WORKING PAPERS IN

Early Childhood Development

Young children and HIV/AIDS sub-series

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Young children and HIV/AIDS:

Mapping the field

by Lorraine Sherr

Bernard van Leer Foundation

About the paper

This paper is one of the first in a dedicated 'Early Childhood and HIV/AIDS' sub-series of our long-standing 'Working Papers in ECD' series. The purpose of the sub-series is to generate work that responds to emerging needs, or that present information, experiences and ideas to inform all those concerned with young children impacted by HIV/AIDS – including ourselves.

Papers will often be 'think pieces' deliberately produced quickly to reflect the fact that ideas, understandings and approaches are developing rapidly, and to share emerging lessons fast and efficiently.

Each is tightly focused and has a specific purpose. *Young children and HIV/AIDS: Mapping the field* offers an overview of what studies show in this field at the moment. Largely drawn from a review of literature and with a psychological slant, it also identifies gaps in knowledge and experience. Importantly, it highlights the fact that attention to children generally, and young children specifically, has lagged, and it shows the complexity that lies behind this reality, surveying physical, developmental and psychological effects, and signalling the need to take the cumulative effects of these into account in the provision of early childhood development input. It goes on to outline key issues around treatment, care, short- and long-term effects of the virus, disclosure, stigma, emerging sexuality and HIV prevention. It explores a range of issues relating to emotional, psychological, social and physical development. Taking a broad view, it reviews associations with poverty, economic deprivation, nutritional neglect, human rights abuse, and poor role modelling. Turning to what is needed, it considers responses to these issues and points up gaps in what is being provided and in the research that should underpin future efforts.

As we present papers in this sub-series, we do so because we believe that they have something useful to offer and are therefore worth publishing. We do not claim they are necessarily exhaustive or balanced in their coverage, nor will we always agree with what they say. In the case of this paper, we believe that it offers a concise but comprehensive mapping of the field of young children and HIV/AIDS, which will improve understandings about what it means to seriously engage with young children and HIV/AIDS, and which will help funders, policy makers and practitioners to see how their own work fits within the bigger picture.

Cover photo: South Africa, HIV+ mother holding her baby behind the punctured veil of her curtain; photo: Alex Fattal.

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Lorraine Sherr is Professor of Clinical and Health Psychology of the Royal Free and University College Medical School, Department of Primary Care and Population Sciences, London. She currently has a research programme spanning interests in reproductive issues, HIV infection, suicide and HIV, bereavement and prevention of HIV transmission. Her international interests have led to collaborative projects on the ethical and legal aspects of HIV infection, a study of pan-European policy on prenatal HIV testing, and other psychological and social issues related to HIV infection and AIDS. She sits on the British HIV Association Psychosocial Committee and was a founder member and chair of the British Psychological Society special group on AIDS.

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Executive Summary

HIV/AIDS has always affected children. Nevertheless, for various reasons, attention to children generally, and young children specifically, has lagged behind. The concentration of children affected by HIV/AIDS is highest in developing countries; and the growing numbers of affected children has made HIV/AIDS an urgent agenda item. The availability of treatment to prevent infection during pregnancy/childbirth and early childhood has focussed attention on children and their needs. There is a welcome, if belated, focus on children now, especially young children, which can capitalise on the errors, oversights and lessons in policy for other groups.

Young children are affected by HIV/AIDS at various levels. The clearest distinction needs to be made between children who are infected with HIV themselves and those who are not. After that, boundaries become blurred as, on each level, the multiple ways in which young children are affected accumulate. It is probably true to say that in societies where seroprevalence is high (most of sub-Saharan Africa for example), all children are affected by HIV/AIDS – the question is simply one of degree. The entry point of HIV/AIDS and the extent to which young children are affected may differ, as may the responses and capacities.

HIV emerges within a context of poverty, illness and need. It is crucial that the problems do not become so overwhelming that they remove the ability of groups to respond. There are clear pathways to coping and adjustment, models that monitor short- and long-term effects and interventions which can produce results.

For children with HIV infection there are physical and developmental effects. The literature on neuropsychological effects of infection is difficult to interpret as it is hard to separate pure virus effects and broader development effects of family infection, illness, death and social ramifications. Notwithstanding, it is important to review what is known. The literature suggests that HIV itself can affect development (directly or indirectly), and subtle rather than gross changes are commonly noted in HIV-infected children. The cumulative effects on development must be taken into account in the provision of early childhood development services.

The psychological effects of HIV/AIDS in the family or community may affect childhood experiences, particularly in terms of quality parenting, stimulation and opportunities to play. The effects then spiral up as economic deprivation, nutritional neglect, human rights abuse, inheritance obstacles, poor role modelling and the cycle of poverty contribute. At this point it is difficult to distinguish between individual factors in the experience of child development. Suffice it to say that intervention needs are high and anything that can reverse the cycle may be appropriate.

For HIV-positive children there are a host of HIV/AIDS-specific issues that need study. These include treatment, care, short- and long-term effects of the virus, disclosure, stigma, emerging sexuality and prevention of infection.

For all children there are specific psychological issues to be considered. These relate to emotional, psychological, social and physical development. HIV/AIDS can affect their experience of love and being loved, their parenting experience, levels of attachment and separation occurrences. The disease brings with it premature exposure to grief, loss and bereavement. Illness as well as stigma and social circumstance may trigger widespread emotional trauma. A social situation where HIV/AIDS causes illness, death or disruption may affect a child at all levels of development, learning, role modelling, self-esteem, schooling, relationships and families. Behaviour and psychosocial and psychosexual adjustment are all challenges.

Behavioural problems of children associated with HIV/AIDS have been consistently documented. It is unclear, however, whether HIV/AIDS is a causative or compounding factor. No studies on interventions have been done to provide clear guidance on effective interventions, or to provide indicators of desired outcomes indicators. This gap should be redressed.

HIV is known to enter the body and permeate the nervous system, and numerous developmental/neurological problems have been consistently documented. The studies show mild rather than severe problems, with findings such as developmental delay, attention deficit disorder, hyperactivity, anxiety, depression and cognitive challenges. However, there are numerous methodological problems which limit the certainty of the findings and the extent to which they can be generalised. Clinic samples may skew the data, western-based samples may compound other factors (such as parental drug use), and comparison and control groups may vary. But special needs in education may well emerge, and field programmes should be aware and prepared for this.

Care for children in the presence of HIV/AIDS may be disrupted. Parental (maternal, paternal or multiple) death may occur, and alternative childcare arrangements may be disruptive. The quality of care is often seen as the best predictor of adjustment. Stretched resources, child-headed households, economic deprivation and care by elderly grandparents may affect the experiences of young children. Parental mood, state and illness may affect the quality of parenting on young children, irrespective of their HIV status.

Cycles of deprivation occur in the presence of HIV/AIDS, and it is difficult to understand the complexities of these or to identify the individual contribution of relevant factors to ultimate outcomes.

Greater understanding is needed for siblings, grandparents and fathers. Research is minimal on these groups, yet are affected by HIV/AIDS and they play a clear role.

Gender is an issue which needs particular attention. There are various levels of infection according to gender, and the impact of family disruption and the care burden is distributed differently or unevenly according to gender.

Alternative care arrangements have evolved, and these need to be evaluated and understood. The effects on the young infant growing up in an alternative care situation, or changing to an alternative care situation, needs careful monitoring. Clear standards and measurable indicators for optimum provision should be developed.

Multiple coping mechanisms are brought into play, yet these are not clearly understood; and they may vary or differ according to group. Both positive and negative coping pathways need clarification. Causality is difficult to sort out within complex environments. In other areas of HIV/AIDS a strategy of harm reduction has been used to approach complex problems. This may well be a useful pathway for early childhood so that vulnerability and buffers can be explored.

The future holds many challenges. There is a strong focus on biomedical research but insufficient attention to psychosocial factors, although these are clearly important for young children. Evaluation of interventions is lagging, and evidence based progress is needed in the early stages of this epidemic. The voices of children are soft and often not attended to. Yet they should be heard.

Young Children and HIV/AIDS: Mapping the Field

Children in our midst

The years of childhood have a disproportionate impact on carving out developmental pathways. Childhood is a time of learning, development and laying of foundations. When HIV creeps into the equation, the ramifications are manifest and far reaching. The focus of attention in HIV has always been dominated by the western experience and by medical models. When these two are taken in tandem, developing countries, children and mental health are often overlooked. Yet this is short-sighted as a generation struggles with a new reality – the reality of HIV infecting children, affecting children, disturbing the balance of parenting and family life, and challenging the cultural and societal provision for social development and expression.

This paper explores some of the psychological and other issues associated with HIV infection in children. Although the majority of studies are in the West, a growing core of information is emerging from other centres. The disparities in treatment and care provision weigh heavily on the shoulders of children – who face multiple jeopardy – including parental infection, family infection, lack of treatment, environmental hardship and the relentless cycle of need. In order to understand the vast potential impact, a number of systematic questions need to be understood and addressed. This paper will attempt to summarise the complexity of who the children are, examine emerging orphan and vulnerability issues, explore HIV/AIDS treatment interventions and how they affect the emerging scenario in terms of child and parent infection, and then focus on the widespread psychological effects of HIV/AIDS on the young child. Clearly these will vary according to the HIV status of the child. In areas where the incidence of HIV and AIDS is high, it is probably safe to assume that all children are affected in some way – according to the degree of distance and the presence or absence of direct viral assault on their development. There are multiple contributors to the environment of the young child, all of which are susceptible to HIV/AIDS onslaught. Entire institutions such as health care, education, economy, social networks and families can be affected to different degrees.

Who are the children?

As the number of children affected by HIV/AIDS is growing, so is the sense of the complexity of how children are affected. This makes it difficult to define the concept of 'affected'. The following levels can be described, and they are not necessarily mutually exclusive:

- **Level 1 – The child is HIV positive** (HIV+).
- **Level 2 – The child is HIV negative** (HIV–), but has been indirectly affected by one or more of the following situations:
    - *Exposed to HIV in utero (often described in the literature as seroreverting).*
    - *The child has one HIV positive (HIV+) immediate family member (parent, sibling).*

  - *The child has multiple HIV+ immediate family members (parents, siblings).*
- **Level 3 – The child is HIV-, their immediate family members (parents and siblings) are HIV-,** but other family members are HIV+ (grandparents, aunts/uncles/cousins, half brothers/sisters, step parents).
- **Level 4 – The child is HIV- but lives in a social system where HIV has affected many people.** The social system is stretched from bereavement, illness burden, orphans, and the net result is a vulnerability and/or burden experienced by the child living in this social ecosystem.

Within these levels there is an additional consideration of health status of both the child and the infected family member(s) which has a bearing on the psychological issues. Is the child and/or others who are HIV+ well, ill, dying or deceased? With HIV there may be multiple categorisations with various members of a family network in different stages of illness.

The scale of the problem

Numerous attempts have been made to map the scale of the problem (Children on the Brink 2002; HIV AIDS and Early Childhood 2002). All such attempts conclude that while it is a growing problem, in some cases one that is out of control, it is difficult to assess the scale of the problem with any accuracy. The mathematical and epidemiological approaches simply give a count based on indicators such as the number of known children, the number of adult deaths and the number of infected children. All such counts are probably underestimates, and they never truly reflect the nature of the challenge. Caution is needed when interpreting accounts of scale: the counts give estimates at a given time point but fail to address the cumulative and lifelong nature of the problem. Another approach would be to categorise the scale of the problem according to impact, with groupings such as:

- no discernible impact;
- mild, containable impact;
- contained impact;
- stretched resources;
- burst, uncontained impact.

Another approach has been to focus on orphaned children with a number of definitions of orphanhood.[1] Studies often describe an orphan as a child who has lost one or both parents. From an emotional and psychological perspective, however, these are very different groups; the resources, love and attention of a surviving parent need to be differentiated from a child with no parents. Table 1 shows how a number of key studies on orphanhood define the concept of 'orphan' and whether they separate or combine children who have lost one or both parents, and if one parent, which one is studied. Clearly there is a lack of consistency in the literature, and this ought to be remedied.

In a recent study of 3,988 children in South Africa (Brookes et al 2004), it was shown that 2.2 percent of the children had lost both a mother and father, 3.3 percent a mother and 10.1 percent a father. It would be important to know if these

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[1] *While concluding that orphaned children represent a particular challenge, workers emphasise the need to include all vulnerable children.*

Table 1: Various definitions of 'orphans' in the international literature

Study	**Place**	**Orphan definition**
Lee et al (2003)	USA	Loss of mother
Shetty et al (2003)	USA / International	Loss of mother or both parents
Nyambedha (2003 a, b)	Kenya	Loss of one or both parents
Lindblade et al (2003)	Kenya	Loss of or both parents (gender of parent lost is studied)
Whiteside et al (2000)	South Africa	Loss of mother
AIDS Weekly (1996)[a]	Brazil	Loss of mother
Brookes et al (2004)	South Africa	Loss of mother or father or both (separately analysed)

[a] *In "AIDS causes sharp rise in number of Brazilian orphans"*

proportions are similar in other countries and what the relative weighting of the different levels of loss are on early child development.

HIV/AIDS and early childhood development

It is well established in the literature that infant development is intricately bound up with subsequent development and capabilities. Early experiences and development affect socialisation, maturation, achievement and emotional qualities in the future. These concepts are well established in terms of parental mood (depression, anxiety, eating disorders, mental illness), social state (poverty, access to education, school and home socio-economic conditions) and health (access to immunisation, nutrition, health treatment). HIV and AIDS can dramatically affect all these levels – and more.

Impact can be explored under a number of domains. These may be rank ordered or viewed in totality to describe the world of the child. The major strands of enquiry relate to:

- physical health, including growth, illness;
- biological outcomes including illnesses, prevention (immunisation) and access to basic health care;
- nutrition and access to food, including infant feeding and nutrition in early life;
- care and shelter, including care arrangements, parenting, siblings and housing;
- quality environment relating to stimulation, provision, quality of life;
- education, ranging from availability of education, access, attendance and impact;
- emotional well-being (love, support, enabling environment, safe care, development opportunity).

The situation is compounded by the introduction of interventions to prevent mother-to-child transmission (MTCT) of HIV which did not provide simultaneous intervention for the mother or father, thus resulting in HIV–

children living in families with HIV+ parents/siblings who were ill, untreated and dying. The reduction in transmission rates with intervention from 25–33 percent down to under 10 percent (Minkoff 2003) has dramatically increased the number of HIV-uninfected children with HIV+ family members. The long-term effects of *in utero* exposure to HIV and to antiretroviral treatment or therapy (ART) are unknown at this point in time. These may prove to be beneficial (protective resistance) or negative (viral resistance, treatment resistance, reproductive or development ramifications). Only time and thorough monitoring will allow for this information to filter through as these young children mature. Understanding the effect of HIV in families is in its infancy in terms of research and understanding.

Vertical transmission

It is important to study the child from conception onwards. Although medicine separates obstetrics and paediatrics, this division is arbitrary. Holistic approaches ensure that preconception conditions and in utero factors are considered under the remit of early child development.

There is a range of studies set up to explore the relative risks of infant infection according to maternal or birth variables, including time of infection, disease state, treatment and handling. Surprisingly, there are very few studies (see for example Semprini et al 1994; Ryder et al 1994) which study the effect of paternal HIV infection on child outcome.

The majority of children born to HIV+ mothers are not themselves infected. This has been the case throughout the epidemic, even in the absence of treatment. Over time, numerous studies tracked vertical transmission rates and showed variation according to a number of consistent variables, namely geographical location, virus strain, background medical health, stage of illness in the mother, biological markers such as CD4 count (a measure of immune functioning in the blood), presence of opportunistic infections in the mother, socio-economic factors, drug use issues, age of mother, prematurity and previous obstetric history. The rates varied between 12 percent and 33 percent (see table 2). All such studies predated the advent of ART (Connor et al 1994), which showed a dramatic effect on reduction of transmission to the unborn baby.

Since 1994, when a randomised controlled trial was carried out to evaluate the effect of zidovudine treatment in pregnancy in reducing MTCT of HIV (called ACTG 076 trial) showed that using Zidovudine in pregnancy reduced transmission rates to babies by two-thirds (Connor et al 1994), a variety of interventions have been trialled, and a policy of HIV testing in pregnancy and promotion of treatment has been implemented, but not to all. Treatment regimens using different compounds and combinations of antiretroviral compounds are studied, but the science is in its infancy. The ideal compound and timing is not yet known (Semprini et al 2004). It is too early to establish any long-term effects of any of the compounds on the infected baby, on the uninfected baby

Table 2: Rates of transmission of HIV to infants in the absence of treatment

Study	**Place**	**Vertical transmission rate %**
Boulos (1990)	Africa (n=199)	23%
European Collaborative Study (1991)	10 European centres (n=372)	12.9%
Hira et al (1989)	Zambia (n=227)	39%
Holt (1990)	Haiti (n=160)	15.4%
Pruzuck (1990)	Burkina Faso (n=23)	36-45%
Spira et al (1999)	Rwanda (n=218)	33%
Muhe (1997)	Ethiopia	29-47%

and on the mother. Ideal interventions are not yet clarified. The mechanisms of effect are not established. It is unclear whether infection occurs early on in gestation, during pregnancy at differing rates or during birth. It is currently believed that the majority of infection occurs at the time of birth. Yet it is also clearly established that virus has been found in tissue from foetal tissue as young as 8 weeks old. Post partum infection through breast milk has also been clearly documented. Young children can also be infected by exchange of contaminated body fluids – exposure to blood or other body fluids in body piercing, injections, or sexual assault can also infect the child. The growing understanding of HIV in childbirth and the efficacy of ART has resulted in a global policy of care and interventions during pregnancy, yet many questions remain unanswered:

- This policy seems to have had a dramatic effect on reducing rates of transmission, but the wider effects of these protocols on outcome for children exposed to compounds who would otherwise have been uninfected are unknown.
- The longer-term effects of exposure to treatments for the child if they become HIV+ as adults is unknown. Will the medications be less effective on them given their exposure *in utero?*
- The effect of monotherapy, or brief exposure to ART, for the mother and her subsequent resistance patterns are unknown.
- There is evidence that treatment failure is associated with exposure to monotherapy in unrelated adult samples (Phillips 2000), and this may clearly affect maternal survival, health and parenting.

The availability of treatment interventions has also served to dominate attention to testing and treatment with monitoring of transmission rates. Little attention has been paid to the mental health needs of the group and how experience may affect parenting and child development. Stigma, abandonment, violence, non-adherence, feeding and illness, all have potential to affect the environment in which a young child is born and raised. This is compounded by parental illness and death.

Current issues around transmission reduction management at time of birth concentrates on a three-pronged approach.

- **Antiretroviral treatment in pregnancy.** There is a well-established reduction in transmission, with ongoing research on ideal compounds/times of administration/dosage.
- **Mode of delivery.** It is established that in the absence of treatment, delivery by caesarean section has a protective effect on infant infection. But there are costs associated with the procedure (financial as well as physical health costs for the mother). It is unclear what the policy should be in situations where medical care is not of a high standard, is not accessible or may not be available for subsequent deliveries. It is unclear what the added benefit of caesarean section is in the presence of ART for women with an undetectable viral load.
- **Avoidance of breast feeding.** It is well established that HIV can be transmitted in breast milk, with complications of breast feeding such as mastitis. An area of great interest is where the balance of nutrition and formula feeding is difficult to establish, where poverty and access to clean water may weigh against safe formula feeding and where stigma may play a role. Alternative concepts (such as exclusive breast feeding and rapid weaning) and interventions to reduce viral load while breast feeding are all currently under exploration.

All this occurs in an environment of HIV testing promotion for pregnant women. The identification of all positive pregnant women may be at some psychological cost to all clinic attenders, and may result in an upsurge of resource need. Few studies monitor HIV in fathers or promote HIV discussion in family planning, general practice or termination of pregnancy clinics.

The net effect is to enhance the medicalisation of childbirth and potentially produce a situation of high emotional burden, mental strain, coping with stress and adjustment problems for mothers at the point of birth. It is established that the experience of childbirth may dramatically affect mothering, and the best interest of the child is served by optimalising this experience.

Diagnosis and HIV testing for children

Definitive diagnosis of child infection via antibody testing is hampered by the presence of maternal antibody in infant blood.
If antibody testing is the only means available, a period of uncertainty, lasting up to two years, may follow the birth of a child. Polymerase Chain Reaction tests (PCR) allow for a more rapid definitive diagnosis of new-borns, with

increasing accuracy as the infant becomes older (Midani and Rathore 1997; Nesheim et al 1997), but are often not available in resource-poor settings. Many of the MTCT programmes which promote HIV testing and treatment for pregnant women do not follow up and provide HIV test results for the baby. Parents may live in uncertainty, may overreact to minor childhood illnesses in the absence of definitive diagnosis, or they may focus desperately on spurious signs to denote that their baby is infection free. Temmerman (1993) showed that women who had a child diagnosed (or ill) with HIV were more likely to conceive another baby.

Some parents choose not to know the HIV status of their child, while others find the task of disclosure of diagnosis – to others and to the growing child – difficult (Melvin and Sherr 1995). Not all children are monitored or informed by antenatal HIV programmes which offer HIV testing to pregnant women and treatment to prevent MTCT. Even when they are, there is no individualised HIV testing of the infant to allow the mother and family to know the success or failure of the intervention. Indeed, many parents are left in a void after such programmes. For some, an illness in a child is the first presentation of HIV in that child, and for mothers not tested during pregnancy, childhood illness may be the first indication of HIV permeation into the family. The point of child testing may be the trigger moment for mother, father and other siblings to be tested, and the possible outcome of multiple diagnosis of HIV in a family is a highly significant psychological burden.

Voluntary counselling and testing is well established for adults, with clear protocols and provision. However, HIV testing for children raises many questions. Initially, consent is an issue. Test outcome and the appropriate time for a child to learn of their own status is also a challenge which is neither clearly studied nor guided. In order to understand HIV status, a child needs to be sufficiently developed to integrate the knowledge and its implications. Withholding such information has implications for trust. When to tell, as well as how to tell, are clear challenges for early childhood.

Treatment

The early literature describes two patterns of illness progression for children with HIV: those who become ill with opportunistic infections early in life and have a poor prognosis, and those who remain relatively well. Prematurity has been linked to shorter survival in positive infants (Abrames et al 1995). In the absence of treatment, this pattern still prevails.

Illness progression and disease manifestation in children has been studied in many contexts. Evans et al (1997) studied 302 children with vertically acquired HIV, recorded in UK surveillance by the year 1995. At follow up, over half the children had developed AIDS-indicator diseases, such as Non-Hodgkin's Lymphoma. When compared to children aged 5 and under in the general population, the HIV+ children showed a 2500 times greater prevalence of this particular disease. Blanche et al (1997) studied 392 infected European children and found that the majority of children have experienced either minor or moderately severe illness by the age of 4. They conclude that the risk of death by the age of 1 was 20 percent with a rate of 4.7 percent per year thereafter. By 6 years of age, the mortality rate was 26 percent. Surviving children were relatively well with two-thirds having only minor symptoms. The European Collaborative Study suggests that around a quarter of children with HIV develop AIDS-defining illnesses before their first birthdays and that by the age of 4, 40 percent of children will have developed AIDS (European Collaborative Study 1996, 1994).

Prophylactic interventions as well as disease management and ART has resulted in extended survival times and opportunistic infection avoidance. Extended survival brings with it a host of other problems, often associated with development in the face of life-threatening illnesses, hospitalisation, parental illness or multiple bereavement and the burdens of lifelong treatment adherence (Goode et al 2003). Treatment guidelines for children are still unclear, with some units treating all HIV+ children and others only treating at the onset of symptoms (Thorne et al 2003). This has clear implications for medical monitoring, management and access to high-level paediatric services as well as drugs. When treatment is available, adherence is a particular challenge. For children there is mediated adherence, rather than the direct adherence studied in adults. Children rely on adults to administer their medication. Gibb et al (2003) noted that full adherence was reported in 74 percent of their sample, thus revealing that 26 percent were not fully adherent. Younger children had particular difficulties, although ill children had higher adherence than well children. Barriers such as stigma, disclosure and physical taste of the compounds were issues in this study. Mullen et al (2003) also showed low adherence for 50 percent of their sample and noted that this was associated with resistance to antiretroviral drugs. For the majority of children with HIV in the world today, treatment is not available and adherence is, therefore, not an issue.

There is also the question of the effect of exposure to ART while in utero for children who are subsequently infected or who remain uninfected. Infected children may have resistance profiles which compromise their own treatment. Uninfected children need careful monitoring to establish the long-term effects of exposure to HIV in utero in the first place and to ART as well. The European Collaborative Study followed up 2414 uninfected children whose mothers were given ART, and provided detailed examination of 687 who received ART during the pregnancy, during labour/delivery and post delivery to the baby. Congenital abnormalities and birth weight were monitored, and no association between ART exposure and these variables was found (European Collaborative Study 2003). Prematurity was associated with particular regimens (i.e. those without a protease inhibitor. Combination therapies usually combine drugs from three classes of compound, see summary insert below) and with anaemia. No serious adverse events at 2.2 years follow up were seen. However, there may be other parameters that show effects that are worthy of study. A French study (Landreau-Mascaro et al 2002) noted that among 4426 uninfected children born to HIV+ mothers, the risk of febrile seizures was higher for children perinatally exposed to antiretrovirals than those not exposed.

Access to treatment for young children has not featured with as much prominence as access for adults. Advocacy for children relies on adult voices. The delivery of treatment for children is complex, given that it is mediated by an available/responsible adult as well as availability of the compounds in the first place. At present, effective treatment is lifelong and timing of treatment initiation needs careful planning. Long-term effects of treatment on young children are still not clearly established. More simple and pragmatic features of child treatment also deserve attention. This includes straightforward issues such as medication preparation in child-friendly form as well as explanatory material for the child to grow to understand medication and participate in the responsibility of treatment as they grow.

Neurological problems associated with HIV infection

From the beginning of the epidemic, neurological problems in HIV-infected and HIV-exposed children have been monitored and reported. The findings include a range of developmental delays, neurological symptoms, learning challenges, cognitive problems and language issues. Indeed, early predictions (Armstrong et al 1993) were that HIV infection

Combination therapies explained

Most combination therapies – known as Highly Active Antiretorivral Therapy (HAART) or Antiretoriviral therapy (ART) – use a variety of combinations of different medicines from the three classes or types of drugs currently in use. The different classes of drugs work at different stages of the life cycle of HIV. As time goes on, medical advances extend the available drugs, often targeting new points in the virus life cycle.

1. **Nucleoside and nucleotide analogues known as NRTIs.** These are drugs such as AZT, 3TC, ddI, ddC, d4T, abacavir, FTC (emtricitabine) and tenofovir. Two NRTIs are usually the cornerstone of a combination.
2. **Protease inhibitors.** These include compounds such as saquinavir, ritonavir, indinavir, nelfinavir, amprenavir, lopinavir, and atazanavir.
3. **Non-nucleoside reverse transcriptase inhibitors (NNRTIs)**. These include compounds such as nevirapine, efavirenz, delavirdine.

See also <www.aidsmap.com/en/docs/ux/treatment.asp> for easily accessible and more detailed explanations.

would become the primary infectious cause of perinatally acquired developmental disabilities in the USA.

Early studies on central nervous system involvement for children with HIV (Belman et al 1987; Burns 1992) noted that 90 percent of children showed neurological abnormalities at autopsy, although the mechanisms and implications of such relationships are difficult to establish, let alone the ability to differentiate between HIV-caused pathogenesis or treatment-related findings. Scarmato et al (1996) described different patterns of atrophy in the brains of children with AIDS. This suggests that the disease may affect the tissue in some way. Brouwers et al (1995) studied computed tomographic brain-scan abnormalities in 87 children and rated abnormalities with intelligence test and social emotional behaviour ratings. Calcifications were associated with greater delays in neurocognitive development.

An examination of the European data on first presenting AIDS defining illness (Sherr 1997) shows that significantly more children are diagnosed with neurological impairment (2.32 percent) than adolescents (.56 percent). Over-inclusion may result from including any cognitive delay in children. No clear, defining categories exist.

The nature and range of neurological impairment varies dramatically according to studies. This may reflect true variation because of infection source (drug-using mothers, endemic groups, blood transfusion, haemophilia related). Underreporting may be prevalent. In the USA, neurological impairment rates are reported as high as 90 percent, which is in sharp contrast to Europe with rates of 20–30 percent (Msellati et al 1993; European Collaborative Study 1996).

An important study (Coscia et al 1997) examined the relationship between risk and resilience. They noted that in the context of biological risk factors for HIV, aspects of the child's environment could facilitate or even hinder cognitive development.

Table 3 gives a systematic overview of developmental, neurological and cognitive studies in children with HIV infection. Forty-six studies were identified. The total picture is one of common, but not universal deficit. However, there are difficulties in interpreting this array of studies. Over two-thirds of the studies (31 out of 46) come from the USA, although the majority of children live in Africa. A wide array of scales and inventories is used, with little systematic approach. Gender is rarely separated. Control groups contain a range of different groups such as children exposed to HIV in utero who serorevert and/or those who are HIV-, siblings and population controls.

Gathering together the wide array of studies internationally, table 3 shows that there is a consistent finding of subtle effects but little validation of gross effects of HIV on the developing child. The various comparison groups also show that effect is not restricted to virus exposure: family factors, environmental

Table 3: Studies examining the effect of HIV on neurological development

Study	Place	Sample	Measures	Findings
Aylward et al (1992)	USA	N=96 12HIV+ 45 HIV– 39 Reverters	Bayley scales of Infant Development	HIV-positive children scored lower than negative or reverter children.
Bachanas P et al (2001)	USA	36 HIV+ 32 HIV–	Psychological adjustment; locus of control; coping	25% HIV+ clinically significant emotional or behaviour problems but similar to HIV– children. Emotion focussed coping relates to more adjustment problems.
Bell et al (1997)	Côte d'Ivoire	76 HIV+ 77 HIV–	Various	Low prevalence of HIV encephalitis - explained by comparatively early death in HIV - infected children in Africa compared to western children.
Belman et al (1996)	USA	32 HIV+ 99 HIV– reverters 116 controls	Neurological functioning	Reverter children not different from control children in all 8 domains. HIV+ significantly more neurological problems than control and reverter for 7/8 domains. Neurological problems severe and pervasive in those with early AIDS diagnosis.
Bisiacchi et al (2000)	Italy	N=42 29 HIV+ 13 HIV–	Neuropsychological tests	Executive function problems in all HIV+ children, memory and visual-spatial deficits only in those with AIDS. No differences in language and overall IQ.
Blanchette et al (2001)	Canada	N=50 25 HIV+ 25 HIV–	Bayley Scales of Infant Develoment	HIV+ significantly lower scores on mental scale and performance scale. CT abnormalities associated with developmental delays.
Blanchette et al (2002)	Canada	N=25 14 HIV+ 11 HIV–	Intelligence, receptive language; memory; cognitive dev.	Many areas of cognitive function in normal range. Subtle motor impairments in HIV+.
Bobat et al (2001)	South Africa	N=141 48 HIV+ 93 HIV–	Physical measures	HIV+ children lowered length for age, weight for age (but not weight for length).
Boivin et al 1995	Zaire	14 HIV+ 20 Reverters 16 Control	Denver Developmental Screening Test	Motor and visual spatial deficits. Maternal infection undermines cognitive development in uninfected children.

Study	Place	Sample	Measures	Findings
Bruck I et al (2001)	Brazil	43 HIV+ 40 Reverters 67 Controls	Denver Developmental Screening Test; CAT/Clams	Significant neurodevelopmental delay in HIV+ group.
Buchacz (1997)	USA	N=983+		Immunosuppression associated with delayed pubertal onset.
Chase et al 1995	USA	24 HIV+ 27 Reverters	Bayley Scales of Infant Development	Delayed motor development. HIV infection associated with delay in mental development.
Cohen et al (1991)	USA	15 HIV+ 33 Controls	School achievement	Significant effects in school achievement.
Coplan et al (1998)	USA	N=9HIV+ 69 HIV– reverters	Language development; Bayley scales of Infant Development; McCarthy Scales	Language deterioration among HIV+.
Coscia et al (2001)	USA	N=43	IQ	Measures of home environment mediated the association between SES and child IQ, with a stronger association between advanced stages of disease than earlier stages.
Depas et al (1995)	France	N=8		Functional abnormalities precede clinical symptoms.
Esposito et al (1999)	Italy	39 HIV– 78 Controls	Child behaviour checklist; Gittleman version of Conners Question; Anxiety and Depression Scales	Children born to HIV+ mothers significantly higher depression and anxiety.
Fishkin et al (2000)	USA	40 HIV+ 40 HIV–	Wechsler Scale	Overall no significant differences. HIV+ significantly lower scores on block design.
Fowler et al (2000)	USA	N=595 114 HIV+ 481 HIV–	Bayley Scales; Cognitive and Motor Growth	HIV infection significantly associated with all events related to abnormal mental and motor growth. Early and marked cognitive delays and declines, independent of other risks.
Frank E et al (1997)	USA	27 HIV+	Various	Visuomotor skills sensitive to stage of disease, mode of transmission and living environment.

Study	Place	Sample	Measures	Findings
Gay et al (1995)	USA	N=126 28 HIV+ 98 HIV–	Mental and motor scores	Mean mental and motor scores significantly lower in HIV+. One third of HIV+ exhibited normal cognitive development and half demonstrated normal motor development.
Havens J et al (1994)	USA	26 HIV+ 14 Reverters 20 Controls	Psychiatric diagnosis interview and behaviour checklist	High rates of disruptive and behavioural morbidity. Similar between all groups. Drug use seen as a key factor.
Hilgartner et al (1993)	USA	N=333 62% HIV+ 38% HIV–	Various	HIV+ children 3-fold more height decline, delays in sexual maturation. 50% more likely to score 1 standard deviation below expected level.
Hooper S et al (1993)	USA	18 HIV+ 20 HIV–	Child behaviour checklist	No significant differences.
Hooper et al (1997)	USA	N=58 25 HIV+ 33 HIV–	Neuropsychological measurement and IQ	No differences between HIV+ and HIV– over time.
Knight et al (2000)	USA	N=50 25 HIV+ 25 HIV– reverters	Bayley scales of Infant development	HIV+ significantly lower Bayley Scale score at baseline (mental development) and follow up (motor development).
Levenson et al (1992)	USA	N=49 41HIV+	McCarthy Scales of Children's Abilities	44% scoring low on the inventory. HIV+ significantly worse than seroreverters.
Llorente et al (2003)	USA	N=157 HIV+	Bayley Scales of Infant Development, Neurological markers and mortality	Survival analysis showed greater mortality in those with Bayley Scales scores in lower quartile. Bayley Scales predicted for mortality.
Macmillan et al (2001)	USA	N=1094 147 HIV+ 383 Drug exposed	Bayley Scales of Infant Development	Scores were lower for HIV+ children, and for those dually exposed to recreational drugs and HIV+. Delay persisted at 24 months for HIV infection only.
McKinney r & Robertson J (1993)	USA	N=170 62 HIV+ 10 HIV–	Physical	HIV+ smaller weight for age and length for age.
Mellins & Ehrardt (1994)	USA	25 families	Baley Scales of Infant Development	Loss and separation particular problems. Sibling anger and high burden from caregiving tasks.

Study	Place	Sample	Measures	Findings
Mellins et al (2003)	USA	96 HIV+ 211 Reverters	Behavioural rating scale	High level of behaviour problems. No HIV effect on outcome. Demographic characteristics showed strongest correlates.
Mialky et al (2001)	USA	N=85	School related issues	76.5% in the appropriate class. 53% required some special services.
Msellati et al (1993)	Rwanda	N=436 218 born to HIV+ mother (50HIV+) 218 born to HIV– mother	Various	Motor problems 31% at 1 year and 40% at 1.5 years. 1 severe encephalopathy in 50 HIV+ children Delays related to stage of AIDS.
Ndugwe et al (1997)	Uganda	N=436 79 HIV+ 241 HIV- 116 HIV– born to HIV– mother	Neurological battery and social interactions	HIV+ children greater deficits in motor development and neurologic abnormalities. Information processing did not differ according to status.
Nozyce et al (1994)	USA	21 HIV+ 65 Reverters 95 HIV–	Various	HIV+ symptomatic scored significantly lower. HIV+ well children similar to controls.
Piazza et al (1995)	Italy	N=138 58 HIV+ 80 Reverters	Various	CS involvement 36% for symptomatic HIV. No group differences for developmental deficits and psychological problems.
Pilowsky et al (2001)	USA	N=73	Depression	Children of depressed parents were at higher risk of depression and anxiety symptoms.
Pollack et al (1996)	USA	N=65	Cognitive motor development	HIV+ infants impaired compared to HIV- and compounded by viral load.
Scafidi et al (1997)	USA	N=48	Brazelton Behavioural Assessment	Infants of HIV+ mothers had more orienting problems and abnormal reflexes which may be early precursors to later visual spatial delays and hypertonicity.
Smith et al (2000)	USA	N=114 HIV+	Neurological functioning	Early HIV infection increased risk of poor neurdevelopmental functioning.
Tardieu et al (1995)	France	33 HIV+	Various	29% show affective disorders; 67% normal school achievement; 54% abnormal visual-spatial and time orientation; 44% speech and language delay.

Study	Place	Sample	Measures	Findings
Watkins et al (2000)	USA	66 HIV- 79 HIV+ well 28 HIV+ ill	Attention deficit measures	Attention span affected in HIV+ children, but associated with premorbid history of illness.
Whitt et al (1993)	USA	N=63 25 HIV+ 38 HIV-	6 domains of functioning	No differences in groups of similar age, race and socio-economic status defined by HIV status. High incidence of subtle deficits when compared to age norms.

factors and treatment factors all have a part to play. Of the 44 studies identified, 31 emanate from the USA and 2 from Canada (73 percent from North America). Europe (France n=2, Italy n=3) account for a further 13 percent. There are only 6 studies reported from Africa and South America, where the vast majority of children with HIV are found.

Methodological problems associated with these studies abound. If the groups are drawn from clinic samples there will be an overrepresentation of illness and the severe end of the spectrum. Thus the studies run the risk of finding more problems than one would expect in a community sample. Community samples which compare HIV+ children born to HIV+ mothers with HIV– children born to positive mothers are more reliable given that they account for the potential developmental impact of an ill, dying or absent mother and developmental disruption of family illness and disease management. Other methodological problems relate to the HIV exposure risk in the first place, such as drug use or migration, which affects cognitive development due to illness, isolation from the extended family, economic disadvantage and having a home (and first) language which differs from that of the test centre and the test items.

The test inventories themselves may create bias and a lack of comparability, especially if they are translated and not validated against the normative population. Studies need to control for additional factors such low birthweight, prematurity and feeding, which are factors associated with HIV+ children and are also noted as possible contributors to developmental differences. Even if neurological problems are found, mechanisms are still ill understood. There may well be complex contributors, including virus, environment, psychological and biological factors.

Uninfected children

The burdens of uninfected and exposed as well as unexposed children are still heavy. The long-term effect of exposure to HIV *in utero*, compounded by exposure to antiretroviral medications may have effects which do not come to light until later. In the UK, surveillance of such children is ongoing. As the epidemic is in its infancy, uncertainty and unanswered questions remain.

What is certain, however, is that the mantle of HIV in the family may well affect all children. The uninfected child will still experience parenting in the presence of HIV as well as possible bereavement and orphanhood. For HIV– children in a family with an HIV+ child, there may be an attention shift to the ill child, which may result in behavioural problems, adjustment challenges and attention need. Resources may be directed at the infected child and the affected child may be left wanting. The well child will carry a burden of caring as well as a possible burden of survivor guilt.

Sibling bonds are usually strong and could be harnessed as a resource in families destroyed or devastated by HIV. There is a general literature on siblings and their relationships/roles, and this should be applied to HIV-affected families.

Psychological issues: We know their head circumference, but do they cry at night?

For all children living under the mantle of HIV, there are a number of psychological ramifications – rarely experienced singly. Although the literature tries to tease these out, the reality involves a complex coexistence of psychological effects, all of which may conspire to have a dramatic and long-lasting effect on the young child. These are briefly discussed under headings of emotional, social, psychological and physical development. Yet the dividing line is often unclear, the categorisation is arbitrary and there is deep interlinking of these concepts in reality.

Emotional development

Love is a commodity without which human beings cannot thrive. Love ensures an environment where a child is made to feel special, valued, with an individual meaning and focus. A loving environment provides children with role models and blueprints for future relationships. Close family members are traditionally the providers of love and affection. HIV and AIDS may cause their premature death, and thus the patterns and blueprints for love and the recipients of love are disrupted. New loving relationships may be hampered by HIV/AIDS. Unconditional love of an infant and young child is seen as important for their capacity for social adjustment, ideas of self and relationship formation.

Parenting in the presence of HIV is a challenge not fully understood. When HIV enters a family, it is invariably associated with multiple infection. Although some of the effects of HIV infection and the ramification of disease on parenting may be articulated, the multiple nature of the effect has not been quantified. This may differ according to circumstances. The literature shows that parenting is stressful and challenging under normal circumstances, let alone in the presence of illness, separation and even death. The overriding messages, however, should be recalled. Often the quality of parenting is of greater importance than the quantity. Separation and loss can be balanced by the quality of subsequent caring arrangements. Parenting is traditionally examined as the task of the biological mother and father. However, there are many successful variations on this model. The strengths of all forms of parenting provision need to be harnessed. Parenting style is known to contribute to child outcomes, child development and child reactions (Miller et al 2002).

Parenting in the presence of HIV is in itself stressful. Wiener et al (2001) monitored distress and need for psychosocial services of fathers of children diagnosed with HIV/AIDS. Over half of the sample experienced significantly elevated levels of parenting and psychological stress with a high uptake of services (97 percent). Parenting in poverty adds an additional strain to HIV-infected parents (Beeber and Miles et al 2003). Family styles have shown to affect child development and outcomes, such as enmeshed (overly close) families (Rothbaum et al 2002), marital conflict (Zimet and Jacob 2001). An application of such theories to a situation where HIV is present may help anticipate the effects on family systems.

Attachment and separation. The literature on attachment and separation has been used to describe the loving bonds between parents and children, the importance of such bonds and the role they play in child development, security, achievement and role formation. Although the literature is not definitive and not without flaws, it can be concluded that attachment figures are important. Peterson et al (2001) explored the security of attachment in Ugandan infants with and without HIV (n=35 and 25 respectively). Of interest is the fact that there was no difference in security of attachment according to HIV status, but when mothers with AIDS were compared to those who were well, security of attachment was compromised. It seems that it is not the presence of HIV which acts as an obstacle, but the presence of illness in the mother and its ramifications on parenting. An ill mother may be unavailable for care, absent, or too ill to carry out daily mothering and caring tasks.

Separation can occur when either parent or child are ill and hospitalised. Death of a parent is an absolute separation. Children can experience more subtle separations when HIV stigma results in family avoidance or abandonment. The European Collaborative Study (1997) described the patterns of hospitalisation in the first five years of life for HIV+ children in Europe (n=1189: 151 HIV+ and 811 HIV–). Uninfected children had 0.5 admissions per 5 child years in comparison with the four-fold increase (2.4 admission) for HIV+ children. Hospitalisation affects children in many ways. Although this study shows that HIV-negative children do have hospital admissions, the rate is significantly higher for HIV-positive children. The effect of hospitalisation can be directly from the illness itself, the treatments associated with the illness and the recovery levels. It can also be indirect as a result of separation from family, trauma of the environment, effect of any procedures, especially those involved with pain such as injections or surgery and those involved with fear-arousing experiences such as unpleasant-tasting medication, barrier nursing or simply the environment effects of a hospital. Children can overhear other children in distress, can observe unpleasant incidents, can be frightened by parental absence and may feel neglected, ill or scared.

Unconditional relationships are the basis of validation, emotional appreciation and mental growth. Such unconditional regard, especially unconditional positive regard, is regularly vested in deep family relationships and may nurture or succour development and growth. HIV may sever this provision at a number of levels. It may remove the key individuals who feel and give unconditional love by illness, death or separation. It may strain the substitute or second-tier providers by stretching their resources to breaking point. This can be seen with extended family members caring for orphaned children, by grandparents suddenly stepping into caring roles – often at a time when they have needs associated with ageing. The very existence of grandparenting roles by definition describes bereaved grandparents who have lost their own children and are now substitute caretaking for their grandchildren.

Friendship and peer relationships. HIV can cause problems in establishing friendships as well as continuing them. In addition, disclosure of HIV has been associated with subsequent bullying (Lewis 2001). Illness itself was related to loneliness in the accounts of the children in this study. The very pattern of existence in the presence of HIV may predispose to social barriers and friendship impediments. The triggers can relate to discrimination and stigma, to parental illness, to family demands which remove the child from social encounters or simple exhaustion and failure to engage on the part of a child who is multiply burdened, ill or hungry.

Social development

The early childhood development literature devotes much attention to socialisation, the development of social skills, attitudes and behaviours. All three main theories involve parents and parenting (social learning theory, psychoanalytic theories and ethological theory). HIV can disrupt, destroy or alter such relationships, with potential ramifications for all areas of social development.

Although infant attachment (see above) is a key element in social development, there are a host of other social development hurdles facing a developing child. Young children need to understand groups, to operate effectively in a social environment, to evolve a sense of other, a sense of the minds of others, an ability to form relationships, relate to others and to attract peers. HIV can be an issue in all these processes. Stigma is a social construct and a child labouring under a stigmatised medical condition will have to face social consequences which, whether real or feared, can have dramatic influences on behaviour and happiness. Integration into a group may be affected directly by the diagnosis, or indirectly by the lack of continuity of presence due to illness or hospitalisation, by the lack of a welcoming family environment, by poverty, by lack of time availability or even motivation because of powerful conflicting concerns. Death and bereavement as well as illness and fear may limit the social opportunities and abilities of a child to seek out, establish and maintain social relationships. One of the tragedies of a social impediment is the well-established fact that social support is a mediator in adjustment and coping.

Role models may hold a particular key to development. Children often integrate role models in their early child development years. HIV may alter such role models, and may generate substitute role models who differ for the child. In circumstances where inadequate care arrangements precede parental death, children are not only deprived of their parent(s) and their nurturing love, but also of the strong grounding of role models for their future relationships.

Moral development is a phase of social development that is key in social operations in later life. The literature on moral development does not clarify the mechanisms by which children achieve a sense of morality. However, for children who are challenged in their caretaking as a result of HIV infection, moral development may be affected. This has both a direct and an indirect effect on them in terms of future adjustment and decision making.

Learning occurs in many different ways. Childhood is essentially a time of rapid learning. This includes both formal and informal learning. Much of the early cognitive phases, according to theorists such as Piaget and Bruner, require early exposure, experience, adaptation and guidance for children to learn about their world and to integrate these cognitions. The effect of HIV can be experienced at multiple levels. Simple language acquisition is a function of language exposure, language guidance and reinforcement. Social environment is seen as key in language acquisition (see for example Chomsky). Subsequently, language becomes a key to accessing other learning items. Children affected by HIV may have their learning abilities challenged and their learning opportunities curtailed. Coplan et al (1998) noted frequent deterioration in language in young children with HIV, even in the absence of neurological abnormalities. Such language deterioration may precede cognitive ability problems.

There is more to learning than academic and school learning. Coping styles, risk, resilience, social interaction and social rules are all part of the learning curve. Coscia et al (1997) propose that a risk and resilience model of development should be considered for children affected by HIV, whereby, in the context of biological risk factors, aspects of the environment may either facilitate or hinder cognitive development. These notions are endorsed by others (Pilowsky et al 2000). The general literature also advises that children cope better than adults or adolescents with potentially traumatic stress (Sigal et al 2001). In a study of concentration camp survivors, these authors looked at later psychological and psychiatric problems and found that survivors who were adolescent or young adults during the experience fared worse. Longer-term resilience by child survivors was linked to caretakers, endowment and subsequent development. In the absence of any long-term information relating to HIV and AIDS, which is a relatively new disease, the body of learning from disaster and life trauma in other areas should inform decision making where possible. Caution should be exerted where the negative effects of prolonged exposure to excessive stress is observed in subsequent generations with a long-lasting effect (Sigal et al 1988).

Integration of social rules and norms. Children are essentially social beings and much of their social learning stems from early childhood. Personality, interactions, social relationships and social skills start very young. HIV can alter the course of many social exposure opportunities. Limitations due to illness and separation are the obvious ones, but blurring of understanding through unsatisfactory care arrangements, rapid turnover of adult figures, lack of clarity of role models and many such phenomena can affect this element of child development. Social functioning, experience, rehearsal and learning is vitally important for future achievement and limitations in social integration and function can have long term effects on child achievement.

Theory of mind describes how children learn to 'know' and anticipate the thoughts of others. This is an important area of development if children are to anticipate action, plan, cooperate and navigate their social environment. Application in terms of future social navigation generally, and sexual decision making specifically, may be an important theoretical implication for children affected by HIV.

Self-esteem is seen throughout the literature as an important component in development, in achievement, in confidence and coping. Yet few workers fully understand the mechanisms by which self-esteem is built up or broken down. It is vital to ensure that children affected by HIV have particular attention paid to self-esteem – something of a challenge in the face of illness, death, stigma, social uncertainty, fear and the constant battle for physical survival.

Identity is the individuality of the person and reflects an array of relatively permanent traits shown in given situations (Bee 1998). Personal identity is built up by the construction of the self through self-knowledge. Some (e.g., Freud) believe that an infant starts without a sense of self. Others (Piaget and Lewis) describe how experience and interaction with the world hues the meaning of self and development of identity. HIV infection, family disruption, quality of parenting, experience of love, hurt, rejection, may all affect the ability to sustain and maintain close relationships.

Reconstituted families. The realities of 21st-century life presents children with experience in reconstituted families through divorce, separation, remarriage, mobility and varying social arrangements. The significant factors for the well-being of children are well understood. But for children in families reconstituted because of HIV/AIDS, additional factors come. For example, the literature on the well-being of the children of a deceased HIV+ mother in a society with multiple wives show that surviving children fare less well than those whose mother is alive, uninfected or less stigmatised. The literature also cautions that upbringing in multiple reconstituted families may well have adverse effects on child achievement. This should be applied to HIV situations and forced family reconstitution.

Schooling is the universal key to educational opportunity, and access to such schooling is seen, internationally, as a child's right. HIV may impede such access for a variety of reasons. Directly health and illness may pose a barrier. Indirectly, parental ill health, destitution or disappearance may hinder access to school, regular attendance or financial/learning support for school attendance. This is not confined to Africa. Sanz Aliaga et al (2000) studied social and family characteristics of Spanish children born to women with HIV and noted that infected and non- infected children had similar social and family characteristics. However, less schooling, problems with school integration and more and longer hospital admissions were related to HIV infection in children and not so much to their status as children of HIV+ mothers.

The effects may be direct in terms of literacy, numeracy and socialisation as well as indirect in terms of access to learning, future achievement, social exposure and many other ramifications.

Psychological development

Psychosocial adjustment. Adjustment to and coping with HIV poses a challenge. Hough et al (2003) tried to postulate pathways by which a mother's HIV status affected the psychosocial adjustment in uninfected school-age children. They examined a number of variables to explain coping and showed that factors which are key in explaining child adjustment include maternal HIV associated stressors, maternal emotional distress, social support for the child, the child's own coping ability and style and, finally, the quality of the parent-child relationship.

Behavioural problems have been consistently documented in the literature for children affected by HIV. It is unclear, however, whether HIV is the causative agent or a compounding factor. Furthermore, these descriptive studies do not give insights into ways of changing, ameliorating or avoiding such problems.

The literature does suggest that HIV+ children are at risk for behavioural problems (Mellins et al 2003). The relative roles of various factors are unclear. This is compounded by the fact that many of the descriptive studies emanate from the USA, where HIV+ children acquire their HIV during childbirth. They are born to mothers whose risk for HIV infection is drug use. Thus these children have a double issue. First, the problems of drug using parents and second, the problems of HIV infection. This means that it is unclear to what extent environmental, drug or HIV factors contribute to findings in the first place and, of greater importance, whether these findings generalise to groups where drug use is not an issue. It seems probable that whatever the background, the stresses of illness, stigma, separation and death may well trigger or exacerbate behavioural problems in children. In order to tease out these various contributory factors, studies need to be large enough to explore individual factors and combination factors and provide relevant and appropriate control groups.

The true nature of the causes of behavioural problems may not be discernible. If HIV does cross the blood brain barrier and affect children neurologically, ramifications should be expected. Yet it seems impossible and perhaps undesirable to attempt to isolate pure virus implications on development without understanding the dramatic psychological impact of this disease on childhood development, behaviour and environment. Indeed it would be impossible to separate the contributory factors from their interaction, let alone quantify these. Suffice it to say that studies have measured different outcomes, used different tools, used different groups, studied different locations and cultures and, at times come up with disparate findings. Yet in almost all, an underlying theme of potential behavioural problems is a common thread, and all care provision must accommodate the harsh circumstances experienced by children in families where HIV has permeated.

In an attempt to understand these variables, Mellins et al (2003) studied 307 children in the USA and found that indeed there was a high prevalence of behavioural problems, but HIV infection and prenatal drug exposure did not account for this. The authors believed that biological and environmental factors were more likely as triggers.

Cognitive development, including critical thinking, decision making and intelligence. Intellectual and personality development refer to the understanding of normal as well as unusual cognitive development. This feeds into educational practice. Understanding of emotional and social development feeds more into child rearing practices and care. Cognitive developmental theories focus on how thinking and problem-solving skills develop and how cognitive activities contribute to development in general. Piagetian, Neo-Piagetian and information-processing theories all provide insight into information, understanding, memory, abilities and how experience and exposure shape and affect these faculties.

It is well established via batteries of cognitive tests that HIV jeopardises children in a number of ways. The studies are set out in more detail under the section on neurological problems (see above). Suffice it to say that intelligence, emotional intelligence, language and development all contribute to subsequent efficiency and style of decision making, the ability to think critically, laterally and independently as well as the ability to apply knowledge. This may set up a cycle of effects and the cognitive abilities of a child may be a dramatic influence on their own sexual debut, sexual risk taking, decision making and pathway choice.

Mental health. Burdens such as anxiety, depression, panic, abandonment, engagement and loss are wide-ranging and extend beyond the HIV+ child to all those under the umbrella of the HIV-affected family. Multiple burdens and their consequences may result in a complex web of interrelated emotional trauma without much precedent in the general literature Mental health brings suffering in its own right but has also been found to relate to developmental outcomes (Maikranz et al 2003). Murphy et al

(2002) noted higher depression among mothers living with HIV, which in turn was associated with poorer cohesion in the family as well as poorer family sociability. They noted, not surprisingly, that children of depressed mothers had increased household responsibilities. HIV related depression thus compounds the burden for children.

Children with HIV are seen as at risk for increased admission to psychiatric hospital. Gaughan et al (2004) studied 1808 HIV-infected children under the age of 15 to monitor hospitalisation for psychiatric reasons. They found higher hospitalisations for psychiatric reasons than among general paediatric populations. The 32 children who were hospitalised were suffering mostly from depression (n=16) or behavioural disorders (n=8). Forty-seven percent of those hospitalised had multiple admissions with the median age at first hospitalisation of 11 years. These findings are confirmed in other studies. Pao et al (2000) reported that adolescents with HIV had a 44 percent prevalence of depression. It is unclear at what age this begins to manifest and how these figures compare to younger children, where depression is more rare as a diagnosis. Again in the USA, the WITS study looked at younger children (3–7 years), studying HIV+ children and HIV– children from HIV+ mothers. They found 52 percent of the sample had an abnormal score on at least one inventory scale, with 29 percent scoring abnormally two; and noted that the problem areas are mostly around attention deficit and hyperactivity. They failed to see a specific factor associated with HIV infection in itself, and concluded that these high rates of problems were associated both with infection and with being affected by HIV in terms of lifestyle factors. Moss et al (1998) studied a small group of children (n=28) and found levels of depression and a cluster of life events experienced by these children directly related to HIV or the circumstances of HIV in their families.

Suicide and self harm. Gaughan et al (2004) raise the problems of suicide and self harm as potential mental health difficulties with the group they study. Suicidal ideation has been associated with HIV infection in adults, but no study has been carried out on young children. However, it is well established that self harm and teenage suicide are problems facing many young people, and suicidal thoughts, self harm and suicide attempts should be catered for if the life circumstances for children with HIV becomes an unmanageable challenge for them. Suicidal thoughts are more common among HIV orphans than non-orphans (Makame et al 2002).

Sexual development. Mahoney et al (1999) noted delays in maturation in a cohort of HIV+ adolescents, which may reflect underlying disease progression, but has relevance in its own right in terms of psychosexual development and maturation. De Martino et al (2001) studied similar issues in Italy and noted that perinatal HIV infection interfered with onset of sexual maturation. They were unclear about the mechanisms that resulted in this effect, but noted psychological distress and the effect of such differences on emerging adolescents and their self image. Buchacz et al (2003) further confirmed that suppression of the immune system was associated with delayed pubertal onset in perinatally HIV infected children – for both girls and boys.

HIV underlines the importance of strategies for sex education for children. This includes consideration of methods of dialogue, materials and opportunities to talk and address queries and skill building to enable educational debate to occur at appropriate age levels. Clearly children have questions that need to be answered as well as informational needs.

Death and bereavement. The death of a child is always a tragedy – signifying a lost loved one as well as lost opportunity. Psychologically there are issues of dying and preparation for illness and dying. Those left to support and mourn the child also carry a psychological burden. HIV has added dramatically to this burden. Palme et al (2002) showed that HIV+ children in Ethiopia had a six-fold higher mortality than HIV- children. Zijenah et al (1998) examined mortality in infants born to HIV+ mothers (n=367) and HIV– mothers (n=372). By 2 years of age, 19.6 percent born to HIV+ mothers had died, compared to 5.4 percent born to negative mothers. Ota et al (2000) looked at similar factors in the Gambia, including a comparison of mortality for HIV-1+ mothers (n=101), HIV-2 + mothers (n=243) and HIV+ mothers (n=468) at 18 months of age. Fifteen percent of infants born to HIV+ mothers died, compared to 7 percent and 6 percent of HIV-2 and HIV– mothers. In subsequent follow up in the Gambia (Schim van der Loeff et al (2003), mortality hazard ratios for children with HIV-1 and 2 was elevated compared to HIV- children.

A five-year follow up with 218 children born to HIV+ mothers and 218 to HIV– mothers was conducted in Rwanda (Spira et al 1999). Risk of death at 5 years was 62 percent in the HIV+ group – 21 times higher than the rate for uninfected children. In the USA approximately one quarter of children died by 18 months (Simpson et al 2000). This is lower than in the African studies and only covers the period prior to full integration of paediatric antiretroviral treatment. Taha et al (2000) examined mortality in Malawi over time and found that by 3 years of age, 89 percent of the HIV+ children had died, with a rapid progression from the onset of symptoms to death. Clearly, the picture emerging from Africa is of high mortality, with the death of very young children, often preceded by opportunistic illness and associated concern. Bobat et al (1998) looked at mortality in South African children with HIV infection and noted that in their group followed up for a mean of 26 months, mortality in infected infants was 35.4 percent. Two-thirds of deaths occurred in the first year of life.

Chearskul et al (2002) studied mortality in Thai children with HIV and found 46 percent mortality rate in the HIV+ children followed up for 18 months, compared to no deaths in the HIV– children. Growth failure and advanced maternal disease were predictive of death. In the UK (Cooper et al 2004), outcomes for children admitted to a paediatric unit were described over a 10-year period. Forty-two children experienced six admission episodes and 14 died in hospital. Of the 26 who survived, 5 died later. Despite the significant mortality, the authors point out that for over 80 percent of the survivors there were good outcomes in the presence of treatment.

Physical development

Physical needs and dependency issues are age related. Basic caring and nurturing provide physical comfort as well a sense of love, comfort and security. Early child development work set out by the Harlow studies (1963) showed that infants would preferentially respond to warm loving nurturance. Death, illness, separation and institutional care all mitigate personalised warmth and love, hugs and cuddles, which are all part of child security and love.

Physical development is associated with nutrition, and clearly HIV directly impacts on access to nutrition. Breast and bottle feeding are immediate issues with ramifications on physical development. Indirect factors such as poverty, illness, unemployment, the death of significant people around the child, caretaking arrangements, all affect access to nutrition.

Newell et al (2003) studied children in Europe born to HIV+ mothers for 10 years, including 1403 uninfected and 184 infected children. They found that uninfected children had normal growth patterns from early ages, whereas HIV+ children were significantly shorter and lighter than uninfected children. The differences enhanced over time. Severely ill children had affected growth at all time periods. Although this data emerges from a large European cohort, it does include data from the time preceding the availability of treatment and also includes a disproportionate number of children living in socio-economically deprived situations. Thus the data may well serve as a guide for children in poorer situations.

Mother and family effects

The literature shows that HIV in the family is associated with numerous difficulties. However, it may well be that the HIV itself is a compounding rather than a causative factor. The background of poverty exists for many children, and HIV is an added complexity rather than a single challenge.

Maternal preoccupation with illness has been shown to affect parenting behaviour and behavioural symptoms in children (Sigal et al 2003). These findings may have particular implications for HIV infection in mothers and their parenting challenges. The challenges and skills of mothering are complex phenomena – even more so in the presence of HIV. Broadly speaking, the child’s mothering experience will be affected by:

- the HIV status of the mother (positive or negative);
- the illness status of the mother (well, ill with transient opportunistic infections, terminally ill);
- the treatment status of the mother (no treatment with poor prognosis and high

illness burden, treatment available with the burdens of lifelong treatment regimes, disclosure ramifications and future uncertainties);

- the presence of the mother (time and frequency of separation, hospitalisation, death);
- mother substitutes (remarriage, adoption and fostering) all provide new mothering figures who are not the biological mother of the child. The age at which this occurs, the situation within which it occurs and the frequency of mother-figure turnover can all affect the child. It is not uncommon for an HIV+ father to remarry after the death of his wife only to suffer the death of that second wife through AIDS.

The body of learning from general child development shows the vital importance to the child of the mother, of mother-child relationships and of continuity and quality of maternal care. Maternal deprivation is well documented as a hurdle for young children in all spheres of development. HIV and AIDS presents a new set of avenues through which children may be deprived of mother love and mother care.

Mother and family effects: Key issues

Maternal mental health
Bonding
Breast feeding/nutrition
Maternal health/illness
Maternal death
Maternal isolation/abandonment/abuse

Fathers

Relatively little is known or researched on fathers, which represents a gap. Fathers are often overlooked and understudied when it comes to children. This is not because fathers are meaningless in children's lives – on the contrary. It is probably a mixture of research bias, availability for study, difficulty in access or a lack of will on the part of the research community and providers to reach out in a father-friendly way. What is well established in the general literature is the fact that fathers play a key role in child development, that fathers are involved, that they love and care for their children and that they are a force to be harnessed and not alienated.

In the face of illness, unemployment, bereavement and alienation, fathers may well suffer negative moods, withdrawal and alienation. They are invariably excluded from pregnancy voluntary counseling and testing (VCT) programmes and not sufficiently supported in caretaking when the burden falls on their shoulders alone. Fathers may well represent an unharnessed resource. The literature often sets up barriers where the focus on abuse, neglect, violence and abandonment serves as a shield to other positive qualities and may tear families apart. In the face of negative fathering, abuse, violence and abandonment, children suffer greatly.

Parentless children

There is an emerging literature documenting the effects on children of being parentless. Crampin

Fathers: Key issues

Paternal depression
Paternal illness
Paternal health
Paternal mood
Paternal involvement
Paternal absence – death, disappearance, disassociation, distance

et al (2003) carried out a comprehensive study of 2,520 children for more than 10 years. Child mortality rates were high for those with an HIV+ parent (27 percent in infants, 46 percent in under-5-year olds and 49 percent in under-10-year olds). Death of HIV+ mothers (though not of HIV– mothers or of fathers) was associated with an increased child mortality rate. The authors did not see evidence of discrimination against surviving children whose parents had been ill with HIV or had died of AIDS.

There are a number of issues to be addressed with the care of such children, especially young children. What is the best environment in which to be cared for? What caretaking arrangements help and hinder emotional development and well-being? What are the long-term consequences of current caretaking arrangements? The general literature may give some insight into these questions, even though HIV/AIDS conditions and situations are somewhat unique. Sigal et al (2003) have gone as far as middle age to explore the effects of institutionalisation at birth or early childhood and describe higher levels of psychosocial dysfunction, chronic illness and stress-related problems. These lessons need to be considered when planning care for children affected by HIV/AIDS. Indeed the style of orphan care, decision making and care provision (global or units) has been the subject of study (Wolff and Fesseha 1998). When there is no option and orphanage-type care is the only means of survival, authoritative group care is less desirable than care with shared responsibility and decision making.

Nathan et al (2003) looked at children in long-term care and examined mortality as well as other diseases such as tuberculosis. Makame et al (2002) looked at the psychological well-being of orphans in Tanzania (n=41). They noted that the orphans were less likely to be in school, and, not surprisingly, scores on arithmetic tests were lower (but equivalent when school attendance was controlled for). More orphans went to bed hungry. Of note was the mental health burden, with problem-solving strategies via internalising more frequent, and over a third reporting that they had contemplated suicide in the previous year, while seldom experiencing any reward for good behaviour. The emotional burden was higher among females than males.

The mental health of carers needs to be included in the discussion. A child whose parents have died as a result of HIV may well be cared for by a teacher, a caregiver or a relative who also, in turn is exposed to HIV. Baggaley et al (1997) described the stresses experienced by teachers in Zambia, many of whom had several orphans within their classes, HIV infected, ill or dying children in their schools as well as AIDS ravaging at home and in their social lives. The picture is not one of isolated experiences, but of a society with integrated HIV burden, affecting all. Clearly, a holistic approach is needed to understand and tackle the effects of HIV (Forsyth 2003).

The general literature has well established findings that the effects of parental deprivation are reduced by the quality of substitute care (Rutter 1987, 1998) and that single isolated life events are less likely to mould children than the continuum of caretaking causality, which allows for incorporating life challenges, adjusting and coping (Baum 1977).

Parentless children: Key issues

Institutionalised
Group care
Charitable care
Prioritising of physical over mental well-being

Cycles of deprivation

Deprivation works in cycles. There is a profound literature that shows that childhood traits predict adult functioning. There is also good evidence that psychosocial adversity plays a role in child psychopathology (Rutter 1999). Simonoff et al (2004) showed that childhood behavioural problems predict adult antisocial behaviour. Yet developmental catch-up is possible and well established (Rutter 1998).

The phenomenon of AIDS orphans and vulnerable children is clearly set out and described in the literature (Shetty et al 2003). The numbers are large and the only sense made out of them is that they continually increase with every report over time. The authors conclude that without care of parents or an appointed caregiver, children are exposed to 'extraordinary' risks. These relate, generally, to malnutrition, poor health, inadequate schooling, migration and rootlessness, homelessness and, ultimately, abuse.

There is weak support for the findings that negative life events for children can provoke psychiatric episodes in later life (Sandberg et al 2001). Although the methodology and causal pathways in these kinds of postulations need rigorous understanding, the cycle of negative events associated with HIV infection may well be a trigger. Yet this must be viewed hand in hand with the resilience literature which shows how children cope, bounce back and adapt, despite high levels of adversity.

Child neglect

It is well established that past and current neglect can have severe, negative short- and long-term effects on children (Hildyard and Wolfe 2002). Areas documented that are affected include cognitive development, socio-emotional parameters and behavioural development. A variety of theories on early child development, the importance of attachment, stimulation and security may explain the fact that neglect which occurs early in life is particularly detrimental to subsequent development. Given the mortality and morbidity statistics related to parental HIV and the lack of treatment for parents, these findings have particular resonance for HIV infection and HIV-affected children. Of interest is the finding by Hildyard and Wolfe that when compared with physically abused children, neglected children showed more severe deficits in cognitive and academic measures as well as problems with social withdrawal and peer interactions. The quality of the home environment may well affect or even mediate cognitive attainment (Coscia et al 2001). O'Connor (2003) pointed out that children who experience early deprivation have problematic attachment with subsequent adoptive parents. Yet Croft et al (2001) remind us that longitudinal follow-ups of children show a child-prompted beneficial effect where children who make cognitive gains are able to affect subsequent relationships for the better – casting doubt on the idea that change is not possible and that intervention and development cannot mediate towards an improved or enhanced outcome.

Developmental delay

Perrino et al (2000) noted that families provide the most proximal and fundamental social system, which can influence child development generally and sexual risk taking specifically. The role of families is seen as fundamental in the ecodevelopmental systems that provide context and social guidance for emerging adolescents. By the same token, it is important to note that AIDS orphans may be deprived of such social systems, may be exposed to different systems, and may inherently be in greater danger and at higher risk as a result. From the earliest childhood infections, the concept of developmental delay has been discussed and monitored. In the early years of the epidemic there were serious concerns and calls for educational planning and special needs provision. However, these predictions were not realised, and a more complex picture seems to be emerging, although it is one whose development is hampered by the fact that the majority of impacted children are in Africa, while the majority of studies have been conducted in the USA. It may be that generalisations can be made, but there is a vast difference between settings where treatment is available and those where it is not; and associated local factors such as the use of crack cocaine or haemophilia in the USA. Furthermore, some of the findings are disparate and inconclusive. Failure to find gross deficits is common in the literature, although many studies elaborate on subtle findings which cannot be overlooked or ignored (Whitt et al 1993; Nozyce et al 1994). Some studies compare HIV+ children with HIV-exposed but negative children (often called seroreversion); while others compare them to uninfected and unexposed controls or to age norms. Studies have used a variety of measures, so it is unclear which measure definitively describes elements of development. Table 3 above summarises a wide range of reported studies. It is clear from this table that neurological and developmental delays are observed in some, but not all studies.

It is also clear that they tend to be mild rather than gross, and that illness factors are related to more significant deficits (Tardieu et al 1995; Papola et al 1994; Hilgartner et al 1993).

Levenson et al (1992) noted difficulties with memory tests and verbal scores. This is important as many tests are language dependent. Expressive and receptive language effects were confirmed by Wolters et al (1995), who showed a relationship between CT scan brain abnormalities and language functioning. Yet Havens et al (1993) specifically looked at language and found no effect, but confirmed memory and reasoning disparities. Nozyce et al (1994) recorded that impairment was often related to subsequent illness.

There is more to development than simple maturation and neurological factors. Stimulation, environmental factors, nutrition, opportunity, encouragement and feedback/ reinforcement all play a role in development. These key themes form the basic tenets of much of the theoretical understanding of child development, irrespective of focus (e.g., early behaviourist theory, Piaget, Vygotsky, Bruner and the theories of others who incorporate social context and environment to a greater degree).

For the HIV+ child, where the virus may well have penetrated the developing neurological system, and where opportunistic illness may limit opportunity and life engagement, the social situation, parental caretaking and encouragement may be directly affected by HIV. Ill parents are less available to stimulate children. Nutrition and economic deprivation also affect nurturing environments. Death and debilitation may lead to large groups of children cared for by a single caretaker. This stretches resources and reduces the proportion of undivided individual attention that the child receives. Motivation, curiosity, confidence and pleasure are all variables that assist a child in exploration, learning and skill acquisition. Any environmental or caretaking deprivations can have a clear impact on opportunity as well as ability.

For the HIV– child, the ramifications are very similar – with variation occurring as a result of the child's health status, which may be unimpeded by HIV but may be challenged by a host of other illness factors which form the mosaic against which many children who live in poverty struggle.

Developmental delay: Key issues

Subtle rather than gross

Interaction with neurological problems unclear

Interaction with environmental problems unclear

Interaction with predisposing risks unclear (such as parental drug use, illness)

Additional chronic illness (coinfection)

School attendance affected by orphanhood which compounds development delay

Availability of extended family buffers children against adverse effects

Emotional and mental health considerations

Disclosure. HIV is stigma bound, and disclosure of status, unlike with other illnesses such as cancer or diabetes, is problematic. The problems exist irrespective of who the person with HIV is (parent/child or all). Disclosure and secrecy issues affect children in relation to both their own status as well as the status of family members.

Mialky et al (2001) studied 85 HIV+ children and noted that 43 percent had been told their diagnosis (the average age at disclosure was 9 years). In 23 percent of the cases had school staff been made aware of HIV+ status. Funck-Brentano et al (1997) studied 35 HIV+ children in France and observed partial disclosure in 40 percent of the children and full diagnosis disclosure for 17 percent. Secrecy and deception were common caregiver strategies. It is not only the disclosure of the child's own status that is relevant, but also an understanding by the child of parental status. In this study, few children were aware of their parent's infection. Furthermore, 74 percent reported stressful experiences due to HIV, regardless of the disclosure pattern.

Lee et al (1999) note that there is a gradual change in perspectives. In their USA sample, 41 percent of 6-year-old children had complete disclosure of HIV status and a further 19 percent had partial disclosure. Melvin and Sherr (1995) recorded that only 7 percent of their sample of HIV+ children knew of their own HIV status. Even when children know of their status, secrecy, sibling and wider family ignorance often abounds, and full information is often missing. Kirshenbaum and Nevid (2002) studied 58 HIV+ women and disclosure to their children. Fifty-seven percent of the children had been told of the diagnosis. Disclosure does not simply refer to identification of infection, but includes providing greater detail regarding prognosis and the possibility of death, and promoting the sharing of the knowledge and prohibiting the maintaining and spreading of secrecy and silence. Kirshenbaum (2002) found that details disclosed did not affect child functioning. However, Sherman et al (2000) studied the consequences of child disclosure to other children in a follow-up study of 64 children. They believed there were positive consequences of disclosure to a friend, and that disclosure did not impact on behaviour or self concept. However there are limitations in this study that relate to variables within families, variables that depend on whether the families facilitate or prohibit disclosure.

Stigma associated with HIV is a rather unique factor and cannot be underestimated. It embroiders a web of secrecy, fear and shame which adds a burden to young shoulders. Stigma can have direct and indirect effects. The fear of stigma may link to parental caution with disclosure, parental mood difficulties and secrecy in the family. Experienced discrimination is well documented, and people with HIV may be excluded from certain environments or activities with direct effect on the child. School attendance has been prohibited. Those experiencing discrimination report an array of experiences, including barriers to employment, relationships, health and welfare needs and social opportunities. The young child may experience such discrimination directly or be affected indirectly. Both the fear of stigma and the experienced stigma may be limiting factors on child opportunity and experience. Few remedies for stigma have been fully developed so far. Basic education and fact sharing are seen as necessary components in helping to ensure community integration but are not sufficient in themselves; and even when communities report a high prevalence of HIV, stigma abounds.

Feeding and nutrition are core considerations at many levels of HIV disease. Mode of feeding (breast or formula) of a young infant has been shown to play a decisive role in subsequent HIV transmission. The tensions between breast feeding and formula feeding, especially in cultures where breast feeding is normative and formula feeding not available without risk of other infections, has proved difficult. Solutions in terms of exclusive breast feeding have been explored. In addition to the transfer of nourishment, infant feeding has elements of nurturing which should not be overlooked. Feeding is a loving time, a vehicle for bonding, learning and relationship formation. Feeding provision and reading feeding and hunger signals from a baby establish early patterns of response and love. HIV can affect nutrition in various ways. An ill child may be less able to eat wholesomely. A child in a family ravaged by HIV/AIDS may have less access to food and less access to a caretaker who will provide feeding and the nurturing environment around feeding. Gulgolgarn et al (1999) reported on infants who were formula fed in Thailand and noted that in formula-fed infants, malnutrition signs were predictive of HIV infection.

From the general literature there is a fascinating association between parents with eating disorders and infant outcome. These studies (Stein et al) suggest that a child fed by a mother with eating disorders is affected; and HIV may be viewed in the light of these findings – where maternal illness, lack of resources, mood or absence may affect infant nutrition. Leandro-Merhi et al (2000) studied 124 children born to HIV-infected mothers (1 HIV+ and 53 HIV–). They noted that the growth of infected infants was significantly affected.

Brouwers et al (1996) argued that nutrition may play an additional role to that of HIV infection in neurobehavioural manifestations of HIV in children. The role of reversing this with antiretroviral treatment was ambiguous in this study.

Failure to thrive has been commonly described in HIV+ children – although the mechanisms underlying this phenomenon are unclear. Miller et al (2001) studied 92 HIV+ and 439 uninfected children. They concluded that failure to thrive was associated with both clinical factors and maternal factors (in this case drug use during pregnancy). Bobat et al (1998) also noted that risk of illness was associated with failure to thrive. It seems that the phenomenon is complex with multiple contributory causes.

Sleep disturbance has been described in HIV+ children (Franck et al 1999). This may have extended implications in terms of the level of functioning in daily activities for a sleep disturbed child.

Sibling relationships

Sibling relationships are well described in the literature (Dunn 1983; Dunn and Plomin 1991; Dunn et al 1994, 1998) and typified by an uninhibited emotional quality (unlike with peers), mutual interest in one another, high frequency of interaction, well-established attachment (Brody et al 1998), but also by well-described aggression (Aguilar et al 2001). Siblings can influence each other's later development (Beardsall and Dunn 1992).

In the arena of HIV, siblings are often a silent group of children deeply affected by the epidemic, but rarely studied, other than in the capacity of 'control groups'. Yet they are directly affected by infection in the family – which is often multiple. The affected child experiences a disrupted family, loss and separation, secrecy, interrupted parenting, disproportionate attention to the ill child and associated hardships that are the inevitable companions of this infection. Such hardships include poverty, financial hardship, all the financial and social consequences associated with HIV illness such as unemployment, health-care expenses, exclusion, stigma, discrimination, caretaking tasks, school interruption and parental discord. Melvin and Sherr (1995) noted that siblings were often kept in ignorance of family infection, assumed caretaking responsibility and, in time, become the primary carer of ill siblings if parents died.

The long-term damage on such children has simply not been documented in HIV/AIDS, although the lessons from other diseases are there for a precedent (Labay and Walco 2004; Pilowsky et al 2004). The growing orphan problem will create wide-ranging international problems (Foster 1996). Kamali et al (1996) studied a rural population in Uganda, where seroprevalence of HIV was 8 percent among adults, and they found that over 10 percent of children under the age of 15 had lost one or both parents. Paternal loss was more common than maternal loss (6.3 percent compared to 2.8 percent) with continued loss three years later at 43 percent. School attendance was directly affected by orphanhood – a factor which may compound developmental achievements.

Foster et al (1995) tracked 570 households in Zimbabwe and noted that by as early as 1992, 18.3 percent included orphans primarily below 15 years of age. Care was invariably by extended families, which suffered from strains but did not discriminate or exploit the orphaned children. Sibling headed orphaned families were emerging.

Levine (1995) listed some of the unmet needs of orphaned children in the USA, particularly in relation to mental health services with a growing burden of orphan needs. Schable et al (1995) studied 541 HIV+ women in 10 US centres and noted that 88 percent had living children, and 49 percent had more than one child. Caretaking patterns were mixed: the most common scenario was that of a single mother (46 percent), grandparents in 16 percent of cases, and mother and father in only 15 percent. Ryder (1994) studied the psychosocial and economic impact on orphaned children over a four-year period in Kinshasa. No less than 1,072 children were studied, comparing orphaned children first with a group living with an HIV+ mother who was alive and second with an HIV– mother. Orphan rates were 8.2 per 100 HIV+ women-years-of-follow-up. The availability of a caring extended family buffered these growing children against adverse health and socioeconomic effects.

Siblings: Key issues

- Silent group
- Often kept in ignorance
- Undertake caretaking duties
- The bonds of siblings need to be studied

Grandparents and carers

In this era of mass AIDS-related death, grandparents are often called upon to provide childcare – for both well or sick children. This may be in the face of their own child's illness or death. The needs of grandparents can be totally overlooked at the point where they are relied on to be providers rather than receivers of care.

Aunts, uncles, cousins and friends are all, inevitably, drawn in. In some cultures the extended family is the core of support networks. These are often stretched to their limits, or even to breaking point. Seeley et al (1993) describes the extended family as a 'safety net with holes in it'. Children are at high risk of multiple placement (Adnopoz 2000). Carers, from voluntary sector to health-care service, are also affected, but very few studies have documented their needs and their burdens or the interventions which successfully alleviate these (Baggely et al 1997). Appleton (2000) described resilience and adaptation in communities facing AIDS deaths and orphans. Joslin and Harrison (2002) described compounded stress and neglected self health in the presence of surrogate parenting. Brookes et al (2004), in their study of 2,878 children aged 2–14 years, showed that 65.3 percent were cared for by biological parents, 20.3 percent by grandparents, 4.2 percent by siblings and 5.4 percent by other family members. Only 4.6 percent were cared for by non-family carers and of note was the fact that 0.2 percent of the children had nobody caring for them: a tiny but significant number. Of note, as well, was the fact that 13 percent of carers were over 60 years of age while 42 percent were less than 18 years of age.

Alternative care arrangements

HIV and AIDS may undermine traditional nuclear or extended families. In the presence of HIV, a number of alternative care arrangements have evolved or been set up. Children may be abandoned in hospitals and become 'boarder babies'. Unplanned orphanages or institutional care settings may emerge. On the other hand, planned orphanages have evolved to respond to childcare needs. A number of other forms of care have been observed, such as alternative family-member care (such as grandmother/aunt) and forms of foster caring where community members who are not related to the child undertake care. In many cases sibling care has been documented with the emergence of child-headed households. Few of these provisions have been evaluated in terms of their impact on children's emotional, physical and educational development.

Gender

We know gender matters later on but few under five studies control for gender. When gender is studied it is clear that it matters. Newell et al (2003) has noted significant survival and infection differences according to gender, where female babies are more likely to become HIV infected in utero and male babies are significantly more likely to become HIV infected via breast feeding. Table 4 below attempts to highlight a few findings where gender issues (the gender of the child or the parent according to the study), seems to be a factor.

What's missing: Areas that need better understandings

This overview summarises much of the HIV data and attempts to tie in key child development issues. It serves as an introduction to a rapidly changing field. Many issues are only briefly touched upon and could benefit from detailed discussion. The changing issues in HIV and the rapid evolution of research, studies, understanding and experience mean that frequent updating is necessary. A number of issues have not been included in the focus and may well merit separate consideration in depth:

Table 4: Gender in HIV studies

Study	**Issue**	**Gender findings**
Makame et al (2002)	Psychological well-being of AIDS orphans in Tanzania	Females scored higher than males for internalising problem scores
Kamali et al (1996)	Orphans in Uganda	Paternal loss > maternal loss
Lindblade et al (2003)	Impact on child development of parental death (mother vs father)	Paternal loss significantly associated with reduced development scores
Brookes et al (2004)	Not enough money for food and basics according to gender of parent loss	Maternal orphans – 4.2% Paternal orphans – 12.9% Father loss results in higher deprivation of basics and food
Levenson et al (1992)	Neurological development of children with HIV	No significant differences according to gender

1. Training of adults (family members, teachers, preschool teachers) around the following:

- family involvement and empowerment;
- linkages between ECD and primary school (building on the preprimary benefits rather than damaging them);
- sexuality, sexual taboos;
- children as 'beings' as well as 'becomings', but never allowing the being to be swamped by focusing on the becoming – don't lose childhood.

2. Individual behaviours:

- how does the consciousness of children about what they are learning develop so that they respect what they are learning, their own personality and the social environments in which they are growing?
- linking development and behaviour: what are the lessons for the early years and beyond (ECD programming, parents/caregivers, primary schools)?
- relationships should be the focus rather than specific outcomes;
- what's the balance between the child's developing 'intuitive' responses that are experience derived, and conscious choice-influencing behaviour.

3. Gender:

- discrimination and links to violence/abuse against young girls especially;
- no violence is ever acceptable but how to counter?
- girl children's submissiveness in many cultures, but it's OK for girls to maintain traditional caring roles in family (not discrimination).

4. Mental health:

- psychological/mental health focused on death, dying and end of life;
- living with HIV/AIDS vs dying from AIDS;
- adaptation of understanding and interventions for child behaviour, child problems, child development and environmental challenges

5. Stigma, discrimination and legal redress:

- access to justice;
- human rights;
- the rights of the child;
- the ramifications of discrimination in terms of financial and social wellbeing.

6. Causal pathways:

- there are a number of interlinking concepts which should be explored in more detail;
- cycles of problems, and roots of problems need exploration;
- an understanding of the longer-term links between childhood experience in the presence of HIV and future development, risk behaviour, adulthood, social wellbeing and indeed parenting.

Concluding comments

This review has set out to catalogue some of the literature and understanding of HIV/AIDS and to look beyond the boundaries of HIV/AIDS to the general early childhood literature, to gather insight, direction and meaning. Such an exercise serves only to highlight large chunks of missing information. Gender differences must be explored and understood. Studies need to examine their findings by gender. Even when gender findings are set out, they are rarely explained, acted upon or translated into policy. Some glaring findings are emerging associated with HIV transmission and gender:

Stigma abounds. Children are often denied a voice at policy or redress levels and as such can only be represented when they are advocated for. In the scramble for resources they are at risk. Yet the prevention of HIV infection in children has been the very key to opening up HIV/AIDS services in Africa, to prompting treatment access on the continent and to the provision of internationally revolutionary provision in terms of the global AIDS fund.

Even when findings are established, causal pathways are poorly understood. Provision is rarely evaluated and this results in haphazard resources rather than evidence based provision.

The medical focus may have blurred the psychosocial issues. Yet these coexist. The presence as well as the absence of treatment brings these into sharp contrast. In relation to early child development there is a literature on the beginning and end of life issues for children affected by HIV/AIDS – but the middle is missing. In between birth and death comes life. Early childhood development is the springboard for life.

The future

The future holds many keys but is shrouded. The clarity of vision often depends on the clarity with which those in power care to look. There are clearly gaps in care provision, and these gaps have short- and long-term consequences. Much is written in the literature about tomorrow's generation. Yet the reality is they are today's generation. It is imperative that the world does not sit by waiting for what tomorrow may bring without preparation.

Although many effects of HIV/AIDS can be catalogued, there is no reason to doubt resilience, the enormous human capacity, the elasticity and inner resources of children and the possibility that effects are reversible.

The future may be an inevitable extension of the past. But, unlike the past, the course of the future can be chiselled. The psychological aspects are often neglected in pursuance of medical understanding. The balance needs to be redressed so that emotional health and well-being move centre stage.

Key questions

Who is evaluating the impact of the care provision?

What are the gaps and the consequences?

Tomorrow's generation is here now: Are we preparing them for tomorrow? Are we listening to them, yet alone asking them?

Do we recognise that quality, not quantity, of care is shown to determine long term effects?

Do we understand that effects are reversible?

Can we redress the imbalance between the physical to mental?

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(A fully annotated and expanded version of these references is published as Working Paper 34)

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About the Bernard van Leer Foundation
The Bernard van Leer Foundation, established in 1949, is based in the Netherlands. We actively engage in supporting early childhood development activities in around 40 countries. Our income is derived from the bequest of Bernard van Leer, a Dutch industrialist and philanthropist, who lived from 1883 to 1958.

Our mission is to improve opportunities for vulnerable children younger than eight years old, growing up in socially and economically difficult circumstances. The objective is to enable young children to develop their innate potential to the full. Early childhood development is crucial to creating opportunities for children and to shaping the prospects of society as a whole.

We fulfil our mission through two interdependent strategies:

- Making grants and supporting programmes for culturally and contextually appropriate approaches to early childhood development;

- Sharing knowledge and expertise in early childhood development, with the aim of informing and influencing policy and practice.

The Foundation currently supports about 150 major projects for young children in both developing and industrialised countries. Projects are implemented by local actors which may be public, private or community-based organisations. Documenting, learning and communicating are integral to all that we do. We are committed to systematically sharing the rich variety of knowledge, know-how and lessons learned that emerge from the projects and networks we support. We facilitate and create a variety of products for different audiences about work in the field of early childhood development.

Information on the series and sub-series
Working Papers in Early Childhood Development is a ‘work in progress’ series that presents relevant findings and reflection on issues relating to early childhood care and development. The series acts primarily as a forum for the exchange of ideas, often arising out of field work, evaluations and training experiences.

The purpose of the *Young children and HIV/AIDS sub-series* is to share information, ideas and emerging lessons with readers who are concerned with young children affected by HIV/AIDS. As ‘think pieces’ we hope these papers will evoke responses and lead to further information sharing from among the readership.