is more difficult for children affected by AIDS and AIDS orphans, then this is perhaps not so much because AIDS is 'unique' as terminal illnesses go but because it is complicated by a set of material and psycho-social stressors which tend to correspond with HIV/AIDS. In this section, the main reasons why parental AIDS morbidity and mortality are thought to have a different or more severe effect on the psychological well-being of children as compared to other terminal illnesses will be briefly summarised (The importance of poverty as a primary psychological stressor in the context of HIV/AIDS has already been highlighted).

Parenting With a Terminal Illness

Parenting capacity is likely to be compromised for any parent suffering from a terminal illness. Denial, anxiety, depression and anger are common reactions in people diagnosed with HIV/AIDS (Nagler, Adnopoz & Forsyth, 1995). Parents may alternate between overprotecting their children in an effort to compensate then for their future loss and distancing themselves from their children as a way of reducing the intensity of that loss (Taylor *et al*, 1999). As parents become sick, normal parent-child roles may be reversed, as older children take care of the ill parent and assume household and childcare responsibilities (Smart, 2000; Wild, 2003). According to Smart, this 'parentification' process is associated with increased social isolation. A very common experience described by children is the constant worry about going to school and leaving their parents in case they die alone. Children also described worrying about their futures once their parents die (Save The Children report on Participatory Workshops, 2001; Smart, 2000).

Witnessing an HIV/AIDS Death

The clinical course of HIV/AIDS is uncertain, and there is a period of prolonged illness before death occurs. Children with parents infected with AIDS are likely to experience more disrupted routines and more periods of informal fostering than other children who have parents with a terminal illness. With most AIDS care in the home, children are often present during the final stages of their parent's illness (Van Dyd, cited in Cluver, 2003). They usually have to witness or nurse parents through profound and debilitating sickness including the loss of bodily functions (Andiman, 1995; Dane, 1997; Geballe *et al*, 1998).

The Psychological Impact of Death

Apart from grief at the death of a parent, Fox (2002) identifies fear, insecurity and hopelessness as additional emotional traumas experienced by children confronting the death of their caregivers. A child's sense of security is deeply undermined by the loss, or imminent loss, of a caregiver. This is augmented by the failure of those around to explain the situation, leaving children to reach their own conclusions about what is happening. Inability to understand and make sense of a grief experience can undermine a child's sense of safety just as much as the actual loss involved. A sense of hopelessness and despair is a natural reaction to loss. In the case of children, such despair may be compounded by the inability to express fear and grief effectively.

Multiple Losses

Common reactions of children to the death of a parent include depression, hopelessness, suicidal ideation, loneliness, anger, confusion, helplessness, anxiety and fear of being alone (Aronson, 1995; Foster *et al*, 1997; McKerrow,

1995; Sengendo & Nambi, 1995; Williams and Stafford, 1991). In addition, children who lose one parent to AIDS are at risk of losing their other parent and/or younger siblings to HIV/AIDS. When one parent dies, a child may live in constant fear that the remaining parent or substitute caregiver could die too. Apart from their parents, these children will in all likelihood be exposed to other HIV/AIDS related and non-related deaths (Dane, 1997; Hudis, cited in Wild).

Such losses are compounded by the fact that, subsequent to parental death, orphans are often sent to different households, separated from their siblings, and relocated away from schools and friends (Dane, 1997; UNAIDS, 2002).

Stigma

Arguably, it is the stigma attendant upon HIV/AIDS which makes AIDS orphans experiences a qualitatively different set of traumas and long-term effects from those who lose parents to other illnesses (Bray, 2003). Stigma is the primary cause of social isolation, a sense of shame and a lack of emotional and financial support after the death of a parent from AIDS (UNAIDS 2002). Stigma results in what has been described as 'social' death, which affects children long after their parents, are gone:

> 'Children have a lot of problems in the communities. When your family member passes away, they say that you are also dead or that you'll also die.' (Thandi, 15 years old, National Children's Forum on HIV/AIDS, 2001).

It seems likely that it is stigma which is the root cause of governmental as well as social and community neglect of OVCs. Daniel, who studied orphans in Botswana, argues that stigma undermines government's efforts to provide a basic safety net for AIDS orphans. Some orphan families studied by Daniel (2003) have chosen not to receive relief services (food and clothing benefits) in order to avoid the associated stigma attached to such welfare benefits. Other researchers also highlight the fact that families may cut themselves off from social support networks long before death occurs in order to avoid disclosure and stigma (Nagler *et al*, 1995).

The role of stigma and discrimination in increasing the vulnerability of OVCs is highlighted in a Save the Children report (2001) describing extensive participatory research workshops with HIV positive children in South Africa, as well as children whose caregivers live with HIV/AIDS.

Researchers used a variety of research tools, including drawing and allowing children to talk about the impact of HIV on a fictitious family if they so chose. This psychological technique was used in order to give children a protective

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distance from which to tell painful stories. Corroboration of stories elicited in this way was gained by interviewing counsellors working with these children.

Findings from this study show that orphaned children face discrimination within their own families as well as in their communities, churches and schools, both before and after the death of their parents. Such discrimination is often based upon fears that the children of those infected with HIV may be infected too. However, children vocalised other forms of discrimination that were not related to fear of infection. For example, those living with extended family generally reported that they were expected to work harder, and that they tended to have less access to food, school fees and emotional support.

The researchers point out that many children refused to discuss how they are treated by family. They suggest that this is probably because discrimination from family members is often a topic too painful to discuss.

Children asked to tell stories often described being teased by other children:

> 'This child is at a party. Other children are happy. …They say he should go back home, they don't want him. He is crying.'

While the innovative techniques used in the National Children's Forum participatory research on stigma yielded rich findings regarding the impact of HIV/AIDS on children, these findings were not corroborated by another, more recent study conducted by Cluver in 2003. Cluver's standardised psychological assessment tools found no significant difference in overall peer problems between AIDS orphans and non-orphans. However, she found significant differences on the single item 'I have one good friend or more'. Her findings show that 97% of orphans perceive themselves as having no close friends.

Despite her mixed findings, Cluver (2003) argues that HIV/AIDS stigma in South Africa is such that it influenced her ability to investigate the psycho-social impact of AIDS on orphans in the first instance. Aware that few children are actually told the cause of their mother's death, she did not mention HIV/AIDS at any point during her research and HIV/AIDS was not mentioned on any information sheets, consent forms or questionnaires. The word AIDS was also removed from the study title whilst the research was taking place.

The children in South Africa involved in the National Children's Forum participatory workshops on stigma had been given little previous opportunity to express their grief, despite the effects of unexpressed grief on children's development (O'Toole, 1989, cited in Save the Children report on participatory stigma workshops, 2001). Given the opportunity to speak about stigma, these

children indirectly expressed the grief they had experienced when parents had been ill or died:

> 'Please can I have a doll and a dummy for my doll, because then I can play with my doll in my mother's room and near her grave. The doll will be my friend because I don't have friends because they say I am dirty.' (Busiwe, 7 years old, National Children's Forum on HIV/AIDS, 2001).

Section Three

Predicting the Consequences of HIV/AIDS on Children's Psychological Adjustment: Delinquency or Depression?

Nine studies regarding the impact of HIV/AIDS on OVCs' psychological adjustment in Africa were considered in this review. Available descriptive studies suggest that AIDS orphans show heightened levels of *internalising* problems such as depression and anxiety. For example, a Zambian study has found that changes in children's behaviour following AIDS-related illness in parents were related to loss of self-esteem rather than decreased sociability. Orphans were found to 'exhibit internalised behaviour changes such as depression, anxiety and low self-esteem *rather than* acting out and sociopathic behaviour such as stealing, truancy, aggression and running away' (Forsyth *et al*, cited in Foster & Williamson, 2000: 282; Kirya, 1996). There is some evidence from other such studies that AIDS orphans do show elevated levels of externalising or acting out of their problems. However, this finding was limited to two out of the nine studies considered during the course of this review.

Five out of the nine studies conducted in Africa (two of which are unpublished) had control groups, and compared the psycho-social adjustment of AIDS orphans with that of non-orphaned children from the same community (Cluver, 2003; Makame *et al*, 2002; Manual *et al*, 2002; Sengendo and Nambi, 1997; Wild, 2003). All of these studies suggest that AIDS orphans experience significantly more depression than non-orphans.

These findings are not surprising when considered in relation to other available research regarding orphans in general, as opposed to that relating to HIV/AIDS orphans in particular. General research on orphanhood from any cause suggests that orphanhood does not result in conduct disorders and delinquent behaviour,

but rather in depression, anxiety, somatisation problems and symptoms of post-traumatic stress-disorder (Gersten *et al*, 1991; Stoppelbein & Greening, 2000; Worden, 1996).

Apart from depression, there is also evidence from Cluver's (2003) Cape Town study to suggest that AIDS orphans exhibit post-traumatic stress-disorder type symptoms, including emotional detachment, difficulty in forming close relationships and difficulties in concentration. One of the most interesting findings from Cluver's study concerns higher levels of reported somatisation in orphans than non-orphans, as compared to equal levels of reported emotional distress. Although AIDS orphans did not report higher levels of distress, they were significantly more likely to report stomach-aches, headaches or sickness than non-orphans. Ensinck *et al* (1999, cited in Cluver, 2003) have pointed out that black South Africans tend to internalise psychological distress through somatic complaints, and that somatisation is a culturally appropriate measure of emotional distress in an African context.

The literature cited above substantiates Bray's argument that there is little research evidence to suggest a link between the long-term effects of AIDS orphanhood and rising rates of juvenile delinquency. Foster and Jiwli (2001) also argue that it is difficult to make predictions regarding the impact of AIDS on children. A detailed review of the literature makes it clear that there is no evidence whatsoever to suggest that the presence of high numbers of AIDS orphans could be precipitating social breakdown.

Prior to the AIDS epidemic, the only studies relating to the impact of large orphan populations on society were from genocide and war-related events. Clearly, these are of limited application insofar as war-related death is not stigmatised, and wars, however prolonged, do have a foreseeable end. By comparison, AIDS orphanhood is heavily stigmatized and high rates of orphanhood from HIV/AIDS are likely to persist indefinitely (Foster & Jiwli, 2001). The fact remains that there are also no historical precedents regarding large orphan populations in Africa to suggest that they present the kind of social threat currently being envisaged. In fact, available longitudinal research suggests that, on the contrary, such children have been integrated despite huge economic constraints and have grown up without causing long-term strain or damage in their communities (Charney, 2000; Hunter, 1990: 683).

If the mythical link between orphanhood and delinquency is nonetheless so unquestioningly accepted in AIDS literature, then this is probably because parentless children threaten norms regarding appropriate care and control (Bray, 2003). This relates especially to children who live in child-headed households and therefore appear to survive without adult authority. Griffin points out that, if

the family with parents is seen to be so 'good', then this is based less on evaluations of child-care arrangements than it is on the need to organise and control the way society deals with its young (Griffen, 1993, cited in Dimmock, 1997).

Section Four

Disclosure to Children: Death and the Culture of Silence

Only one research study was found which compares levels of anxiety in children who are told that their parent has a terminal illness with those who are not told (Rosenheim & Reicher, 1985). Those children who were informed of their parent's terminal illness showed significantly less anxiety than children who were *not* told. The authors note that uninformed children, although they have not been explicitly told, nonetheless are seldom wholly oblivious to the terminal nature of the parent's disease.

Unpublished research being conducted in Khayelitsha by the AIDS and Society Research Unit of the Center for Social Science Research (UCT) suggests that mothers will invariably delay disclosure, on the grounds that children are too young to understand the nature of HIV/AIDS. Mothers also argued that disclosure is not in the children's best interests. Certainly, the decision of many parents to delay disclosure to children is understandable, given the multiple difficulties attached to an HIV diagnosis. Not least among these is the stigma attendant upon the disease and the fact that parents may fear the impact of this stigma on their children. In the absence of full public disclosure, telling children implies asking them to keep a secret that will weigh heavily (Soskolne, Stein & Gibson, 2003).

The only African study found specifically concerning disclosure to children was conducted by Marcus (1999) in KwaZulu-Natal, South Africa. Marcus found that children are frequently excluded from discussion about both the imminent and recent death of a parent, on the grounds that death is only an appropriate topic for adults to discuss. The idea that 'children are too young to understand' is almost universally accepted as a valid reason for ongoing silence regarding parental death.

The reasons given for not talking to children in Marcus's (1999) South African study were that children would be upset, would not understand, would not know

how to cope and would not benefit from knowing. The following quotation from Marcus's research exemplifies this understanding:

> 'It is better for a child to see for itself when the coffin arrives what is going on, rather than to tell her that her mother is dying.' (*ibid.*)

While silence and exclusion remain the norm, Marcus argues that a sizeable number of participants in KwaZulu-Natal argued, to the contrary, that AIDS orphans aged five and over *should* to be told about the death of their parents. However, some of the quotations Marcus uses to illustrate what she argues are a well-intentioned willingness to talk to AID orphans do not, in fact, indicate a sympathetic attempt to help these children deal with their grief. Rather, they seem to indicate that those adults who advocate honesty with AIDS orphans may be more concerned to ensure that these children accept subsequent compromises in their care arrangements without causing any trouble:

> 'It is important for the child to know because should he encounter problems, he must be aware it is because he is an orphan and he can't compare himself with children who have parents. He must not expect anything because he has no parents to defend him.'

> 'It is important for the child to know so that he can respect the people that he lives with. That will prevent him from doing things wrong and expecting to be rescued by me.' (*ibid.*).

Marcus argues that these quotations show a progressive change in attitudes towards discussing death with children. What these quotations also make clear, however, is that there is an expectation that children orphaned by HIV will need to learn to live without any expectation of parental love and protection and should respect their surrogate parents while nonetheless expecting less than other children. It is unlikely that this sort of approach to dealing with parental death will help children overcome their grief. Arguably, by comparison, silence regarding parental death is at least intended to be protective.

Other academic literature regarding disclosure of an HIV/AIDS diagnosis to children suggests that interventions attempting to convince adults to talk to children about death should not underestimate the strength of cultural norms in this regard. However, some authors have noted that culture is frequently invoked as an excuse for silence regarding death. In fact, silence around death is typical of most societies and is not limited to dealings with children. According to Williamson (2000), taboos in this regard are so strong that, in some instances, a person who talks to another about their impending death lays themselves open to accusations of witchcraft.

Daniels (2003) argues that the failure to discuss death and dying with children is expedient avoidance behaviour on the part of adults, designed to avoid the difficult and frightening task of explaining death to children. Brouard (quoted in Stein, 2000) also suggests that lack of disclosure has less to do with the need to protect children than the need to protect adult caregivers:

> 'We need to ask ourselves: Is the desire to protect the child because it's right for the child. Or does it reflect our own inability to deal with death?'

Clearly, it takes courage to talk directly to children about death. Practitioners should not underestimate the psychological, emotional and practical difficulties attached to the task of disclosure to children. Resistance to disclosure with children needs to be understood and respected before it can be addressed.

Differences in attitudes about what can and should be shared will inevitably arise between professionals and families, and these should be negotiated with the utmost respect. This includes responding to worries about the distress that may be invoked when information regarding terminal illness is shared with children (Altschuler, 1997).

In a press article about disclosure, Stein (2000) points out that parents who disclose to their children are an exception and that many counsellors themselves advise parents and caregivers to wait until such issues are raised by children themselves.

While any parent would feel guilt and anxiety about 'abandoning' their children when they die, Lewis (2001) argues that it is the stigma associated with AIDS, rather than its nature as a terminal or chronic disease, which often underlies non-disclosure to children. She argues that parents need to be empowered to deal with feelings of guilt and shame when discussing HIV with their children.

For parents to disclose to their children is perhaps the hardest disclosure of all. By comparison, disclosure to friends, family and even partners is relatively easy. Yet there is little external support available to parents attempting to disclose to children (Fox, 2001). According to Fox, projects like the Memory Box are invaluable in this regard:

> 'Children can see that things are changing at home and while they may not completely understand the implications, it can make them feel anxious, guilty, depressed and misunderstood. They may not

want to upset the situation further or may feel overwhelmed and internalise their emotions.' (*ibid.*).

Fox (*ibid.*) also points out that, while the issue of death cannot be avoided altogether, the best way of assisting the children of those with HIV/AIDS is to prolong the parent's life by promoting positive living and the physical and emotional well-being of the parent. At the same time, however, the inclusion of children in the process of coming to terms with an HIV diagnosis is critically important. Without genuine and clear communication regarding their situation from adults, children are left feeling increasingly isolated and alone. Practitioners and professional psychologists argue that the ability of children to resolve their losses is greatly enhanced if children receive accurate information on their situation from adults, and if they are allowed to participate in grieving. Once death is imminent, discussing it with a child prevents rather than increases anxiety and distress. A supportive environment can allow a child to begin the grieving process before the actual death (Bowlby, 1995; Jewett, 1994). Discussion allows children to prepare themselves for what lies ahead and gives them the confidence to grieve a parent's death. Allowing children to say goodbye and exchange wishes and thoughts regarding death is healing and leaves less 'unfinished business' for children to manage subsequent to death.

Consultation with young people in South Africa suggests that children feel betrayed when they are finally told about a parent's HIV infection in adolescence or late adolescence, even if this disclosure occurs prior to illness or to the death of the parent. The failure to disclose until a child is felt to be 'old enough' implies a lack of sharing and trust that can undermine or even substantially damage parent-child relationships (Avert, 1999, cited in Lewis, 2001).

Lewis uses her extensive research regarding children living with HIV infected parents in London to make a useful distinction between children with 'full' and 'partial' knowledge of a caregiver's HIV infection. Clearly, the complexities of disclosure of HIV results in *degrees of knowing*. What is striking about Lewis's interviews with parents is that, while most initially said their children did not know about their illness, this was usually not really the case. In reality, it is often only the label of 'HIV/AIDS' that is withheld, in order to avoid the stigma associated with the disease:

> '…the word is scary and you know, it might be blown out of context if he hears the word and then associates it with home. You have to give them some sort of explanation, I feel that definitely. Without the label; without the word; you can still give them explanations.' (parent cited in Lewis, 2001: 36).

Lewis argues that children with limited or partial knowledge experience additional distress when full explanations for parental illness are not provided. Altschuler (1997) also argues that children learn to observe their parents, to recognise fear and uncertainty, and to recognize when to remain silent. As a result, they may 'act out' fear, anxiety and anger rather than give it a voice. He also argues that regardless of whether they are told or not, children become aware of impending death and may try to bargain with fate by promising to 'be good'.

It is important to recognise that knowledge of an HIV diagnosis and what that means is not, in and of itself, sufficient information to impart to children. Having knowledge about an HIV infection, and HIV/AIDS in general, does not necessarily mean that young people have either full understanding or full involvement in the illness within their family. Lewis therefore argues that it is a mistake to view 'telling' or 'disclosure' as intrinsically beneficial, and that understanding and coming to terms with parental HIV/AIDs is a gradual and unfolding journey.

In some cases, however, children, like adults, may not in fact want 'full' knowledge. Melvin (cited in Lewis, 2001) points out that 'a few children give very definite signals that they don't wish to know and care must be taken to respect their wishes too.' When children do not react to disclosure as badly as would be expected, they are often protecting themselves from a hurt that is too painful or deep for them to manage. Inappropriate reactions on the part of children are attempts to distance themselves from the pain of loss.

On the other hand, parents who disclose to their children need to be reminded that if their children do not continue to ask questions about HIV/AIDS, then this may not be because they don't want to know. Indeed, many of the children studied by Lewis are quite clear that if they do not discuss HIV, then this is to protect their parents rather than themselves:

> 'Because she'll [mother will] end up in tears. Because she always does if I bring up the subject…' (Claudia, 10 years old, National Children's Forum on HIV/AIDS, 2001).

Preparing a child for the death of a parent is very painful for everyone concerned. The most important benefit is that it gives the child and parent time to share what they need and want to share. This may well be the basis for healing after the death of the parent (Mallman, 2002).

Practitioners working with children in South Africa interviewed by Stein (2000) were unequivocal that children, including those who are HIV positive themselves, need to understand what is happening to them. Stein (2000) suggests that the trauma a child experiences around the issue of death has as much to do with the way caregivers deal with it than anything else. Tanchel (quoted in Stein, 2000) argues that children need to be supported through, rather than protected from, illness and death: What is most frightening for children is "when they know something unspoken is terribly wrong."

Section 5

Children's Conceptions of and Responses to Death and Dying

Professional psychological knowledge about bereaved children has largely been developed in a western context (Kessen, 1979). There is a wide literature available in this regard, although most of it is not HIV specific (Dyregrov, 1990; Jackson, 1972; Krementz, 1981; Mallon, 1997; Pennels & Smith, 1998; Ward & Associates, 1996). This modern theoretical understanding of child psychology and bereavement is being increasingly exported around the world despite the fact that communities in developing countries have their own understandings of childhood and of the natural rights of children and may have different assumptions about what is best for children (Boyden, 1990). Clearly, it is important to develop models relevant to the contexts that characterise the southern African region. However, it would be foolish not to incorporate knowledge and experience that has universal applicability.

Most practitioners follow Elizabeth Kubler-Ross (1983) in believing that children do have an inner knowledge of death. However, it is also generally accepted that children's understanding of death is age dependent. (Boyd-Franklin, 1995; Furman, 1974; Jewett, 1994; Mallman, 2002). Helping parents and caregivers to understand their children's probable reactions to death will enable them to respond appropriately. In this section, points made in the literature in this regard will be summarised.

The fact that infants have no concept of death and cannot understand what has happened to their absent parent does not mean that they do not miss their parent (Mallman, 2002). Up until the age of three or four a child may well equate death with abandonment, thinking that the dead person does not want them any more.

They often assume that dead people can reappear, which is disconcerting to adults.

Between the ages of 3-7, children are in the stage sometimes called the phase of 'magical thinking'. During this phase, children believe they have control over what happens in their lives. This usually helps them to cope with fears and worries, but it may also make them feel guilty if they believe that their own thoughts, wishes and actions are what caused the death of their parent (Fox, 2002). By the same token, a child may believe that if they are 'good' enough, then perhaps the parent will not die, or a deceased parent will return.

In coming to terms with the concept of death, children at this age may show a great interest in the process of dying. They will want to know how and why a person died: all difficult questions to answer. Children are also interested in what will happen to the parent after he or she has been buried. They will need to understand concepts of what happens to a person after death, (heaven, ancestors, re-incarnation), according to a families culture and religion. In this regard, parents and caregivers working with children need to be sure of what they themselves believe. However, they should be aware that children with a spiritual belief system find it easier to give a deeper meaning to their loss. Allowing children to take part in rituals after death and attend the funeral are all helpful (Altschuler, 1997). Children coming to terms with death will start to play sickness and death games with other children. This is a normal process of trying to come to terms with a death and encourages healing. Maintaining 'contact' with a deceased parent is also helpful. Talking about the dead parent, having some of their belongings, regularly visiting the grave etc, helps children maintain their sense of connection and identity.

Children who are old enough to understand that death is final are severely affected by death, but may nonetheless have difficulty expressing this. The danger that their emotions of grief will be repressed is extremely real, such that grief manifests as insomnia, ill health or regressive behaviour (Boyd-Franklin, 1995).

All children may show signs of regression (including, for example, bed-wetting) caused by a sense of abandonment, vulnerability and helplessness. Mallman (2002) provides a variety of techniques for dealing with sleeping difficulties, nightmares, bedwetting, intrusive memories, hyperactivity, aggression and other problems which may be encountered during the grieving process. The games she outlines to help children relieve tension and cope with frustration are particularly useful. Mallman points out that, unlike adults, children grieve inconsistently, such that their grief appears to come and go. She also points out that some children try to avoid dealing with the death of their parents. They do

not want to think or talk about their parents and may prefer to live in their own fantasy world. In Cluver's (2003) research with orphans of HIV positive mothers in Cape Town, children were asked to draw pictures of who they live with. Of the 28 children involved, 6 included their dead mothers in their pictures.

Altschuler (1997) looks at the impact of chronic illness on children and argues that witnessing physical deterioration in the bodies of those they rely on impacts heavily on children's hopes and expectations, and on their trust and confidence in those who care for them, and may even alter a child's own body image. Witnessing a parent in pain can have a profound impact on how children make sense of their lives, influencing their hopes and expectations for the future. The uncertainty surrounding illness evokes many emotions which children cannot name or label. These include fear, anger, resentment, shame and, quite often, fear of personal responsibility.

Segal (1984) argues that bereaved children exhibit one or more of the following behaviours:

- denial of trauma
- guilt and blame
- internalising or acting out anger
- repressed feelings
- obsession with fear of further loss
- search for immediate ways of regaining control over their lives.

Interventions with Bereaved Children

Mallman (2002) points out that children cope better with adversity when they have three capabilities:

- the capability to understand an adverse event
- the capability to believe they can cope with a crisis
- the capability to give deeper meaning to an adverse event.

She suggests that a child's inner resources can be developed in a wide variety of ways. This includes:

- increasing a child's ability to express emotions in words and actions
- increasing a child's autobiographical memory in order to facilitate their recall of positive relationships etc.

- increasing a child's sense of belonging within the community so that they are able to look for and find emotional support
- increasing a child's self-confidence
- increasing a child's ability to envision a future.

Altschuler (1977) makes some additional and equally useful points regarding the need to attend to a child's emotional understanding of illness and death. She argues that providing blanket reassurance is not the same as listening and providing a safe space to share thoughts and feelings. Children need to be not only repeatedly told, but *helped to understand* that they are not to blame for illness. Children often fear that their questions are too dangerous to ask, and must be provided with carefully chosen play and/or books as a tool to prompt them to talk about illness and death. More specifically, Altschuler suggests that, if given the space to do so, children will have questions such as:

- how did this happen?
- is this my fault?
- why couldn't I stop this from happening?
- have they done this to hurt me?
- will it happen to me?
- does it hurt?
- will she/he/I die?
- what happens when you die?

It is impossible within the confines of this literature review to summarise the scope of all the potential interventions with bereaved children described in international literature. Most of this literature involves working with children *after* the event of parental death. This is despite the fact that interventions *before* bereavement are especially important when parents have life-threatening illnesses (Black, 1991). Available resources regarding group work and non-verbal interventions with children include the work of Baker, 1991; Carrol, 1995; Davis, 1995; Fleming and Balmer, 1991; Hemmings, 1995 and Pennels & Smith, 1995.

Baker (1991) explores the therapeutic strategies of non-verbal communication in working with grieving children, and provides guidelines to help caregivers interpret drawings and other non-verbal responses. She argues that pictures are valid and dependable methods of communication with the unconscious and makes suggestions regarding the use of guided imagery (cf. also Carrol, 1995; Davis, 1995; Hemmings, 1995).

Fleming and Balmer (1991) and Pennels and Smith (1995) describe group intervention with bereaved children, and focus on facilitating strategies for encouraging and aiding the expression of children's reactions to parental death. They argue that group work not only provides a safe environment, but also allows children's grief to be validated and normalised. They suggest that children's groups fill an important void in the provision of support for children.

The Availability of Psycho-Social Support Facilities for OVCs in South Africa

Non-governmental organisations addressing the needs of children affected by HIV/AIDS are not as plentiful as one would expect, given the media attention devoted to the plight of AIDS orphans. A list of service organisations addressing the needs of children in South Africa can be found at www.childaidsservices.org. The vast majority of these are non-governmental. It is difficult to ascertain the number of those organisations listed which specialise in providing for the psycho-social needs of children with HIV/AIDS. Certainly, most of the organisations listed as providing counselling services are not, in fact, geared to deal specifically with children. An Eastern Cape study found few NGO's working specifically with children in distress. These organisations were found to be sorely lacking in capacity, and to have inadequate referral, follow-up and coordination systems (Bambisanani, 2001). Loening-Voysey (2002) argues that a primary function of the State is to provide information regarding the availability of services and to develop a system for registering them so that they can be networked, supported and subsidised.

Concluding Remarks

This review has attempted to highlight the gaps in empirical research and knowledge regarding children affected by HIV/AIDS. While a large body of literature on AIDS orphans exists, this has tended to function as a motivation for increased intervention with orphans, on the basis that an epidemic of orphans constitutes a threat to society as a whole. In this way, 'AIDS orphanhood' is conceptualised as a disease in itself. The premise that AIDS orphanhood results in delinquency needs to be firmly refuted as one which is not only ungrounded, but which serves to re-enforce the stigma associated with AIDS.

What little literature there is on the psycho-social needs of OVCs tends to focus on orphans and provide an overview of the multiple difficulties and traumas facing them. What this literature makes clear is that, of all the issues facing

AIDS orphans, the stigma associated with HIV/AIDS is perhaps the greatest obstacle to their future wellbeing. The empirical research that exists on the psycho-social needs of children seldom accesses the expertise of practitioners working in the field. By the same token, there is a need for interventions that have a more adequate research base (Dawes & Donald, 1994).

There is little available literature focusing on interventions helping children come to terms with the stigma they encounter as a result of HIV illness and death in the family. Given the critical importance of stigma as a source of trauma for children, as identified by Save the Children in particular, interventions geared to helping children cope with this specific aspect of HIV/AIDS should be urgently developed. In this regard, projects helping parents and children cope with an HIV/AIDS diagnosis will need to develop innovative methods to help children develop the resilience they will need to cope with stigma, both before and after orphanhood.

While there is a body of literature, mostly case-study based, regarding interventions helping children come to terms with bereavement in general, most of this material is gleaned from experience in a western context with children who are *already* orphaned, rather than on the needs of children whose parents are still living with a terminal illness. This is with the exception of memory box work being conducted in African countries such as South Africa and Uganda, which are geared specifically to the needs of mothers infected with HIV/AIDS.

Clearly, this model needs to be evaluated, developed and, most importantly, extended if disclosure to children, in preparation for the death of their parents, is to become normative in African society. If the rights of children to receive information and support in the face of impending orphanhood as a result of AIDS are to be upheld, then such interventions should become an integral part of service provision to affected families. In the absence of basic service provision addressing the material needs of OVCs, however, such interventions will be severely compromised. Psycho-social interventions must be grounded within a broader net of social service provision to OVCs. [2]

Service providers from the NGO sector will need to develop a strong and vocal advocacy approach, which highlights the inadequate response of governments and society as a whole to all vulnerable children in society, including, but not limited to, children affected by HIV/AIDS.

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[2] Through a partnership with USAID, the Nelson Mandela Children's Fund recently began to implement a five year project (called Goelama) to mobilise community support for HIV affected children. This project will implement and test approaches for meeting the needs of orphans and vulnerable children before rolling out successful programmes to new areas.

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The Aids and Society Research Unit (ASRU) supports quantitative and qualitative research into the social and economic impact of the HIV pandemic in Southern Africa. Focus areas include: the economics of reducing mother to child transmission of HIV, the impact of HIV on firms and households; and psychological aspects of HIV infection and prevention. ASRU operates an outreach programme in Khayelitsha (the Memory Box Project) which provides training and counselling for HIV positive people

The Data First Resource Unit ('Data First') provides training and resources for research. Its main functions are: 1) to provide access to digital data resources and specialised published material; 2) to facilitate the collection, exchange and use of data sets on a collaborative basis; 3) to provide basic and advanced training in data analysis; 4) the ongoing development of a web site to disseminate data and research output.

The Democracy in Africa Research Unit (DARU) supports students and scholars who conduct systematic research in the following three areas: 1) public opinion and political culture in Africa and its role in democratisation and consolidation; 2) elections and voting in Africa; and 3) the impact of the HIV/AIDS pandemic on democratisation in Southern Africa. DARU has developed close working relationships with projects such as the Afrobarometer (a cross national survey of public opinion in fifteen African countries), the Comparative National Elections Project, and the Health Economics and AIDS Research Unit at the University of Natal.

The Social Surveys Unit (SSU) promotes critical analysis of the methodology, ethics and results of South African social science research. One core activity is the Cape Area Panel Study of young adults in Cape Town. This study follows 4800 young people as they move from school into the labour market and adulthood. The SSU is also planning a survey for 2004 on aspects of social capital, crime, and attitudes toward inequality.

The Southern Africa Labour and Development Research Unit (SALDRU) was established in 1975 as part of the School of Economics and joined the CSSR in 2002. SALDRU conducted the first national household survey in 1993 (the Project for Statistics on Living Standards and Development). More recently, SALDRU ran the Langeberg Integrated Family survey (1999) and the Khayelitsha/Mitchell's Plain Survey (2000). Current projects include research on public works programmes, poverty and inequality.