This is the manuscript of a chapter published in *Protecting childhood in the AIDS pandemic: Finding solutions that work*

RUNNING HEAD: Psychosocial interventions for AIDS-affected children

Healthy Minds: Psychosocial Interventions for School-Aged Children Affected by HIV/AIDS

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Children Affected by HIV/AIDS: Psychosocial Interventions for School-Aged Children

For any child the school years are essential in the transition into young adulthood. During these years children establish friendships, form relationships, and build resilience to cope with life's challenges. For young children, the family and primary caregiver are often the strongest influences; however, during the school years this rapidly and irreversibly expands to include the influence of teachers, peers and the wider community. Importantly, for children in families affected by HIV/AIDS these formative years often take place alongside familial experiences of severe illness and death. The psychosocial difficulties associated with growing up in an AIDS-affected family are only just beginning to be understood and are the focus of the current chapter. Specifically, the chapter has three major aims: first, the psychosocial needs of children affected by AIDS will be discussed; second, potential mechanisms through which familial HIV/AIDS may influence children's psychosocial development will be described; and third, the evidence-base for psychosocial interventions targeting AIDS-affected children will be reviewed. Throughout the chapter we will discuss real-world examples, with a particular focus on sub-Saharan Africa, as well as identify gaps in the research literature.

We use the ecological model of Bronfenbrenner[1] as a broad conceptual framework. This model was specifically developed to further the understanding of risk and protective factors associated with children's psychosocial health. Recently, Richter, Foster and Sherr[2] have adapted this model for use with AIDS-affected children. The model sees children at the centre of multiple, interacting layers of influence. Most proximal to the child are relationships with caregivers and their everyday care-giving environment. More distal to the child are school and community influences, followed by the wider political, policy, and cultural factors that contribute to the contexts in which children live. The model suggests that the impact of severe adversity (such as belonging to an AIDS-affected family) in a particular 'sphere' of a child's life can be mitigated by positive factors in another 'sphere'. This theory has been supported by research examining children's resilience, or their capacity to have psychosocial well-being despite the major life events to which they are exposed[3]. The chapter will specifically focus on children who have lost a parent or carer to AIDS, children who are caring for an AIDS-sick caregiver ('young carers'), children who are HIV+ themselves, and children who live on the streets due to bereavement or HIV/AIDS-related family problems. It is important to note that many children may fall into two or more categories, or may move between categories over time.

Psychosocial needs of school-age children affected by AIDS

Until the early 2000's, there was almost no research into the psychosocial needs of AIDS-affected children, and the literature on child mental health in the context of parental illness or death did not yet address AIDS-affected families. As the number of AIDS-affected children has risen into the million[4], a new body of research has developed. The majority of this research is clustered in sub-Saharan Africa and the USA, although new research in China and India is currently underway[5]. Almost all of this research is still focused on understanding the problems experienced by children affected by AIDS; an area in which our knowledge is far from complete.

Children orphaned by AIDS

There is remarkably consistent evidence from both America and sub-Saharan Africa that losing a parent to AIDS is negatively associated with children's psychological and social well-being. Emerging evidence from China suggests a similar pattern. Although there were early fears that orphans may be 'potential rebels' or a 'delinquent generation'[6], recent findings suggests that children orphaned by AIDS are much more likely to suffer symptoms of depression or anxiety than to have behaviour problems. In sub-Saharan Africa, multiple studies have reported that being orphaned by AIDS is associated with high levels of emotional distress, particularly symptoms of depression, anxiety, and poststraumatic stress. Children orphaned by AIDS also report difficulties in socialising with their peers[7]. Similar findings have been obtained in the USA, although in the USA children are more likely to also report behaviour problems such as aggression[8]. Recently, a controlled study in China also reported heightened psychological distress in children orphaned by AIDS[9]. However, few of the studies cited above are able to compare the impact of being orphaned by AIDS with the impact of being orphaned by other causes. A recent South African study compared children orphaned by AIDS, children orphaned by other causes, and non-orphans on mental health outcomes. Results revealed that being orphaned by AIDS was consistently associated with more depression, PTSD and peer problems (see Figure 1) than parental death by other causes[10].
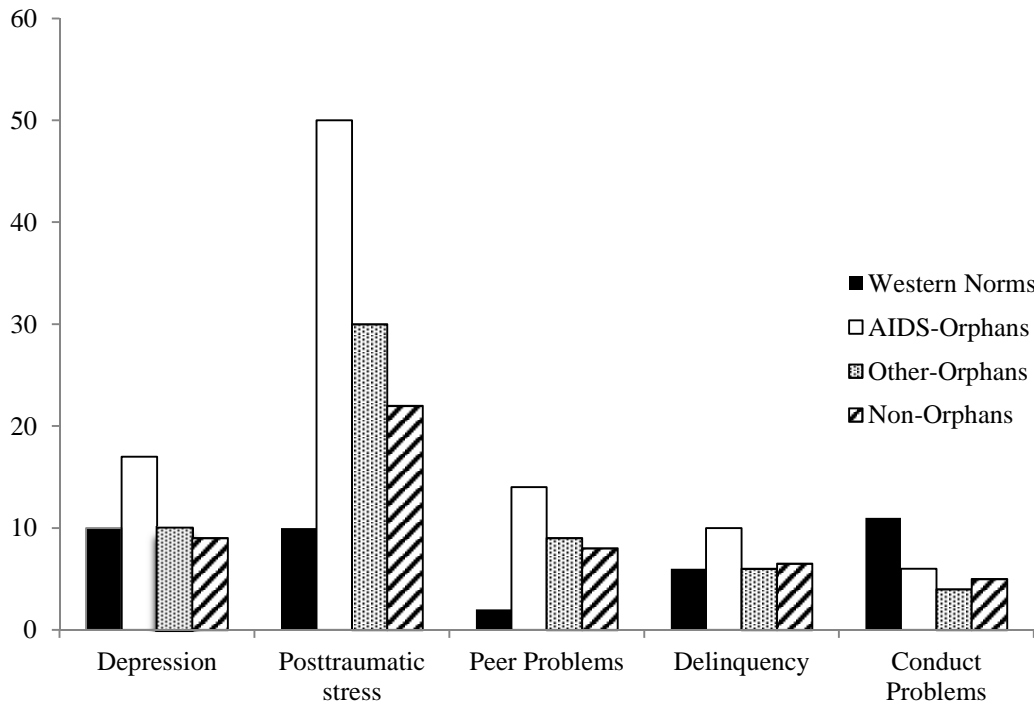
Figure 1. Proportions of children in the clinical range in South Africa

New evidence also suggests that orphaned children may be at greater risk of becoming infected with HIV in later life. A recent review[11] found four studies worldwide, reporting higher levels of HIV-infection amongst adolescent orphaned children in Zimbabwe[12], South Africa[13], and Russia[14]. Three more studies reported higher levels of sexual risk behaviour in orphaned children[15]. Although we do not yet know the mechanisms through which orphanhood may be influencing sexual behaviour and HIV infection, one study does suggest that psychological distress may be contributing to risky sexual behaviour amongst orphaned children[16].

Children living with HIV+ or AIDS-sick adults

Orphanhood by HIV/AIDS is not a single acute event, rather it is a process preceded by a parent's chronic and debilitating illness[17]. In sub-Saharan Africa, health systems are often overburdened by HIV-related illnesses. This has resulted in most terminal AIDS-patients remaining in the home. Therefore, children in AIDS-affected families are likely to witness a caregiver's debilitating illnesses and death.

It has been established that HIV is often a 'family secret' and that this can reduce a child's opportunities to seek support from school or peers[18]. Research also shows that HIV-

positive mothers find disclosure of their status to their children stressful and worrying. A particular worry is whether or not school-age children will be able to keep their parents' status confidential, and this prevents many mothers from disclosing[19]. The evidence on the effects of disclosure to children is mixed, and most of it comes from the USA, which may limit its generalisation to the developing world. The few studies conducted in sub-Saharan Africa have focused on parents' views of the effects of disclosure, and there is a clear need for research exploring children's perspectives[20]. The little research that has been conducted suggests that disclosure to children is often left towards the terminal stage of the disease, as parents are often not ready to disclose in the initial stages of the illness. In most cases non-disclosure is linked to avoidance of stigma and protection of the children[21]. We do know that children who are not told of their parent's status often suspect that something is wrong, and may become confused and anxious[22]. Similarly, some studies report more behaviour problems and depression in children after mothers disclosing HIV+ status[23]. On the other hand, disclosure to children may be helpful and essential for long-term family coping. When disclosure does happen, some parents report that it increases family closeness[24]. It is imperative that we better understand how to make parental disclosure as positive as possible for children and parents

We know very little about the psychosocial needs of children living with HIV+ or AIDS-sick caregivers in the developing world. In the USA, studies have found both emotional and behavioural difficulties for children whose parents are HIV+[25]. In China, children with AIDS-affected parents showed higher distress than children in healthy families[26]. In the developing world, qualitative evidence certainly suggests that these children suffer from distress, and this is supported by some initial quantitative studies[27]. In South Africa, the extent of caregiver sickness was found to be a mediator of children's mental health problems[28], and a small study found more psychological distress amongst children whose parents had full-blown AIDS than amongst children whose parents did not[29].

It is also likely that many children who live with AIDS-sick adults are acting as 'young carers'; taking on medical care (including tasks such as washing and bathing the sick adult), household tasks, and care for younger siblings[30]. Evidence from the West suggests that 'young carers' (of parents with other illnesses and disability) are at risk of psychosocial problems[31]. However, almost no research to date examines psychological outcomes for 'young carers' in the contexts of AIDS or in the developing world. Bauman and colleagues[32] compared 50 young carers of AIDS-sick parents in Zimbabwe to 50 young carers in the US. Results showed high levels of depression in both groups. In qualitative studies, children

report both emotional distress as well as positive experiences and competencies associated with responsibility and contribution to the household[33]. Understanding the extent to which the psychosocial problems experienced by children orphaned by AIDS are established during the period of parental sickness is of the utmost importance for future research.
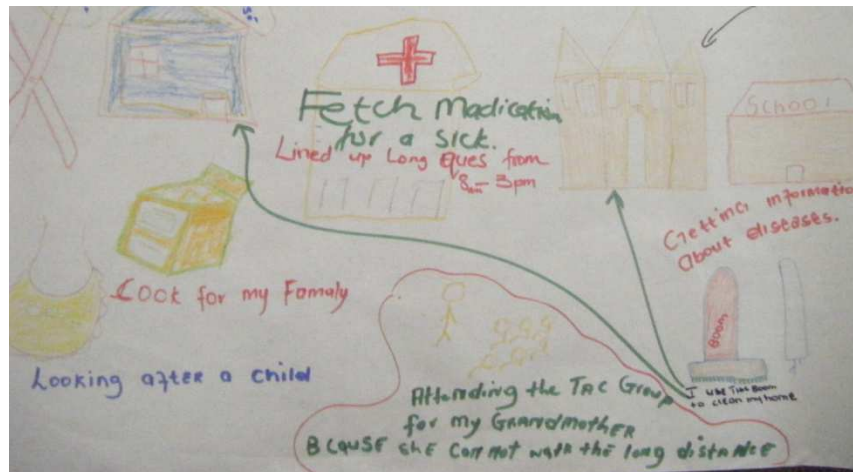

Figure 2. Things which I do: cook for my family, looking after a child, fetching medication for a sick person – lined up in long queues from 8am-3pm, getting information about diseases, attending the HIV support group for my grandmother because she cannot walk the long distance. Young Carers Study Teen Advisory Group, 2010 www.youngcarers.org.za

HIV+ Children

For school-aged children, being HIV+ brings specific psychosocial needs and risks; however, again these are not yet well understood. This section will only focus on children who have been infected perinatally (i.e. by an HIV+ parent at birth) as psychosocial outcomes may be different for children who are infected via abuse, injection drug use, infected blood, and consensual or forced sexual contact. This is a newly recognised group of children. Before the introduction of paediatric anti-retroviral medication (ART), few perinatally-infected children survived infancy[34]. Recent estimates for Africa suggest that mortality amongst HIV+ perinatally-infected children is 36% by age 1, 62% by age 5, and 83% by age 15[35]. A 2010 review finds that this low rate of survival is due to variable access to child anti-retrovirals, delayed diagnosis, and poorly-resourced health systems[36]. However, as more children are surviving beyond early childhood, it is important to consider their specific psychosocial needs during the school-aged years.

The very limited evidence suggests that having the HIV virus may cause developmental, motor and emotional delays for children[37]. However, a recent review found almost no studies which looked at HIV+ children over the age of two, or at psychosocial effects of children's HIV-infection[38]. Studies of young children found that HIV+ children scored lower on the personality-social domain of the Denver scale[39] and had less secure attachment to their mothers[40]. A recent qualitative study in South Africa of HIV+ children found psychosocial challenges including dealing with loss of biological parents, coming to terms with their HIV-status, external stigma and discrimination, and disclosure difficulties[41]. For all studies of HIV+ children, it is difficult to distinguish effects of HIV-infection with the social, economic and family impacts of the illness.

In the USA, paediatric ART provision since the mid-1990s has resulted in a cohort of HIV+ children who are now progressing through adolescence[42]. Research with this group suggests they experience emotional challenges in adjusting to a chronic, highly-stigmatised and parentally-acquired disease[43]. These children are also at greater risk of psychiatric hospital admissions for depression and behaviour problems (with an incidence rate of 6.17 cases per 1000 person years, as opposed to 1.70 cases per 1000 person years in the general population)[44]. In particular, disclosure to children of their HIV-status remains a major issue. Most children who have been infected at birth are not told of their own status until they are thought to be old enough to understand (and often to keep the family secret). Disclosure to the child also often means disclosure of the parent's HIV-status, and the causes of infection. Studies in the USA suggest that this can be a stage of great disruption for families, although children feel strongly that disclosure is important, and many have already guessed by the time they are told[45]. The school-age years are also those in which adolescents develop relationships and often have their first sexual experiences. HIV+ children report concerns about relationships and safe sex[46], and fear that disclosure to sexual partners could lead to social stigmatisation or rejection[47]. Research also suggests that this can be a time of rejection or inconsistent use of ART medication, due to unpleasant side-effects such as developing of embarrassing fat deposits, and adolescent 'acting out'[48]. Lack of medication adherence can have severe individual and public health outcomes of opportunistic infections and viral resistance.

Rollout of anti-retroviral treatment to children in the developing world has been far slower than in the developed countries. But the next five years will see increasing numbers of perinatally-infected children on long-term ART surviving through adolescence. The experiences of these children will certainly be in a different context to that of the USA, but it

is essential that the developing world (particularly sub-Saharan Africa) does not ignore the possibility of similar challenges in the future.

Children living on the streets

The stress of familial HIV/AIDS can contribute to children living on or working on the streets. The word 'street-child' is often used for two groups of children; those who live with their families, but spend time on the street (often in order to earn money) and those who sleep on the streets (but may have occasional or regular contact with families). Although evidence is scattered and on a small scale, research does suggest that a disproportionate number of children orphaned by AIDS are living as street-children[49]. There is very little empirical research on the effects of living on the streets in the developing world, but qualitative work and a small number of quantitative studies suggest major daily risks of violence, drugs, transactional sex and abuse[50].

Potential mechanisms through which familial HIV/AIDS may influence psychosocial development

What is it about living in an AIDS-affected family that makes the lives of these children more difficult than even other orphans? Research is beginning to elucidate potential mechanisms through which familial HIV/AIDS may influence psychosocial outcomes. These are briefly summarised below. Understanding the mechanisms through which familial HIV/AIDS impacts upon child well-being will have important implications for the development of effective interventions.

Caregiver sickness: HIV diagnosis and illness in parents is often associated with depression and reduced social support[51]. Although we could find no studies exploring the direct effects of HIV on parenting, there is strong evidence from other groups that children are negatively affected by parental depression and reduced social support[52]. In one South African study, the extent of caregiver illness positively predicted the level of psychological problems for children[53] and in Uganda, having a chronically ill adult in the household was strongly associated with child psychosocial distress[54].

Extreme poverty: Many studies in the developing world have shown that AIDS-sickness has major financial impacts on households. These include loss of income from the sick person and carer, medical costs and funeral expenses[55]. In South Africa and in Ethiopia,

mental health problems for children orphaned by AIDS were shown to be mediated by poor nutrition, school exclusion for financial reasons and lack of access to social grants[56], although in Uganda hunger was not found to be a key mechanism[57]. We know less about the effects of poverty on children whose parents are alive but unwell, or the effects of poverty on HIV+ children. There is some qualitative evidence suggesting that extreme poverty may result in children engaging in transactional sex in order to support their families or pay school fees[58].

AIDS-related stigma: Stigma is one of the strongest mechanisms accounting for mental health problems such as depression and post-traumatic stress in children orphaned by AIDS[59]. Qualitative evidence suggests that AIDS-related stigma is also a cause of great distress for children whose parents are visibly AIDS-sick, with people gossiping about them or calling their parents promiscuous or prostitutes[60]. Families of HIV+ people may also be stigmatised due to inaccurate fears of infection through touching or sharing food with a person from an AIDS-affected household[61]. Bullying is also an important mechanism accounting for psychological distress, and seems to be directed both at children with AIDS-sick parents, and children orphaned by AIDS[62].

Social Support and family support: Research suggests that social support from family, friends, and school staff can mitigate the effects of trauma amongst children orphaned by AIDS[63]. Attitudes of fostering families towards orphaned children and ill-treatment in their homes were also predictive of child psychosocial adjustment[64]. Importantly, a recent review and study of caregivers of children orphaned by AIDS (mostly grandmothers) found high levels of mental and physical health problems, suggesting that foster families may need increased support themselves[65].

Cumulative factors: The Bronfenbrenner model, and other theories of child well-being, use a cumulative risk approach[66]. This means that a child may be able to cope with one stressor, but that multiple stressors can interact to increase risk of psychosocial problems. This is supported by evidence from a large (n = 1025) South African study, where poverty and AIDS-related stigma interacted to increase the likelihood of child psychological disorder (defined as scoring above western clinical cut-offs on widely used measures of depression, anxiety or PTSD) from 19% to 83%, and bullying increased likelihood of disorder for children orphaned by AIDS more than for others[67].

Intervention for AIDS-affected children

Over the past 20 years, there has been a particular focus on developing and funding intervention programmes for AIDS-affected children. Many of these programmes focus on children's psychosocial wellbeing; however, there is an almost total lack of rigorous evaluation of these intervention programmes. A 2009 Cochrane systematic review of interventions for improving the psychosocial well-being of children affected by HIV and AIDS found no studies for inclusion. The authors concluded that current practice is based on anecdotal knowledge, descriptive studies and situational analyses and that such studies do not provide a strong evidence base for the effectiveness of these interventions[68]. Additionally, there is a lack of longitudinal data that would allow stronger inferences regarding *causal* relationships between potential risk and protective factors and child outcomes. Understanding the mechanisms through which familial HIV/AIDS impacts upon children's wellbeing is vital for both intervention programme and social policy design.

Debates in intervention design

An important and hotly debated issue regarding interventions for AIDS-affected children is that of 'targeting'. Many NGO and government-led programmes are targeted specifically at orphaned children (or children orphaned by AIDS). With regard to psychosocial health this presents two important questions. Firstly, is there sufficient evidence to show that AIDS-affected children have different psychosocial needs to those of other children living in poverty? The evidence presented earlier in this chapter suggests that children orphaned by AIDS and HIV-positive children are suffering from greater psychosocial problems than other children. We do not yet have enough research to know whether this is also true for children with AIDS-sick parents, but qualitative studies suggest that this may be the case. Secondly, are targeted interventions feasible in the context of stigma? There have been strong objections to this approach. These objections have highlighted the differing definitions of 'orphan' in different communities[69] and children's reports of stigma associated with receiving HIV-targeted or orphan-targeted relief[70]. This has led to a drive for programmes which instead focus on improving outcomes for all 'vulnerable' children. With very limited resources in the developing world, it is difficult to know how we can reconcile the need to help this specific group of children, with the need to avoid stigma which may come with targeted interventions.

Another important debate in programming for AIDS-affected children is whether or not psychosocial problems in the developing world should be addressed using traditional models of psychosocial interventions. The Western therapeutic model of approaching child mental health is resource intensive and often requires skilled professionals to conduct intervention programmes. Policy-makers, and increasingly the research community, are accepting that interventions are not sustainable in developing countries unless they are scaleable and feasible in resource poor communities, able to be based within existing structures (such as NGOs), and make use of existing capacity[71]. There are no simple answers to these issues and they are currently being debated by researchers and policy-makers. The following section discusses some widely-used interventions in terms of their evidence-base and feasibility in resource poor communities.

Interventions where evidence suggests effectiveness

School-based peer group support: King and colleagues review[72] found no studies which tested the effectiveness of interventions for children orphaned by AIDS or AIDS-affected children under the age of 18. Since this was published, our literature searches have identified one published study; a cluster randomised controlled trial (n=326) of a school-based peer group support programme in Uganda[73]. This programme was for children orphaned by AIDS and it included 16 group sessions of psychosocial exercises, as well as monthly physical health assessments and treatment (e.g. antimicrobial medication) or referral to a paediatrician. The group sessions were facilitated by trained teachers, who were supervised by a psychologist and the researcher. At ten week follow-up, children receiving the programme showed reduced levels of depression, anger and anxiety. This programme certainly shows promise, although its scaleability may be limited by the human resources required (i.e. an experienced counsellor as supervisor) and the cost of medical care and treatment.

Mentoring: Another potentially valuable new study involved a mentoring programme for heads of youth-headed households in Rwanda[74]. The quasi-experimental study included 593 heads of households, of which 441 received regular visits from trained mentors. After 18 months of mentoring, youth reported greater perceptions of adult support, and less feeling of marginalisation. Whilst feelings of grief in the comparison group rose, grief in the mentored group stayed stable. There was also a slight decrease in depressive symptoms in the mentored

group. Although most of the youth in this study were over school-age, these generally positive findings suggest that this intervention could also be helpful for younger groups[75].

Solution-focused stories: Many interventions focus on therapeutic storytelling. Importantly storytelling has a high level of cultural acceptability in sub-Saharan Africa, and this kind of intervention can be done by lay people. In particular, hero books (which use story-telling and drawing to encourage children to develop problem-solving skills) and memory work (where parents/carers develop a 'life history' and discuss post-bereavement plans with their families) have gained increasing popularity[76]. There are no published studies of the effectiveness of hero books in relation to AIDS-affected children; however, the Regional Psychosocial Support Initiative (REPSSI) has recently conducted a controlled trial of hero books in schools with 285 children in South Africa[77]. This found that the intervention group showed improved educational outcomes, and reported less worries, although there were no differences on children's reports of resolution of self-identified major problems in their lives. It would be very valuable to use standardised tools to test these interventions.

Popular interventions which lack sufficient evidence

Residential camps: A study (not yet published but with a report available online[78]) in Zimbabwe compared 1258 orphaned and vulnerable youth aged 14-20 years, who received either community psychosocial support (formal and informal services that address psychosocial wellbeing either directly, e.g. counselling, or indirectly, e.g. school and nutritional support programs), attended the Salvation Army Masiye Camp (a residential, faith-based program for vulnerable children), or no intervention. Unfortunately, no pre-intervention scores were collected, the groups were not randomised, and no standardised measures of mental health were used, so these findings are difficult to interpret[79].

Broad-based psychosocial support programmes: Many programmes use a combination of material support and 'psychosocial support'. This is often loosely defined, and can include organised therapeutic or non-therapeutic groups, HIV-prevention education, individual counselling and mentoring or home visits[80]. Unfortunately, there is almost no evidence to allow us to know whether these programmes are making an impact on children's mental health or social networks. A study in Zimbabwe used UNICEF guidelines to develop a teacher-led psychosocial support programme (including counselling, a buddy system, provision of school uniforms and supplies, and scripture lessons). Teachers reported better classroom behaviour. Unfortunately the study was small, without a control group, and did not

use child-report or mental health measures, so we do not know whether this has positive impacts on children's psychological wellbeing[81].

School-based activity groups and school strengthening: In South Africa, a cluster randomised controlled trial is currently evaluating the impact of two linked interventions by Soul City. SoulBuddyz clubs are groups, facilitated by teachers, which meet weekly and follow curricula based on developing skills such as safety, increasing children's self-esteem and encouraging preventative behaviours for HIV and future violence. 'Schools as Nodes of Care and Support' aims to enable schools to identify and support vulnerable children. Findings will be available in 2011-2012 (University of Witwatersrand and University of Oxford).

Similarly, the Caring Schools Project aims to support South African schools in offering sustainable physical, social, and emotional care to orphans and vulnerable children. Youth facilitators are placed in the school to identify orphans and vulnerable children and provide support for these children. In a recent evaluation of the programmes school principals and youth facilitators in 25 schools were interviewed. Overall, they reported improved school attendance and lower rates of drop out[82]. However, rigorous evaluation of the project, using pre- and post intervention measures as well as control schools, is required before firm conclusions regarding its effectiveness can be made.

Community-based psychosocial support programmes: The National Association of Child Care Workers (NACCW) Isibindi programme is a community-based child and youth care service in South Africa. Community members are recruited to be trained as Community Child and Youth Care Workers (CYCW) to work holistically and developmentally in the 'life space' of children and ensure children's rights are met. Through home visits, CYCWs provide a caring and reliable adult presence for children. Caregivers are assisted with accessing social security grants, basic child care, advice and counselling. An external evaluation showed some positive impact on the targeted children and families[83]. Unfortunately as the evaluation was not designed to provide evidence of children's wellbeing outcomes, it is not possible to make a firm conclusion about the Isibindi model's effectiveness. However as the evaluation suggested some positive potential for delivering effective support services to affected children and families, it will be worthwhile to undertake a more rigorous evaluation to determine the model's effect on chidlren's psychosocial wellbeing.

Additionally, USAID is currently conducting a series of evaluations of their community-based programmes, which differ by location but include elements such as

community volunteer home-visits, community-based social workers, health centres and schools[84]. However, as yet no results regarding mental health outcomes have been published

Interventions which address proven mechanisms of psychosocial problems

We are clearly far behind where we need to be in terms of evidence-based interventions for AIDS-affected children. However, we do have useful knowledge of some of the potential mechanisms which are leading to psychosocial problems for AIDS-affected children, and some of the preventable risk factors associated with psychosocial distress. If we can find evidence-based interventions targeting these *mechanisms and risk factors,* even if they have not yet been tested with AIDS-affected children, it could help to guide the development of effective interventions. Targeting these mechanisms may also force us to think 'outside the box' of our established psychosocial interventions and theories.

Providing ARVs to parents: We know that both parental death from AIDS and parental AIDS-sickness) are directly linked to children's psychosocial wellbeing. The provision of anti-retroviral medication (ARV) to parents or carers can prevent HIV-infection from progressing to AIDS and death. Therefore, providing ARVs to HIV-infected parents can be viewed as a primary preventative psychosocial intervention for children. ARV use can also reduce visible signs of AIDS in parents, and evidence suggests that this could reduce community-level stigma for their families[85]. No known studies have tested the psychological impact of parental anti-retroviral treatment on children, but an ongoing study in South Africa will have findings on this by 2011[86]. Importantly, in the developing world only 42% of people eligible for ARVs currently receive medication[87]. Interventions focusing on increasing this proportion are likely to result in benefits to the children of these adults.

Prevention of parent-to-child transmission and provision of paediatric ART: Research suggests that HIV-infection can lead to cognitive and neurological problems for children. In addition, the emotional impacts of diagnosis, and the social impacts of being HIV+ put children at risk of psychosocial distress. A major preventative measure of these outcomes would be to stop transmission of HIV to children in the perinatal period. A short course of highly-active anti-retroviral therapy (HAART) to both mother and child can reduce (PMTCT) transmission rates from 35% in sub-Saharan Africa to below 2%[88]. In 2008, PMTCT access in low and middle-income countries was 32%[89]. It is important that this is combined with either sole breastfeeding or sole formula-feeding in order to reduce likelihood of infection in infancy[90]. For those children who are HIV+, early and sustained anti-retroviral

treatment may have positive impacts on motor development, although findings on cognitive development are less clear[91].

Reducing AIDS-related stigma and bullying: To the best of our knowledge there is no research that has specifically tested interventions to reduce stigma for the *families* of HIV+ people. However, there have been reviews of programmes to reduce stigma associated with HIV more generally. Findings suggest that there may be positive results of legal protection for HIV+ individuals, availability and accessibility of anti-retroviral medication[92], and sensitization to and contact with HIV+ people[93]. Stigma seems to be closely connected to lack of accurate HIV-knowledge[94], which suggests that public health measures to increase understanding of how HIV is, and just as importantly is not, transmitted may be helpful. However, recent longitudinal evidence from South Africa has found stigma to be higher amongst those who know someone who has died of AIDS. It also found that increased personal contact with an HIV+ person did not reduce levels of stigma[95]. An ongoing study in South Africa has found positive effects of a US-designed programme called CHAMP, which aims to strengthen family relationships, enhances problem-solving and youth peer negotiation skills. This led to reductions in HIV-stigmatising attitudes amongst both adolescents and caregivers[96]. It is clear that much more research is needed in order to understand how we can best combat AIDS-related stigma.

Anti-bullying: There have been a number of interventions which have been evaluated for effectiveness in reducing bullying. Most of these have been in schools, and almost all have been in the developed world. A recent systematic review[97] examined curriculum-based interventions, 'whole school' interventions, social skills groups, mentoring and social worker support. Only four of the 10 curriculum-based studies were associated with decreases in bullying. Of the 'whole-school' approach, seven out of ten studies decreased bullying. Three of the four social skills interventions showed no reductions in bullying. Both mentoring and increased numbers of school social workers showed decreases in bullying. A year later, a meta-analysis of all developed world school-based anti-bullying programmes concluded that most did not have meaningful effects on bullying reduction[98]. In sub-Saharan Africa, one small evaluation study suggests no impact of a school-based anti-bullying intervention, but numbers of participants were too small (n=54 in three comparison groups) for meaningful conclusions[99].

The evidence from the developed world does suggest that whole-school approaches, mentoring and increased numbers of social workers have potential to reduce bullying. Whole-school approaches involve some combination of school wide rules, teacher training,

classroom curriculum, conflict resolution training, and individual counselling. Transferring these concepts to the developing world requires adaptation to different school structures and cultures, developing low-cost approaches, and allowing for human resource shortages (especially in sub-Saharan Africa). It is also important to incorporate the issues of HIV and AIDS into anti-bullying programmes.

Increasing social support and caregiver/child connectedness: Evidence suggests that improving social support and caregiver-child connectedness has the potential to buffer the impact of belonging to an AIDS-affected family. It is important to remember that both of these factors work in a two-way dynamic: children who are more resilient and personable are more able to gain support and affection than children who are depressed, anxious, traumatised or have behaviour problems[100]. There is evidence from both the developed and developing world, that parenting programmes encourage positive parenting and improve parent-child relationships[101]. In Zimbabwe, qualitative research with teenagers suggested that disclosure and discussion of parental HIV-status was seen as helpful for family closeness[102].

It may be especially important to encourage connectedness in foster families for AIDS-affected children. Although the vast majority of children remain in the kin network, there is evidence of reduced sense of responsibility for children when biological links are not direct[103]. For children who are HIV+ it is especially important that carers have the skills and motivation to ensure treatment adherence. We were only able to find one evaluation of such an intervention. In South Africa, grandmothers were trained in HIV/AIDS knowledge, intergenerational communication, basic nursing skills, accessing social services and grants, and relaxation. Participants reported greater knowledge and competence, but actual care was not tested, and no control group was included, so this only remains indicative of a potentially useful intervention[104].

We could find no quantitative evidence to date of higher levels of child abuse amongst AIDS-affected children. However, some researchers do report heightened risks of abuse in families with extreme stressors, poverty or fostered children[105]. Anecdotal and qualitative evidence also suggests that abuse may be more prevalent for AIDS-affected children. The field of child abuse prevention is extensive, but a recent systematic 'review of reviews' found that home visiting, parent training and child sexual abuse prevention appear to be effective in reducing child maltreatment[106]. However, the authors noted that only 0.6% of the evidence came from the developing world, and that more research was needed there. It is also important to ensure that there is adequate capacity for child protection services, in order to investigate and address cases of abuse. This is often made especially challenging in the

developing world by staff shortages, lack of resources such as vehicles for social workers, and long distances in rural areas[107].

Reducing poverty: A number of interventions aim to improve economic well-being in AIDS-affected homes. These include micro-finance schemes, provision of food parcels, 'sponsoring' of children, and education support. One study of economic empowerment and a savings scheme in Uganda found some positive impacts on child mental health[108]. A widely debated method of poverty reduction is the social welfare grant system. In South Africa, sustained state efforts to increase grant uptake for families with children has resulted in increases of orphaned children receiving grants[109].

Home-and Community-Based Care: We do not yet understand fully the mechanisms by which having an AIDS-sick adult in the home can lead to children's psychosocial distress. But qualitative evidence suggests that children's care-giving responsibilities can mean that they are not able to attend school, do homework or to see friends[110]. New data from South Africa reports that children are preoccupied with worry about their sick parents: 'There are times I can't hear clearly because I think about her, how she is doing, whether she is eating her tablets' (Boy, 12 years)[111]. One potential intervention (to date not yet studied in children) is the provision of Home and Community-Based Care. Home-Based Care involves trained lay workers, who visit homes to provide nursing assistance and psychosocial support for AIDS-affected families. This could reduce the burden on children of both care-giving responsibilities, and of worrying for the safety of a sick person left alone. The 'Case Study' provides a description of Home-Based Care in the South African context

Street-children: To the best of our knowledge there are no interventions specifically targeting street-children which have been empirically evaluated. However, a number of theoretical and descriptive studies do provide guidelines for working with street-children. These include the need to recognise the independence and capabilities of street-children[112]. Anthropological studies highlight the strong social networks which street-children develop among themselves[113]. Many studies stress the heterogeneity within the group of 'street-children', and how it is important for interventions to distinguish between children 'on the street' and 'of the street' (i.e. living at home but working on the street versus living and sleeping on the streets)[114]. Some studies suggest that street-children are at no greater mental health risk than other poor children, but they certainly have higher levels of exposure to violence and sexual risk[115]. Suggested interventions for street-children include: preventative measures within families to reduce children leaving for the streets, outreach work to engage street-children, help with re-entering school , providing vocational training, and specifically

do *not* include reunification of children to families without addressing the circumstances which made them leave[116].

Case Studies: Interventions in South Africa

Within South Africa, three innovative programmes have been widely promoted – all are potential targets for future evaluation studies.

Home and Community-Based Care: The Home and Community-Based Care (HCBC) programme aims to support and empower families in caring for AIDS-affected children. Lay community caregivers facilitate the early identification of orphans and vulnerable children; make referrals to social workers for specialized services including alternative placements; provide supervision and ongoing support to vulnerable households; assist families to discuss and actively get involved in succession planning activities; provide psychosocial support; assist children and their families access basic services including social grants and other material assistance; assist children and families to access legal documents; and help children attend school and restore normal schooling.

Drop-in Centres/Community Care Centres: Community Care centres are local centres providing psychosocial support such as before and after-school feeding schemes, homework clubs, laundry services, recreational facilities, training on skills for domestic work, life skills program and holiday programmes including camps. The centre identifies children and families in need of care and link such families to appropriate services such as access to grants, referrals to legal services and vital registration documents, writing of wills, health care services. Referrals to social workers for alternative care placement in places of safety, foster care and adoption.

Child care forums: Child Care Forums (CCFs) are locally-based organised groups who are committed to advocating for the needs of children within their community. Community mobilisation can include facilitating activities to reduce stigma, community income-generating projects, community-based day care facilities, after-school care and holiday programmes to provide relief for caregivers. These forums are established in the *HIV and AIDS and STI Strategic Plan for South Africa, 2007-2011* (Government of South Africa, 2007). A recent review was commissioned of CCFs, finding 400 Community Care Forums in South Africa, but a total number of child beneficiaries reached of less than 200,000 (Mathambo, ongoing http://www.hsrc.ac.za/Research_Project-915.phtml).

Recommended actions and interventions

To date, there is an almost total lack of rigorously-tested interventions for AIDS-affected children. This means that recommendations for action must be cautious. It also clearly highlights the need for a rapid expansion in high-quality research specifically focusing interventions for this group of children. Qualitative work suggests that it is important to be aware of the potential for stigmatising AIDS-affected children through targeted programmes. However, universal access to support programmes may be impossible to achieve in resource-poor settings.

One preventative approach to psychosocial distress amongst AIDS-affected children is by provision of ARVs; thereby preventing the progression of carers from HIV-infection to AIDS, preventing the early death of carers, protecting children from mother-to-child-transmission, and maintaining physical health for HIV+ children. Studies do suggest that peer-group support, mentoring, and solution-focused stories may be helpful in reducing psychosocial distress and ongoing studies are currently examining school-based peer groups, family-centred training, and community-based strategies. In addition, there is good epidemiological evidence to suggest the value of interventions targeting specific mechanisms of psychosocial problems in AIDS-affected children. These could include programmes which aim to reduce AIDS-related stigma at a community level, to reduce bullying at a school level, and to improve nutrition and reduce extreme poverty for AIDS-affected households. Increasing child-caregiver connectedness, and Home and Community Based Care for families are also potentially protective interventions.

All of these potential interventions unquestionably need further research. We need to understand whether they do impact upon children's psychosocial wellbeing, whether these impacts last over time, and whether or not these interventions are feasible and sustainable in the developing world. However, it is also important to remember that research (especially high quality research such as randomised controlled trials) is time-consuming, expensive and requires specific skills. It is likely to be years before we have a strong enough body of research to guide truly evidence-based practice. In the meantime, the number of AIDS-affected children is rising by millions, raising a dilemma. Do we wait until we know 'what works' for AIDS-affected children before we act and ignore children who are clearly experiencing great psychosocial distress? Or do we continue to scale up programmes and interventions for which we do not have enough evidence to determine whether they help or

harm children? There are no clear or easy answers to these questions, but we propose the following recommendations.

Firstly, a concerted and immediate effort is needed to develop a body of evidence testing the effectiveness of psychosocial interventions for AIDS-affected children. This will require the collaboration of governments, NGOs, researchers and funding bodies. It will need co-ordination to ensure that the interventions tested are acceptable and sustainable, and that they are feasible to reproduce if they are proved effective. It will also need a willingness to be open about interventions which do not work. These are not easy demands. To date, NGOs are under great pressure to prove 'success' of programmes; and reporting lack of effectiveness is seen as failure by funding bodies rather than as an important step in developing our understanding of what will work. Researchers are unlikely to write up negative or ineffective results, and journals are unlikely to publish them. Such a programme of research would need coordination; and a good model for this may be the Joint Learning Initiative on Children and HIV/AIDS[117].

Secondly, the need to continue providing interventions whilst this evidence-base is being developed should be recognised. However, it is essential that these interventions should use the most up to date evidence in order to maximise their potential effectiveness. Many groups and individuals working with AIDS-affected children are motivated by love, protectiveness and a sense of duty. These are important, and should not be undervalued. But it is also important to channel these essential motivating factors into promoting interventions with a strong evidence base. It is also essential that funding bodies, who hold much of the power in determining programmes of intervention in the developing world, commit to supporting programmes which are shown to be beneficial.

The outlook is good. We are, for the first time, in a strong position to develop the essential body of evidence needed to evaluate psychosocial interventions for AIDS-affected children. We have research outlining the needs of children orphaned by AIDS and we have ongoing research identifying the needs of children with AIDS-sick caregivers. Although research addressing the psychosocial needs of HIV-positive children in the developing world is still required, we have evidence from the developed world to guide us in this endeavour. We also have an expanding body of research identifying potential mechanisms through which belonging to an AIDS-affected family may impact on children's psychosocial well-being. By using the evidence which we have already, and making a concerted and combined effort to develop new evidence, we can promote resilience and positive outcomes for AIDS-affected children.

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