

# THE ESSENTIAL PACKAGE



**Distinct Disadvantage: A Review of Children  
Under 8 and the HIV/AIDS Epidemic**

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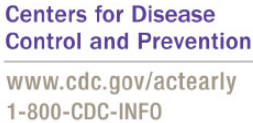
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# Executive Summary

## Introduction and Background:

This review was carried out in 2011 and provides a systematic study of elements of the published literature to guide the process and provides background detail for the conceptualization of the Essential Package for young children affected by HIV. Interventions for children affected by the HIV epidemic have increased dramatically. A number of recent initiatives have attempted to provide detailed understanding of the situation for children and to coordinate policy recommendations. Currently, there is a move to focus on children and to use an evidence-based approach to inform provision and to shed light on the understanding of service delivery. Much of this happens in the context of HIV, yet there is a body of wisdom on children and child related interventions from other areas, which may well inform these initiatives. The aim of this paper is to provide insight from the published literature on facets of child focused issues in the HIV epidemic, with a particular focus on young children. For the purpose of this report, children under the age of 8 are explored. Early childhood development programs have the potential to improve children's development and wellbeing. This paper adds perspective on the situation and needs of young children growing up in an HIV/AIDS context. Young children have specific needs that may often be overshadowed in initiatives that collapse children across the ages.

## Methodology:

The report is based extensively on published literature and evidence and sets out to establish

the current state of the art knowledge on cognitive function for children with HIV infection, children exposed to HIV in utero (i.e. affected) but HIV negative, and control children. Three systematic reviews were conducted as follows: Cognitive effects of HIV on young children; Evaluations of Orphans and Vulnerable Children (OVC) interventions and findings; and Evaluations of effective Early Childhood Development (ECD) interventions and findings. Existing reviews and summaries are incorporated. Studies were identified through an extensive literature search<sup>1</sup>. The review did not identify many studies on effective OVC interventions, with even less found on OVC interventions targeting young children. However, the studies found in the other systematic reviews provide good insight into what is needed for young children affected or infected by HIV.

## Main Findings:

- Children are at particular risk as a result of the HIV epidemic. The response so far has lacked solid evidence-based policy and has failed to disaggregate children by age (or even gender) so that the responses are not necessarily optimal. In the field of health care and medicine, there is sound evidence and a track record of evidence-based interventions.
- The landscape will change with the improved roll out of antiretroviral treatments. Until then, children are at risk of a series of shocks (adverse events) in their early life course as a result of HIV. Such shocks can become sustained, cumulative, and divert children from reaching

their potential. The mechanisms for this deficit are unclear—either direct virus effects or indirect environmental effects. It is probable that both are contributory factors.

- Emerging data from studies on the impact of HIV on infected and affected children show detrimental effects on mortality, health, cognitive development and emotional adjustment. In areas of high HIV concentration, children generally are affected. The rates of parental death are high, and illness among parents leads directly to child vulnerability. This vulnerability is increased for younger children.
- Within the studies of cognitive functioning, mortality and health, it is possible to examine HIV positive children, HIV exposed yet negative children, and HIV unexposed but affected children. Most studies are not set up to do this, but when the data are reanalyzed it is disturbing to see that HIV+ve children are severely compromised, and that HIV exposed children are worse off than control children in terms of mortality and health, with mixed data on cognitive development. No disaggregation to understand virus exposure or ART treatment exposure seems to be available. Long term information is needed on all three groups of children. As HIV prevention in pregnancy is rolled out, data banks should be set up to monitor the long term progress of children exposed to both the virus or to treatments to prevent transmission.
- Children who are exposed to HIV in utero and are born HIV positive have passed somewhat under the radar. The focus has concentrated on their HIV status rather than their developmental

needs for growth and development. Emerging data show detrimental effects on mortality, health, cognitive development and emotional adjustment. At present, known HIV positive mothers receive treatment in just above 45% of cases. When this is universal, transmission of HIV to newborns should decrease or be “virtually eliminated”. Yet, the amount of HIV negative children exposed to HIV (and treatments) in utero will increase. The data suggest that long term monitoring and interventions to reduce or prevent maternal death are urgently needed.

- Mental health overlaps with cognitive performance but is an area of need in its own right. Studies are showing specific mental health problems for children with HIV. Anxiety, depression, externalizing and internalizing behavioral problems and post traumatic stress are all elevated. Emotional status may be affected by functioning, quality of input and burden of experience.
- Care arrangements and the quality of care are clearly important in child development. There is good evidence that large scale institutional care (orphanages) compromises children. The evidence also shows that kinship (i.e. care by extended family members) and community care offers advantages to children. HIV also changes caregiving dynamics at the household level with children taking on caretaking roles for siblings or sick adults. Indeed, emerging studies on ART for adults, who then have improved health, have shown specific benefits for children in terms of reduced household demands and increased school attendance.
- There is good evidence that stressors related

to caring under adversity have negative mental health impacts. Children in the presence of HIV are often shouldering caring responsibilities, either directly (by caring for sick adults, administering medications and so on) or indirectly by taking on household duties, generating incomes and caring for siblings. Both substitute parenting and parentification (old before their time with parenting responsibilities) are being documented. Social structures to support families are an ongoing need. The long term effects of HIV care demands need to be monitored.

- Gender is insufficiently studied or understood in the literature. Mental health and cognition is known in the general literature to be affected by gender. The evidence base does not sufficiently report on gender, analyze the data by gender or provide guidance according to gender considerations. This is particularly important as gender barriers may compound vulnerability.

### Conclusion:

The literature on interventions for OVC is piecemeal. Previous reviews have struggled to find a comprehensive robust evidence base to guide good practice. The area abounds with excellent interventions. This systematic review cast a wide net and endeavored to include any intervention for children. What was of note was the fact that children are usually grouped together and there is little focus on ages and stages—e.g. the data does not naturally disaggregate at 8 years of age. Furthermore, interventions are almost predominantly contained within the biomedical sphere.

The general early childhood development

literature, however, has a steep history in evaluated interventions. There are a wide range of solid interventions, well described and evaluated, that could be adapted to young OVC in high HIV prevalence areas. Programmatic learning for HIV does not need to start from scratch. There is an imperative for community and OVC provisions to meet the challenges of comprehensive evaluation to allow good practice to feed into policy. The vast arena of expertise is not being captured in the evidence base.

No international indicators of OVC wellbeing are globally integrated into protocols. This is complicated as such indicators need to be sensitive, easy to administer, reliable and pick up cultural nuances. In the absence of global indicators, validated measures have been employed. This ensures good quality data, but means that comparisons are difficult across studies and settings. Global indicators (such as those in the DHS studies) are short and provide blunt instruments for picking up the detail of OVC realities. Ideally, global and detailed indicators are needed. A culture of evaluation is urgently needed in the applied field so that evidence as well as experience can guide policy.

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## I. General Overview and Introduction

The Essential Package provides a framework for action to support those at the point of service delivery to deliver assistance to caregivers that enables them to better care for young children. Particular attention was placed on children and their caregivers in high HIV burden settings, specifically because of the known impacts of disease on the development of young children. The Essential Package is tailored

to children 0-8, who may be at increased risk for not reaching optimal development because their families have been impacted by AIDS. In order to understand the dynamics that HIV introduces for children and caregivers impacted by AIDS, Save the Children and CARE USA commissioned a systematic review of the published literature to guide the development of the Essential Package. There is good evidence that an ages and stages approach to children—looking at age-specific needs and responses—is an appropriate strategy. However, many programs targeting young children fail to adequately address the needs of the very young. The Essential Package is, therefore, intended to provide guidance to programs addressing the needs of families impacted by HIV and AIDS by incorporating specific messages and activities targeted to the caregivers of these children, while exploring the linkages for service delivery to promote healthy growth and development. It is based on the evidence around good practice for young children and their caregivers as presented in this extensive literature review.

Young children, as well as their caregivers, have specific needs that may often be overshadowed in initiatives that collapse children across the ages. And interventions for children affected by the HIV epidemic have mushroomed. A number of recent initiatives have attempted to provide detailed understanding of the situation for children and to coordinate policy recommendations. Currently, there is a move to focus on children and to use an evidence-based approach to both inform provision of services and to identify and understand where there are gaps. Much of this happens in the context of HIV, yet there is a body of wisdom on children and child related interventions from other areas, which

may well inform these initiatives. The Essential package also places emphasis on care for the caregivers, and this review includes findings on the mental health needs of caregivers, as the need to address caregiver mental health is paramount.

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## II. Methodology

This report is based extensively on published literature and evidence and includes three core systematic reviews to answer the following questions: 1) what is the trajectory of shocks that HIV introduces in early childhood? 2) What are the cognitive effects of HIV for both infected and affected children in early childhood? and 3) What can we infer from the published literature on orphans and vulnerable children programs on the impact of interventions in early childhood? For each review, a systematic search strategy was employed using Medline, Psychinfo and Cochrane Database that allowed the researchers to identify the studies which were peer reviewed, topic relevant, design competent and included valid sample sizes. A full bibliography of all of the studies reviewed can be found in Annex A.

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## III. Findings

### Section I: Impact of HIV on Children and Caregivers

HIV has profound and immense impacts on young children. There are a number of shocks that accompany the HIV epidemic, which can singly or multiply affect, divert and impact children. These can be divided into the following domains:

1. **Biological Shocks:** These refer to the actual effect of virus exposure on the developing child. Exposure can occur at a number of different

times.

2. **Parenting Shocks:** The presence of HIV can result in an accumulation of parenting shocks. Pregnancy, illness, treatment, job loss, stigma, death and child illness all impact parenting and the ability to create beneficial environments for young children to flourish. Many people parent—mothers, fathers, grandparents, relatives, teachers, the community and even siblings. Thus, the combined impact is difficult to isolate. The psychological literature points to the fundamental importance of at least a single dedicated carer with ongoing long term parenting commitment to a child.
3. **Developmental Shocks:** Child development does not occur in a vacuum. Each developmental step and phase is affected by many factors, all of which may be subject to obstacles in the presence of HIV. The child may be affected in ways which alter learning experiences. The environment may be affected which directly impacts development. Furthermore, as development is an unfolding process, impacts may be felt for a long time. Single shocks may have a different impact from cumulative shocks.
4. **Social Provision Shocks:** Support, care and social environment are all important for children. The social world creates the microcosm within which a child lives, experiences life and gathers meaning. HIV can create shocks at numerous levels within the social web. This may differ in areas of high and low prevalence and depending on the gender and role of other family members with HIV. The sheer number of people affected in a family may be relevant. At other levels, economic considerations, social

facilities, country infrastructure, poverty and stigma all may contribute to the shocks a child experiences.

5. **Medical and Health Shocks:** In the era of treatment, medical interventions may affect the course of HIV for any child, either directly or through treatment and care of their loved ones and family members. Health care and health systems may be wanting, and non availability of care may affect the child. Treatment itself brings with it a burden of responsibility such as adherence requirements and side effects, which play a part in the child's world.

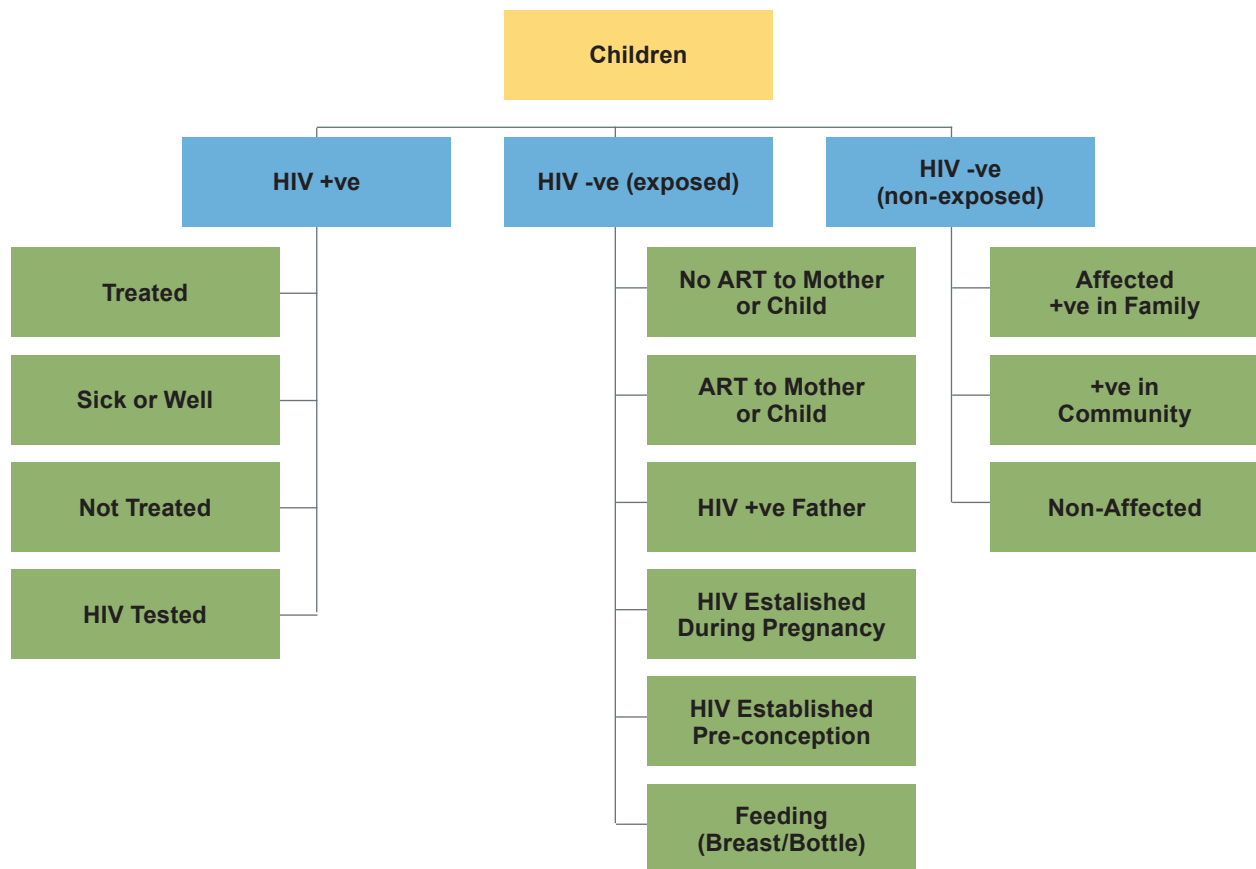
Although these shocks have emerged from the accounts in the various studies, it is important to understand that timing of a shock may have differential impact. Shocks do not occur in a vacuum, and subsequent events also have the ability to attenuate or exacerbate the impact of the shock as well as the ability to recover. For example, there are good studies that show that, in the face of parental loss, the quality of subsequent care is one of the best predictors of child outcome. A comprehensive study in Botswana<sup>1</sup> has shown the dramatic effects of HIV on children under 5 years of age (sample size 2,723). This study showed that orphaned children were 49% more likely to be underweight than non-orphans and were more likely to live in the poorer or poorest of households—despite the fact that Botswana is a country with early access to HIV treatment for both children and parents.

On the trajectory of shocks, a list gives little insight into the impact of multiple shocks. It is well known that effects are not simply additive, and HIV brings with it multiple shocks for many children. It is important to bear in mind, however,

that the trajectories in reality are not necessarily linear. Some shocks create whirlpool effects, and there are often cyclical changes. Some shocks recur constantly, while others are one off events. Furthermore, these all occur within the constraints of daily life, and the ramifications of shocks are often ameliorated or enhanced depending on subsequent management and support. Some studies explore enormous resilience and factors associated with such coping, and adaptation should be fostered. The children under review are drawn from a wide array of potential exposure categories including

HIV-positive children, HIV negative but exposed children and HIV negative and non-exposed children set out in the figure below.

Thus, it is difficult to catalogue a shock trajectory in that they are not all equal. One way is to look chronologically, but some items are not necessarily found in this order. Also, some groups will be exposed to some shocks, whereas others may not. Despite this, a comprehensive list can give some insight into the array of impacts.





**Table 1—HIV shock trajectory**

The table below briefly summarizes some (though not all) of the specific experiences under the above mentioned five key categories: Please note, however, that there may well be overlap.

| Shocks  | Considerations  |
|---|---|
| HIV Exposure in Utero   | HIV infection can occur during pregnancy. HIV exposure may also have long term effects, at present unknown.   |
| Maternal testing for HIV and discovering HIV positive status during pregnancy | Diagnosis of HIV in pregnancy has a severe emotional trauma on the parents. This can directly and indirectly affect the baby.   |
| Exposure to antiretroviral treatment in utero                                 | Exposure to ART has potential benefits and harms. Benefits relate to the reduction of transmission. However other considerations may need to be logged such as the long term effects of such exposure on development.   |
| Medicalisation of childbirth  | In the presence of HIV the labor and delivery may generate heightened medical attention and input. These may directly or indirectly affect the infant.  |
| Prematurity   | HIV infection has been associated with premature delivery. This in turn has been linked to a number of developmental challenges as well as disruptions in parenting if removal of the infant to special care is required. The general literature on special care infants may well apply in the case of HIV.   |
| HIV testing of infant   | It is important to establish the HIV status of the infant. This is of varying availability depending on settings. Antibody tests simply reveal parental status and in the absence of viral testing (such as polymerase chain reaction—PCR) definitive diagnosis for the infant will need to wait until maternal antibodies are shed (approximately 18–24 months of age). This can be an emotionally difficult time. |
| Exposure to monotherapy   | In the HIV treatment literature there are clear implications of prior exposure to monotherapy which enhance the chances of resistance to subsequent treatment. Despite this, many regimes for prevention to infants utilize monotherapy. The long term consequences have yet to be established.   |
| Exposure to interventions (C Section, formula feeding)                        | Some interventions to prevent transmission may have developmental ramifications.  |
| Post natal depression (Maternal or paternal)                                  | There is a solid evidence base that parental depression affects child development. There is also good evidence that depression is associated with HIV. Thus, in the case of parenting in the presence of HIV, depression and subsequent child development challenges may be found.  |

|   |   |
|---|---|
| Over interpretation of childhood illness attributable to HIV and AIDS | In the presence of HIV, over vigilance is quite common, which may result in more attention and intervention for otherwise common childhood conditions.  |
| Low birth weight  | Low birth weight is correlated with a number of long term ramifications. HIV infection has been associated with low birth weight and prematurity.   |
| Infant feeding  | Infant feeding is of fundamental importance to child development as well as bonding and a number of psychosocial interactions. The presence of HIV has potential to alter feeding in a variety of ways with potential longer term and unexpected effects.                         |
| Reduce breastfeeding  |   |
| Abrupt cessation of breastfeeding                                     |   |
| Risks of formula feeding  |   |
| Exclusive breastfeeding   |   |
| Economic  | HIV is known to be an impoverishing disease. Illness in the family has multiple ramifications, all of which affect the young child profoundly. Ill parents cannot work or generate the same earnings as well parents. Resources are diverted and at times family assets are sold. |
| Energy and concentration  | May need to do extra housework.<br>May need to work outside of the house to generate income.  |
| Siblings  | Separation, experience death or need to care.   |
| Disclosure  | Disclosing HIV status (either of the child or parent) is a complex process with many challenges. Stigma creates a barrier to this process.  |

**HIV is known to have severe cognitive effects on young children**

Cognitive issues have always been relevant in HIV. Early data suggests neurocognitive implications for adults. Reviews point to as high as 60%<sup>1</sup> of adults with HIV having some form of cognitive impairment, and, before ART treatment, the vast majority of people had developed some form of pathology prior to death.<sup>2</sup>

At present, it is well established that there are various degrees of impairment, with an internationally used grading system (for adults)<sup>3,4</sup> and well established cognitive effects even in patients on established antiretroviral treatment and with suppressed viral

load.<sup>5</sup> This work, however, completely overlooks children, despite the fact that neurocognitive development is critical in the early years of life when brain pathways

- 1 Asymptomatic neurocognitive impairment (ANI)
  - Performance at least 1 SD below the mean of demographically adjusted normative scores in at least two cognitive areas (attention-information processing, language, abstraction-executive, complex perceptual motor skills, memory, including learning and recall, simple motor skills or sensory perceptual abilities).
  - Asymptomatic
- 2 HIV-associated mild neurocognitive disorder (MND)
  - Performance of at least 1 SD below demographically corrected norms on tests of at least two different cognitive domains
  - Interferes, at least mildly, with activities of daily living
- 3 Grading system for HAND (HIV Associated Neurocognitive Disorder)
- 4 HIV-associated dementia (HAD)
  - Performance at least 2 SD below demographically corrected normative means in at least two different cognitive areas
- 5 Marked difficulty in ADLs due to the cognitive impairment

are established, cognitive skills are acquired and language commences. Furthermore, emerging research in adults indicates that some antiretroviral compounds are better at penetrating the central nervous system (CNS) than others<sup>6</sup>, and that ART treatment is associated with cognitive improvement<sup>7, 8</sup>. Clearly, these findings have important implications for children.

The data overwhelmingly points out various cognitive deficits for the HIV positive children (see Annex B for list of 63 studies reviewed; 7 were excluded from analysis as they included neurocognitive scans or brain data rather than performance



*This review looked at 56 studies on the cognitive effective of HIV on children. It was confined to studies that include children 8 years old or younger. In 91% of the studies, cognitive deficits were recorded.*

related outcomes). In a review of 56 studies on children under 8 years of age or including those who are under 8 years of age (including only those studies with behavioral cognitive outcomes rather than brain or neuronal pathology), the majority of studies (51/56; 91.1%) recorded cognitive deficits for children with

HIV infection. A wide range of measures are used across the studies, making it difficult to compare the data or to do any form of meta analysis. However, it is of note that all the studies use well-validated standardized scales. It seems that it would be of international benefit to harmonize the measures and explore different modalities within cognitive functioning, separating out verbal and non verbal, motor and mental, as well as language skills, processing skills and so on.

There is consistent evidence of cognitive difficulties for HIV positive children. Almost all the studies record significant negative effects, irrespective of measures. The data establish that HIV positive children perform consistently worse than HIV negative children on cognitive development.

This finding is also true on other measures such as pain<sup>9</sup>—with under half of caregivers actually recognizing the child's pain in one U.S. and Puerto Rican study. With a broader remit to look at OVC generally, there is then the question of the performance of the HIV exposed children (i.e. those born to HIV infected mothers, who do not become HIV positive).

1. Are HIV exposed children suffering from cognitive effects? Such data can be found in the few studies that simply examine HIV exposed (yet HIV negative) children compared to controls, or three way analyses (HIV positive, HIV exposed and control children), where the focus on the exposed children needs to be drawn out.
2. Are there any studies which differentiate between HIV exposed children where mothers were given ART compared to those with no treatment? This would give an insight into the effects of ART to mothers on cognitive development. One such study has been identified in the U.S.,<sup>10</sup> in which 1,840 children benefit to harmonize the measures and break down the exact sub components that need to be studied. Some simple measures provide blunt instruments and rough indicators of delay. Others have been fine tuned and follow up, and those exposed to in utero antiretroviral treatment (82%) were compared to those not

exposed (8%) with control for other confounding variables. This study showed no differences between the groups on the outcome measures using the Bailey Scales. These groups need to be carefully monitored over the long term, as other studies are picking up some subtle biomedical effects, and multiple studies are needed to establish the effects or lack thereof definitively.<sup>11</sup>

### **Good mental health is highly correlated with cognitive attainment**

There is an overlap between cognitive measures (purely confined to functioning, IQ, language, etc.) and the more mental health measures (such as anxiety, depression, separation problems, social disorders, conduct disorders, post traumatic stress, attention deficit disorder and emotional and behavioral problems). Mental health is often focused on negative mental health, yet clearly there are positive mental health outcomes as well. This includes items such as coping, well-being, adjustment, resilience and post traumatic growth. Mental health measurement was not part of this review. However, some studies examine mental health in conjunction with cognitive measures, and there is good literature which supports the overlap between mental health and cognitive attainment. Thus, it is important that an addition to the section on cognitive challenges for OVC is supplemented by a consideration of mental health issues.

The literature suggests that HIV positive youth are at high risk for mental health problems,<sup>12</sup> yet there are few studies which explore the origins of this and how these emotional difficulties are picked up and studied in children under the age of 8 years. For example, Chernoff et al (2009)<sup>13</sup>

studied 575 children (aged between 6 and 17) in the U.S., comparing them to a mixed control group comprised of both HIV exposed yet uninfected children and control children living in a household with an HIV positive member but not exposed to the virus during pregnancy. They found that all children had a similar level of mental health problems (61%), although HIV positive children were more likely to receive treatment.

A selection of studies are summarized in Annex C to indicate the various published studies and findings in relation to mental health problems associated with HIV infection for young children.

The studies are also fairly biased towards U.S. samples, where this is studied and, therefore, difficult to generalize to other settings, where treatments are not universally available and the compounding issue of parental drug use may differ. The Mellins and Gadow studies both conflate the exposed and HIV negative but living in a family with an HIV positive member, and thus it is difficult to separate out these effects. They are both notable in finding common levels of mental health problems, yet elevated when compared to population norms.

Two review studies have summarized the findings on HIV and mental health in children (Cluver et al 2007, Scharko et al 2006), although neither study confines itself to younger children in general or those under the age of 8 years—the target age group for this review. The Cluver review looks at all mental health effects on children, while the Scharko review concentrates on mental health effects for HIV positive children. The Cluver review covers 24 identified studies, of which 13 are unpublished. This review shows systematic findings of mental health challenges for children affected by HIV. The majority

of studies examine orphans or children with HIV positive mothers. Few, however, control for the HIV status of the child, which is a severe shortcoming in the studies. Furthermore, with children, many studies rely on caregiver or intermediary reports of behavior. Indeed, Cluver noted that 18 studies interviewed children while four relied on caregiver reports. And the majority of studies are cross sectional, so very little information is provided on change over time. Despite the difficulties in harmonizing measures and coordinating analysis and diverse measurement, Cluver notes that the studies show a worrying prevalence of internalizing and externalizing problems for children. Scharko, on the other hand, reviewed over 500 papers to examine the prevalence of Diagnostic and Statistical Manual of Mental Disorders (DSM) psychiatric disorders in children with HIV infection and found only eight studies which were able to quantify prevalence in some way. This is difficult to do given the small number of studies and the absence of control groups for many of the studies. Within these limitations, they calculated average prevalence of 28.6% for attention deficit hyperactivity disorder (ADHD), 24.3% for anxiety disorders and 25% for depression.

### **The data are equally alarming for HIV affected children**

Children can be HIV negative yet affected by HIV. This can occur in a number of different ways. HIV exposed children are born to HIV positive mothers and are exposed to the virus during pregnancy. Some continue to be exposed during breastfeeding. Within this group, there are those who are then exposed to antiretroviral treatments, while others have no such exposure. The long term effects of

these two exposures (the virus and the treatments) need to be monitored. These children also are born to a family in which a mother and potentially other members of their family have HIV and may suffer from non biological effects such as parental illness, hospitalization and separation. Indirect effects of stress strain, and emotional challenges may distract parents from parenting. Sick siblings and multiple HIV infections may affect the child. Stigma, strains on the family and economic sequelae of parental infection may also play a role. The third group of children who are affected are those who live in the household with another HIV positive member, but have no virus exposure during gestation and feeding and no antiretroviral exposure during maternal treatment.

Newel et al (2004)<sup>16</sup> showed that HIV exposed but uninfected children had risk factors for death associated with maternal death and maternal disease state. Mortality amongst these exposed yet uninfected children has been confirmed in other studies (Wei et al<sup>17</sup>, Marinda et al 2007<sup>18</sup>). Filteau (2009)<sup>19</sup> examines the HIV exposure for non infected children across six studies in Africa (Uganda, Gambia, Malawi, Botswana, Zimbabwe and Zambia) and found elevated mortality rates. Growth rates were mixed with some delays and less rapid catch-up. Similarly, the exposed children were found to be more at risk for infections. In terms of cognitive development, this report showed some delays in motor and language development but was inconclusive with speculation that delays are probably due to environmental rather than biological exposure. In order to explore this concept in some more depth, the cognitive studies were revisited to examine the use of various comparison

groups and to generate some understanding of the effects on cognitive development for young children who are HIV exposed yet HIV negative. Based on the emerging evidence, studies comparing HIV infected, HIV exposed and control (HIV uninfected and unexposed) children were summarized.

The data clearly indicates that HIV exposed children are worse off than control children in terms of mortality, health and mixed data on cognitive development. Most studies were not set up to explore this issue, and the data is gleaned from reports where the data are reported and available in the tables with means for each group. Some additional studies, which use alternate statistical analysis, do not break down the individual scores. Furthermore, although mortality is a finite outcome, cognitive development is measured in many different ways. All studies, however, use a standardized validated scale, and this is used consistently on exposed and control groups. Clearly, there seems to be indications that HIV exposed children experience effects which merit attention.

The next question is to discover causal mechanisms and to understand whether any interventions can reduce, ameliorate or prevent the avoidance of breastfeeding or abrupt cessation of breastfeeding. Environmental factors may play an additional or direct causal role as well. These could be associated with a number of factors known to adversely affect child development outcomes and include parental illness, parenting interruptions, family bereavement, maternal or paternal depression, poor nutrition and reduced socio-economic factors.

There are a few studies which compare outcomes for children who were exposed to HIV but not to treatment with those who were exposed to both

HIV and antiretroviral treatment. They are too few to provide a definitive answer, but this needs to be kept under vigilant watch.

### **Caregivers of young children in an HIV context need special consideration**

Care and caregiver issues are of fundamental importance to children as they grow. This is especially true for young children who are entirely dependent on caregivers and care arrangements for their well-being. For the purpose of this report, three areas of care will be reviewed, namely infected caregivers, children acting as caregivers (for ill parents or for siblings in the event of parental death) and care arrangements.

#### **Infected caregivers and effects on child development, child care and child outcomes**

It is well established that the stresses of caring can result in poor mental health and, if reduced, divert this effect. Possible causes may relate to vitality.<sup>20</sup> HIV infection is associated with illness in utero virus exposure, in utero ART exposure, other birth factors associated with maternal HIV infection (such as prematurity), maternal illness factors, issues associated with feeding (such as the absence of treatment) and numerous debilitating opportunistic infections. The illness has an oscillating trajectory in the absence of treatment. There are also well documented mental health effects of HIV. The most notable relate to widespread depression (on average just over 40%), anxiety (just over 15%) and other effects such as post traumatic stress disorder and suicide. There are, however, very few studies that explore the effects of these conditions on parenting. It is well documented in the non HIV field<sup>21</sup> that mental health conditions such as depression and anxiety<sup>22</sup> affect parenting, and negative or

compromised child development outcomes are consistently reported. Caregiver illness has been shown to directly affect child outcomes.<sup>23</sup> Of interest is the finding that interventions to ameliorate parental mood can benefit child outcomes.<sup>24</sup>

### **Child takes on responsibilities as a caregiver for either the ill parent or the siblings in the event of adult caregiver death**

The complexity of this disease also points to the importance of young caregivers—very young children who undertake care responsibilities in HIV affected families. This includes direct care activities, such as medical care of a sick adult, or indirect activities, such as overseeing even younger siblings, undertaking household chores normally carried out by the ill person and jeopardizing their daily life (such as school attendance, socializing or play activities) in order to contribute to care demands in the home. Such young caregivers are known in non-HIV literature to suffer from a host of psychological problems<sup>25</sup>. But statistics often hide the fact that these caregivers may be very young. For example, in Great Britain, 29% of caregivers were aged 5-10 years of age.<sup>2</sup> There is very little literature for the HIV population, despite the heavy burden of such care. A study in China<sup>26</sup> focused on children from 8 to 17 years, and although they found both positive and negative effects, they did not explore the impact on children under 8 years of age<sup>27</sup> and used a new validated scale<sup>28</sup> to explore the impact of caring on young caregivers<sup>3</sup>. A review of four measures to capture the effects of caregiving on child health and quality of life was conducted (Schlarmann et al 2008), which found the strains well captured in general HQOL measures, and recommends the KIDSCREEN to capture child related effects most accurately.<sup>29</sup>

The few studies in developing settings and directly associated with HIV rarely disaggregate by age. A Zimbabwe/U.S. study showed high levels of depression among young caregivers.<sup>30</sup> Parentification is another phenomenon described in the literature, while delayed development, guilt and low self-esteem have also been described.<sup>31</sup> On the other hand, Bauman et al notes that a strong relationship and good support may ameliorate negative effects, and good bonds sustain the ability to contribute to the family. Skovdal's study in Kenya<sup>32</sup> has shown that, at times, children care for the caregivers, and that orphaned children often contribute substantially to their foster or new households with a reciprocal system of care<sup>33</sup>. They note that "young caregivers cope by mobilizing social support, engaging in income generating activities and constructing positive social identities around their caring roles. Children's ability to cope is determined by the extent to which they are able to participate in their community and negotiate support from it."<sup>34</sup> In Burkino Faso, mothers looking after HIV positive children were caught in the tension between secrecy and the openness, which may be required to garner social support in the stressful task of caring.<sup>35</sup> Their burden is reported in a number of other settings.<sup>36</sup> The stresses come directly from caring and indirectly from the stresses created by survival needs<sup>37</sup>. A long term study of young caregivers in South Africa (Cluver et al) with rigorous methodology may provide much evidence in the future. A number of coping strategies have been explored, ranging from medical and economic to psychological resources.<sup>38</sup> Caregivers seem

2 Cited in Bauman et al 2006 (see references below).

3 Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) – an 18 item inventory, and the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) – a 20 item inventory for young carers to provide an index of positive and negative outcomes of caring.

to function well if they can avoid dependency, reduce household tension and maintain household integrity.<sup>39</sup>

### **HIV impacts care arrangements for young children**

There is growing evidence that children with one or both parents deceased have elevated emotional and development challenges. The growing problems of child care raise particular questions about types of care that should be available, alternative care arrangements and country level planning. This is particularly important for young children. There is an array of care arrangements that have been discussed in the literature. These roughly divide between kinship care of some form and non-kinship care. A large U.S. study examined behavioral problems in children cared for in kinship care versus foster care and found behavioral problems among 32% of the former compared to 46% of the latter<sup>40</sup>. The non-kinship care options range from large institutional care settings and small group homes, to foster care and adoption. Kinship care models include skipped generations, child headed households, family adoptions and fostering. A study in Brazil<sup>41</sup> tracked the care arrangements for children of deceased HIV positive adults (n=1131). It found that 41% resided with their mother, 25% with grandparents and only 5% in institutions. It is clear from this data that families are providing the mainstay of support for OVC children. This study also pointed out the particular problem of HIV positive children. Indeed, HIV positivity was associated with a 4.6 fold chance of institutionalized care.

The table in Annex D summarizes 17 recent studies that have looked specifically at comparisons

between different forms of care in studies with a specific child cognitive outcome and a comparison/control group. The major finding is that 15 of the 17 note negative effects of institutionalized care. Two do not record effects. Given the problems with random allocation of children to care settings, some of the data needs to be approached with caution. The most convincing studies are those in which children are randomly selected for different care options and longitudinal outcome and change data are available. These show that changes from institutionalized care can benefit the child. Age of orphanage placement as well as duration of stay may contribute to outcome. Age of removal from such care is also seen as important. A qualitative study monitoring the voices of children in institutionalized care in Botswana notes:

*“The children report on the importance of having uninterrupted access to food, shelter and schooling and a sense of belonging. However, they also reveal a profound ambivalence towards their paid caregivers and the other children residents. They describe being separated from siblings, missing their families and feeling disconnected from the community at large.”<sup>42</sup>*

### **Section II: Interventions for OVC and Impact on Early Childhood Outcomes**

For the purpose of this report, a systematic review was conducted to examine evaluations of orphans and vulnerable children interventions and to summarize findings, especially in relation to design, methodology, nature of intervention and impact of outcome. The criteria for the search strategy were set up in order to capture all intervention studies in relation to HIV and children, conducted in Sub



Saharan Africa, with a total of 93 papers reviewed. Well designed evaluations of OVC interventions in the HIV era are reportedly scarce.<sup>43</sup> King et al were unable to identify a single evaluation in which adequacy criteria in terms of design and outcome measures were employed. King's Cochrane review confined itself to psychosocial interventions, and it may well be that different forms of intervention or complex interventions may be available for scrutiny. Another recent review by Schenk identified 21 studies, including published and unpublished evaluations, with designs both controlled and uncontrolled and including both qualitative and quantitative data.<sup>44</sup>



*There is a growing body of evidence on interventions for children – yet there are numerous gaps which hinder the evidence base. The focus of interventions for children are predominantly medical. However, there is a clear movement of social support evaluations. Cash transfers show benefits to young children – the evidence is solid. Complex or combination interventions seem to be more readily available and point to an emerging literature.*

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## Findings

The current systematic review raised predominantly medical papers (n=43) and biomedical issues (n=36) including nutrition, infant feeding and HIV testing. Thus the vast majority of evaluated interventions (79/93 – 85%) relate to biomedical issues around children. It is clear from this review that the focus on interventions for children are still internationally

focused on the provision of interventions in accordance with biomedical models. These relate to direct HIV treatments, prophylactic treatments or additional interventions to enhance wellbeing (such as vitamin supplements, treatment access and nutrition). This suggests very clearly that the major vehicle for provision and access to young OVC is concentrated in biomedical approaches and settings, and that the literature has not advanced significantly since the King and Schenk reviews. There is some movement, however, and this is worth capturing. For this initiative, a focus on children under the age of 8 adds further restrictions and complications. Many of the interventions are multilevel, in that pregnancy interventions affect infants, and are thus included in the analysis as long as there was some infant outcome. Given the maximum age of 8 years, a number of youth and adolescent interventions are not included, but may provide some insight to interventions within the older children.

At times, interventions may not be directed at children, yet positive child outcomes are recorded. For example, three studies examined the effect of ART treatment on adult quality of life with household benefits<sup>45</sup>. All studies were unpublished, yet cited in a review by Beard et al (op cit). One such study in Kenya noted that after 16 months boys had a significant reduction in housework and girls were less likely to carry water. Wasting in the under fives reduced from 12% to 4%, hours of school attendance increased (more markedly for boys than girls) and young boys were significantly less likely to work outside the house after 100 days on ART (a finding not seen for older boys or girls at any age). Quality of food consumed was also enhanced, and borrowing was reduced. These studies highlight the

need to have a multilevel approach to benefits for children via family inputs. Indeed, the cash transfer literature also shows a high level of evidence-based findings on the benefits to children of adults receiving small, regular payments. Adato & Basset (2006) note the effects most notable in terms of health, education and nutrition.

### Section III: Systematic Review on Effective ECD Interventions

The next question to pose relates to what is generally known about early childhood development interventions that could potentially be adapted to HIV and OVC situations or could serve as a starting point. This would necessitate a vast coverage of the literature and is beyond the scope of this report. A detailed review has been published recently by Engle et al.<sup>46</sup> This informative review shows that there are a number of tried and tested strategies to promote child development outcomes and to intervene and thereby ameliorate loss of developmental potential. They summarize the elements of efficacy in such programs as being those which “*provide direct learning experiences to children and families, are targeted toward younger and disadvantaged children, are of longer duration, high quality, and high intensity, and are integrated with family support, health, nutrition, or educational systems and services.*” Nutrition programs, for example, have beneficial effects on later child cognitive outcomes,<sup>47</sup> with marked benefit when these are combined with stimulation programs. This paper reviewed 20 studies which met inclusion criteria for developing countries and under 6 years of age with the following components: “randomized controlled trial or matched comparison group, effectiveness or program evaluations (not

efficacy trials), child development assessed and targeted disadvantaged children” covering center-based interventions, parent-child provision or comprehensive provision (multiple components). 18 of the 20 showed beneficial effects, and the learning from this seminal review was that direct children provision was superior to information to parents, skill building is superior to passive information exchange and already disadvantaged children benefit disproportionately. In addition, sustained and lengthy interventions are more effective than one off interventions, and younger children show the most benefit.

Sixty-five systematic reviews were identified with relevant interventions for child development (see Annex E). These are not focused on HIV or OVC, but the lessons learned can be readily adapted. There appears to be robust literature to show through systematic collation of studies according to rigorous criteria that a wide range of interventions have been tried, evaluated and found effective in terms of areas of child development, which are relevant to descriptions of potential challenges faced by OVC. This is a sound starting point, and interventions for OVC should build on this background platform.

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## IV. DISCUSSION AND RECOMMENDATIONS

This review indicates a number of issues discussed below.

***Children are at particular risk as a result of the HIV epidemic.*** This is not new. It has been well established for many years. What is clear is that the concerted action has lacked solid evidence based policy and has failed to disaggregate children by age (or even gender), so that the responses are not

necessarily optimal. In the field of health care and medicine, there is both sound evidence and a track record of evidence.

***HIV results in cognitive deficits for both HIV infected and affected children.*** There is clear and solid evidence that children with HIV infection may have sustained cognitive deficits in all aspects of their development. The mechanisms for this deficit are unclear—either direct virus effects or indirect environmental effects. It is probable that both are contributory factors. Special educational provision is long overdue and will continue to be needed.



*There is a vast history of interventions in the non HIV arena that have proven track records. These should be adapted to the HIV field.*

Children who are exposed to HIV in utero but are born HIV negative have passed somewhat under the radar. The focus has concentrated on their HIV status rather than a holistic account of their growth and development. Emerging data from studies not set up to explore these specific

effects clearly show detrimental effects on mortality, health, cognitive development and emotional adjustment. At present, known HIV positive mothers receive treatment in just above 45% of cases. They account for the majority of effective interventions for children within the literature. And as access to HIV prevention measures increases, children born with HIV will decline. This has been clearly monitored in the west where there is access to antiretroviral treatment. The Global Fund provision for treatment and the policy of Access for All as well as PMTCT plus programs and the UNAIDS strategy of “Virtual

elimination of paediatric infection by 2015” will gain momentum. The landscape will change with the improved roll out of antiretroviral treatments. Treatment for pregnant mothers will avoid HIV infection in the first place. Treatment of sick mothers and fathers will avert bereavement and parental loss. Treatment of HIV positive children will increase survival of children and require new provision as they grow older and enter the teenage and adult phases.

Children are at risk of a series of shocks in their early life course as a result of HIV. Such shocks can become cumulative and divert children from reaching their potential. With universal access, the children exposed to HIV in utero but born negative will increase. The data suggest that long term monitoring as well as interventions to reduce or prevent effects are urgently needed.

***In areas of high HIV concentration children generally are affected.*** The rates of parental death are high and illness among parents leads directly to child vulnerability. The vulnerability is increased for younger children.

***Care arrangements and the quality of care are clearly important in child development.*** There is good evidence that large scale institutional care compromises children. There is also good evidence that kinship care offers advantages to children. Children are in need of care and are affected by the HIV epidemic by demands of care provision for siblings or sick adults. Indeed, emerging studies on ART for adults have shown specific benefits for children in terms of reduced household demands and increased school attendance.

Gender is insufficiently studied or understood in

the literature. Mental health and cognition is known in the general literature to be affected by gender. The evidence base does not sufficiently report on gender, analyze the data by gender or provide guidance according to gender considerations. This is particularly important as gender barriers may compound vulnerability.



*A culture of evaluation is urgently needed in the applied field so that evidence as well as experience can guide policy.*

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***The literature on interventions for OVC is piecemeal.*** Previous reviews have struggled to find a comprehensive robust evidence base to guide good practice. The area abounds with excellent experience and poor evidence.

This systematic review spread the net very widely and endeavored to include any intervention for children.

What was of note was the fact that children are usually grouped together and there is little focus on ages and stages. The data does not naturally disaggregate at 8 years of age. Interventions are almost predominantly contained within the biomedical sphere. Good design, control and power exist in studies of health interventions. This is not matched for studies on psychosocial or community interventions.

The general early childhood development literature, however, has a steep history in evaluated interventions. There are a wide range of solid

interventions, well described and evaluated, that could be adapted to young OVC groups in high HIV prevalence areas. Learning for HIV does not need to start from scratch. There is an imperative for community and OVC provision to meet the challenges of comprehensive evaluation in order for good practice to feed into policy. The vast arena of expertise is not being captured in the evidence base.

No international indicators of OVC wellbeing are globally integrated into all protocols. This is complicated as such indicators need to be sensitive, easy to administer, reliable and pick up on cultural nuance. In the absence of global indicators, validated measures have often been employed. This ensures good quality data, but means that comparisons are difficult across studies and settings. Where Global indicators exist (such as those in the DHS and MICS studies), they are often brief and provide blunt instruments for picking up the detail of OVC realities. Ideally, global and detailed indicators are needed.

Sieze the day. We have reached a clear turning point for children. Treatment rollout, the virtual elimination of pediatric infection, the move towards evidence based provision and the global recession are all markers for a mind-shift in programming and provision for children. The evidence base is emerging, and there are a series of imperatives that are known to provide high quality services for children now, preventing future problems and maximizing current opportunities.

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# Annexes For Distinct Disadvantage

## A review of children under 8 in the HIV and AIDS epidemic

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# Annex B

## Studies Reviewed on Cognitive Impact of HIV on Young Children

| STUDY                            | YEAR | PLACE        | SAMPLE(N)                   | AGE        | STUDY                            | YEAR | PLACE          | SAMPLE(N) | AGE        |
|----------------------------------|------|--------------|-----------------------------|------------|----------------------------------|------|----------------|-----------|------------|
| 1. Abubakar, et al               | 2009 | Africa Kenya | 367                         | < 8        | 33. Havens J et al               | 1994 | USA            | 60        |            |
| 2. Agostoni, et al               | 2000 | Italy        | 36                          | incl - 8's | 34. Hilgartner et al             | 1993 | USA            | 333       | incl -8's  |
| 3. Alimenti et al                | 2006 | Canada       | 63                          | < 8        | 35. Hooper, et al                | 1997 | USA            | 46        | incl -8's  |
| 4. Aylward et al                 | 1992 | USA          | 96                          | < 8        | 36. Isaranurug, Chompikul, et al | 2008 | Thailand       | 388       | incl -8's  |
| 5. Bachanas, Kullgren et al      | 2001 | USA          | 68                          | Incl-8     | 37. Keller, M.A                  | 2004 | USA            | 33        | incl -8's  |
| 6. Belman et al                  | 1996 | USA          | 247                         | < 8        | 38. Knight et al                 | 2000 | USA            | 45        | < 8        |
| 7. Bisiacchi, Suppiej, et al     | 2000 | Italy        | 55                          |            | 39. Koekoeka, Sonnevle, et al    | 2008 | Netherlands    |           | Incl-8     |
| 8. Blanchette et al              | 2001 | Canada       | 50                          | < 8        | 40. Levenson et al               | 1992 | USA            | 49        | Incl-8     |
| 9. Blanchette, Smith. et al      | 2002 | Canada       | 25                          | Incl-8     | 41. Li, Ying et al               | 2000 | China          | 46        | incl -8's  |
| 10. Bobat, Moodley, et al        | 1997 | South Africa | 136                         | < 8        | 42. Lindsey, Malee, et al        | 2007 | USA            |           |            |
| 11. Boivin, Green, et al         | 1995 | Zaire        | Study 1: 50,<br>Study 2: 41 | < 8        | 43. Macmillan et al 2001         | 2001 | USA            | 1094      | < 8        |
| 12. Brouwers, van, Engelen et al | 2001 | USA          |                             | Incl-8     | 44. McKinney, Wesley et al       | 1993 | USA            | 170       | < 8        |
| 13. Bruck, Tahan et al           | 2001 | Brazil       | 150                         | < 8        | 45. Mellins, C.A et al           | 2003 | USA            | 307       |            |
| 14. Chase C et a                 | 2000 | USA          | 421                         | < 8        | 46. Mellins, C.A. et al          | 1993 | USA            | 77        | < 8        |
| 15. Chase, C et al               | 1995 | USA          | 51                          | < 8        | 47. Msellati, et al,             | 1993 | Africa, Rwanda | 404       | < 8        |
| 16. Chiriboga, et al             | 2008 | USA          |                             |            | 48. Nichols, S et al             | 2000 | USA            | 353       | incl -8's  |
| 17. Cohen, Mundy, et al          | 1991 | USA          | 48                          | Incl-8     | 49. Nozyce, et al                | 1994 | USA            | 181       | < 8        |
| 18. Condini, A et al             | 1991 | Italy        | 36                          | < 8        | 50. Pavlakis, S.G et al          | 1995 | USA            | 34        | incl -8's  |
| 19. Coplan, J et al              | 1998 | USA          | 78                          | < 8        | 51. Pelton, J et al (2005)       | 2005 | USA            |           | incl - 8's |
| 20. Cortey, A et al              | 1994 | USA          | 10                          | < 8        | 52. Piazza, Astori, et al        | 1995 | Italy          | 138       |            |
| 21. Coscia, Christensen, et al   | 1997 | USA          | 82                          | Incl-8     | 53. Pollack et al                | 1996 | USA            | 91        | < 8        |
| 22. Diamond, et al               | 1990 | USA          | 40                          | < 8        | 54. Puthanakit et al             | 2010 | Thailand       | 121       | Incl -8's  |
| 23. Drotar et al                 | 1997 | Uganda       | 436                         | < 8        | 55. Ratner et al                 | 1997 | USA            | 333       | incl -8's  |
| 24. Esposito, Musetti et al      | 1999 | Italy        | 117                         | Incl-8     | 56. Sanmaneechai, et al          | 2005 | Thailand       | 65        | < 8        |
| 25. Fishkin, P.E et al           | 2000 | USA          | 80                          | < 8        | 57. Smith et al                  | 2006 | USA            | 539       | < 8        |
| 26. Forehand, Jones, et al       | 2002 | USA          |                             |            | 58. Tahan, Bruck et al           | 2006 | Brazil         | 172       | < 8        |
| 27. Forsyth, Damour, et al       | 1996 | USA          | 52                          | Incl-8     | 59. Van, Rie A et a              | 2009 | Africa Congo   | 160       | < 8        |
| 28. Franck, et al                | 1999 | USA          | 33                          | incl -8's  | 60. Watkins et al                | 2000 | USA            | 173       | Incl -8s   |
| 29. Fundaro, Miccinesi et al     | 1998 | Italy        | 16                          |            | 61. Weng, S et al                | 1998 | Africa         | 530       |            |
| 30. Gay, et al                   | 1995 | USA          | 126                         | < 8        | 62. Whitt et al                  | 1993 | USA            | 63        | Incl -8s?  |
| 31. Gelbard et al                | 1995 | USA          | 16                          | incl - 8's | 63. Wolters, et al               | 1995 | USA            | 56        | incl -8's  |
| 32. Grover et al                 | 2007 | India        | 441                         | Incl-8     |                                  |      |                |           |            |

# Annex C

## Mental Health Problems for OVC

| Study  | Sample   | Measure   | Rate / Findings   |
|--|--|---|---|
| Mellins et al 2009 (USA)                               | 340, HIV+ve vs exposed   | Anxiety<br>Psychiatric disorder   | 46%<br>61% vs 49%   |
| Gadow et al 2010 (USA and Puerto Rico)                 | 575, 319 HIV+ve, 174 exposed, 82 living with HIV family but HIV negative                     | Psychiatric problems  | 27% vs 26%  |
| Cluver et al 2006 South Africa                         | 60, 30 orphaned children and 30 matched controls   | Borderline abnormal pee problems, Post-Traumatic symptoms (orphan group only) | 58%, no difference between groups, PTS = 73.3%  |
| Chatterji et al. (2005) Rwanda and Zambia)             | 160, Orphans, children with chronically ill caregivers (probably HIV), Non-affected children | unstandardized 'worry/stress' scale   | Zambian Orphans: worse than children with ill caregivers, worse than other children (p < .04). Rwanda: no differences between orphans and children with ill caregivers, but both groups worse than other children (p < .03)   |
| Forehand et al 1999 USA                                | 249, 100 (mothers infected), 149 control   | Externalizing problems, internalizing problems                                | Affected group more internalizing and externalizing problems than controls (p < .05). Six months after the death of their parents, there were non-significant improvements in orphans' psychosocial adjustment  |
| Pelton and Forehand 2005                               | 100 (mothers HIV infected or non HIV) before and after maternal death                        | Externalizing problems, Internalizing problems                                | Orphans more internalizing and externalizing problems than control groups both before death and at 2 year follow up   |
| Bauman, Camacho, Silver, Hudis, and Draimin (2002) USA | 190 HIV positive parents and their children  | Externalizing and internalizing behaviour                                     | 75% of children scored above threshold on Child behaviour checklist   |
| Lee et al (2006) USA                                   | 2559, Perinatally exposed, HIV-infected (N 1847, uninfected (N 712)                          | Quality of Life   | 6 months to 4 years: infected children: sign. Worse mean adjusted scores for functional status<br>5 to 11 years: Infected children: sign. Worse health perceptions, physical resilience, physical functioning, and social/role functioning<br>Uninfected: significantly worse psychological functioning |
| Bussing and Burket 1993 USA                            | 91; 23 children with hemophilia, 37 asthma, 31 healthy                                       | Affective Disorders and Schizophrenia Intra-familial stress                   | HIV-positive boys with hemophilia significantly higher rates of anxiety disorders prevalence /66.7%, p_/0.013, high rate of separation anxiety disorder   |
| Havens et al., (1994) USA.                             | 60, 26 HIV-infected, 14 sero-reverted, 20 non exposed  | psychiatric diagnostic evaluation   | HIV infected: , ADHD: 58,3 %, Separation anxiety disorder: 25 %, Oppositional defiant disorder: 25 %, (no significant differences between groups)   |
| Scharko et al (2006) (pooled eight studies)            | N=325  | Psychiatric diagnosis   | ADHD: 28.6%, Anxiety Disorders: 24.3%, Depression: 25%.   |

# Annex D

## Effects of Care Systems on Child Outcomes

Annex D - Effects of Care Systems on Child Outcomes

| Study                              | Sample | Design   | -ve effects | Findings  |
|------------------------------------|--------|--|-------------|---|
| Almqvist et al 2005 (Kurdistan)    | N=142  | orphans in traditional foster care (n = 94) orphanages (n = 48)  | Yes (?)     | The two orphan care systems showed more similarities than differences, but the foster care revealed better outcomes over time.  |
| Beckett et al 2007 (Romania)       | N=156  | 127 (68 girls/59 boys) adopted from institutions in Romania compared to 49 children (17 girls/32 boys) adopted UK from a non-institutions  | Yes         | children adopted from Romania had significantly lower attainment scores than those adopted within the UK  |
| Bos et al 2010 (Romania)           | N=141  | Ever institutionalized vs never institutionalized. Institutionalized group randomly allocated to community care or no change for follow up | Yes         | Children in the EKG performed significantly worse on three of the four measures for memory and on two of the three measures for executive function. After controlling for birth weight, head circumference, and duration of time spent in institutional care, assignment to the foster care group significantly predicted strategy scores |
| Dobrova Kocl 2010 Ukraine          | N=64   | uninfected and HIV-infected institutionalized and family-reared children   | Yes         | Both HIV infection and institutional care were related to delays in physical and cognitive development, with a larger effect of the rearing environment. Family care, even of compromised quality, was found to be more favorable for children's physical and cognitive development than institutional care.                              |
| Gheza et al 2009 (Romania)         |        | Institutionalized children randomized to enter foster care stay in institution and compared with never institutionalized                   | Yes         | Data indicated that at both age points, children who received the foster care intervention showed higher levels of attention and positive affect compared to children who remained institutionalized.   |
| Miller et al 2012 Guatemala to USA | N=103  | Foster care versus institutional care prior to USA arrival   | Yes         | Those who resided in foster care scored significantly better for cognitive skills than those who had previously resided in orphanages (96.3% of age-expected compared with 88.3% of age-expected); other skills did not differ  |
| Nelson et al 2007 R                |        | RCT abandoned children in institutions remain there or sent to foster care   | Yes         | cognitive outcome of children who remained in the institution was markedly below that of never-institutionalized children and children taken out of the institution and placed into foster care   |
| Pollack et al 2010 USA             | N=132  | Prolonged, brief institutional rearing versus natal family rearing   | Yes         | Institution reared children showed neuropsychological deficits on tests of visual memory and attention, as well as visually mediated learning and inhibitory control. No differences on executive processes such as rule acquisition and planning   |

|                                   |         |  |     |  |
|-----------------------------------|---------|--|-----|--|
| Roy et al 2006 (UK)               | N=38    | 19 institutional raised children compared to 19 controls reared in family foster care  | Yes | Reading delay was more prevalent in the institutional group and as a group they had lower reading scores than the children reared in family foster care  |
| Smyke et al 2010                  | N=169   | Institutionalized since birth, randomly assigned to care as usual (CAU) or foster care, and compared to family-reared children   | Yes | Attachment classifications for children in foster care were markedly different from those in the CAU.  |
| Van der Dries et al 2010<br>China | N=92    | Former foster care vs institutional from China   | Yes | At both assessments, the former foster children outperformed the post-institutionalized children on mental and motor skills. Both groups showed a similar catch-up for mental development.   |
| Vorria et al 2006 (Greece)        | N=100   | 61 adopted children (4 years) who had spent their first two years of life in an institution compared to 39 children reared in their own 2-parent families.               | Yes | At four years adopted children still had lower scores on cognitive development, were less secure, and less able to understand emotions than family-reared children   |
| Whetten et al 2009 5 countries    | N=2,837 | 1,357 institution-living and<br>1,480 community-living   | No  | Health, emotional and cognitive functioning, and physical growth were no worse for institution-living than community-living OAC, and generally better than for community-living OAC cared for by persons other than a biological parent  |
| Windsor et al 2007 (Romania)      | N=40    | Institutionalised children compared to peers   | Yes | Children who were institutionalized and children in foster care for a brief time showed substantial language delays  |
| Wolf et al 1995 Eritrea           | N=74    | Refugee children living in families compared to orphan children in overcrowded orphanages  | No  | The orphans showed more behavioral symptoms of emotional distress, but performed at a more advanced level on cognitive and language performance measures.  |
| Zeanah et al 2009 (Romania)       | N=170   | 52 Remained in Institutions, 59 to foster care and 59 matched controls never institutionalised   | Yes | Children with any history of institutional rearing had more psychiatric disorders than children without such a history (53.2% versus 22.0%). Children removed from institutions and placed in foster families were less likely to have internalizing disorders than children who continued with care as usual (22.0% versus 44.2%). Boys were more symptomatic than girls regardless of their caregiving environment and, unlike girls, had no reduction in total psychiatric symptoms following foster placement. |
| Zhao et al 2010 (China)           | N=176   | Care before orphanage admission. Family-based by different caregivers, which included surviving parent (38%), grand parents 22%, other relatives 19%, non-relatives (22% |     | Children under the care of their grandparents reported the best psychological outcomes when their parents were unable to care for them   |

# Annex E

## Outcomes of Systematic Reviews to Evaluate Effects of ECD Interventions on Child Outcomes

| Author                      | Topic  | N of studies | Age >8<br>>/<8 |   | Effective  |
|-----------------------------|--|--------------|----------------|---|--|
| 1. Adato et al 2009         | Conditional cash transfer programs vs unconditional                        | 20           |                | x | Yes, effective for health, education and other wellbeing outcomes                        |
| 2. Anderson et al 2003      | Comprehensive preschool programs on child development                      | 20           | x              |   | Yes  |
| 3. Barlow et al             | Group-based parent education programs for behavior problems                | 18           | 3              | x | Yes and maintained over time   |
| 4. Bayer et al 2009         | Preventive interventions for children's mental health                      | 50           | x              |   | No clear outcomes  |
| 5. Berrick, et al 1992      | Child sexual abuse prevention  | 30           |                | x | Increased knowledge but no studies of actual reduction in abuse                          |
| 6. Bilukha, et al 2005      | Early Childhood Home Visitation in Preventing Violence                     | 28           | x              |   | Yes, decrease child maltreatment and violence by parents.                                |
| 7. Birdee et al             | Yoga for the pediatric population  | 34           |                | x | Inconclusive due to lack of quality studies  |
| 8. Blauw-Hospers et al 2005 | Early Neuro-developmental treatment on motor development.                  | 34           | x              |   | Yes—can improve motor development  |
| 9. Bower et al 2001         | Treatment of child and adolescent mental health problems in primary care.  | 18           |                | x | Small effect but variable study quality  |
| 10. Carfoot et al 2003      | Mother/baby skin-to-skin care on breast feeding.                           | 7            | x              |   | Inconclusive due to methodological flaws   |
| 11. Cedar et al 1990        | Parent effectiveness training  |              |                |   | Yes  |
| 12. Coren et al 2003        | Individual and group- parenting programmes for teenage mothers and child   | 14           | x              |   | Yes  |
| 13. Cuijpers et al 2006     | Screening and early psychological intervention for depression in schools   | 8            |                | x | Yes  |
| 14. Dennis et al 2008       | Telephone support for women pregnancy and early postpartum period          | 14           | x              |   | No significant effect  |
| 15. DeWalt et al 2009       | Health literacy  | 5            |                | x | Yes- health knowledge and health behaviours  |
| 16. Dewey et al 2008        | Complementary feeding interventions in developing countries.               | 42           | x              |   | Yes  |
| 17. Dixon et al 2008        | Reduction of challenging behaviours  | 3            | x              |   | Yes—on children prenatally exposed to drugs  |
| 18. Dretzke et al 2009      | Parenting programmes for children with conduct problems                    | 40           |                | x | Yes  |
| 19. Eccleston, et al 2002;  | Psychological therapy for chronic pain in children and adolescents         | 18           |                | x | Yes Psychosocial treatments are effective in reducing pain (more specifically headaches) |
| 20. Eilander et al 2010     | Multiple micronutrient supplementation for improving cognitive performance | 20           |                | x | Yes with marginal increase in fluid intelligence but not with crystallized intelligence  |

|                          |   |    |         |   |  |
|--------------------------|---|----|---------|---|--|
| 21. Ekeland et al 2005   | Exercise and self esteem  | 23 |         | x | Yes (small effect)   |
| 22. Elmquist et al 1995  | Parent-oriented programs to prevent child alcohol and other drugs.  |    |         |   |  |
| 23. Engle et al          | Strategies to avoid the loss of developmental potential in the developing world                             | 20 | x       |   | Yes  |
| 24. Eshel et al 2006     | Interventions to promote responsive parenting   | 12 | x       |   | Yes  |
| 25. Fuchs et al 1986     | Effects of Systematic Formative Evaluation  | 21 |         |   | Yes  |
| 26. Garner et al 2000    | Routine growth monitoring on nutrition and illness responses  | 2  | no inf. |   | Inconclusive due to insufficient reliable information              |
| 27. Goldring et al 1986  | Preschool   | 11 |         | x | Yes—Math, reading ability, IQ and school performance               |
| 28. Hahn et al 2007      | Universal school-based programs for the prevention of violent and aggressive behavior                       | 53 |         | x | Yes—Programs reduce violence                                       |
| 29. Hahn et al 2003      | Home visitation to prevent violence   | 26 | x       |   | Yes  |
| 30. Hoagwood et al 2005  | Family-based services in children's mental health.  | 41 |         | x | Inconclusive due to lack of good interventions                     |
| 31. Joronen et al 2008   | School-based drama interventions in health promotion.   | 9  |         | x | Small effect on knowledge and attitudes                            |
| 32. Kramer et al 2004    | Optimal duration of exclusive breastfeeding   | 16 | x       |   | Yes—exclusive to 6/12 decreased gastrointestinal risk of morbidity |
| 33. Law et al 1998       | Interventions for primary speech and language delay   | 48 | x       |   | Yes- effect of Speech and Language Interventions                   |
| 34. Lungen et al 2009    | Nutrition and prevention of depression for children and adolescents   | 18 |         | x | Majority of prevention studies have no positive effect             |
| 35. MacMillan et al 1994 | Primary prevention of child sexual abuse  |    |         |   | Improved knowledge of abuse but no studies on actual abuse         |
| 36. MacMillan et al 2000 | Prevention of child maltreatment  | 14 | x       |   | Yes—Home visitation had an effect                                  |
| 37. Mendez et al 2002    | Psychological treatment of childhood and adolescent depression  |    |         | x | Yes—moderate and maintained. Slight effects on self esteem         |
| 38. Mikton et al         | Home-visiting, parent education, abusive head trauma prevention and multi-component interventions for child | 26 | no inf. |   | Yes  |
| 39. Murray et al 2007    | Coordinated school health programs and academic achievement   | 17 |         | x | positive effect on some academic outcomes for some children        |
| 40. Mytton et al 2002    | School-based violence prevention programs   | 44 |         | x | Reductions in aggressive and violent behaviour                     |
| 41. Neil et al 2009      | School-based prevention and early intervention programs for   | 27 |         | x | Yes—Small (0.11) to large (1.37) effect sizes were reported        |
| 42.                      | Child behavior therapy:   | 52 |         |   | Yes—effective with both aggressive and unassertive children.       |



|                             |   |                 |   |         |   |
|-----------------------------|---|-----------------|---|---------|---|
| 43. Poobalan et al 2007     | Effects of treating postnatal depression on mother-infant interaction and child development     | 8               | x |         | Cognitive development in children and mother infant relationships might be improved with sustained interventions. |
| 44. Riethmuller et al       | Movement interventions for motor development in young children                                  | 17              | x |         | Yes   |
| 45. Roberfroid et al 2005   | Growth monitoring and promotion programs on nutrition, morbidity                                | 69              |   | x       | Weak evidence   |
| 46. Romeo et al 2005        | Child and adolescent mental health interventions  |                 |   |         | Slight child behavioural gains and parent satisfaction from parent and child training programmes                  |
| 47. Sachdev et al 2005      | Iron supplementation on mental and motor development  | 17              |   | x       | Yes-, particularly for initially anaemic or iron-deficient children   |
| 48. Sakinofsky et al 2007   | Survivors' bereavement management after suicide   | 1 with children |   | x       | Yes—reduction in symptoms   |
| 49. Serketich et al 1996    | Behavioral parent training to modify antisocial behavior in children                            | 26              |   | x       | Yes—Parent reinforcement method training reduced child antisocial behaviour                                       |
| 50. Shenai et al 1993       | Outreach educational program and neonatal transport   |                 |   |         | Positive effects on neonates  |
| 51. Sherr et al             | Contact opportunities associated with Cash transfers to link with social welfare services       | 12              |   | x       | Cash transfers improve various child outcomes   |
| 52. Singleton et al 2005    | Parent-infant interaction interventions   | 25              | x |         | Yes—affect socio- emotional delays  |
| 53. Statham et al 2004.     | Services to support children in special circumstances.  | unclear         |   | no inf. | Inconclusive  |
| 54. Stein et al 1987        | Companionship therapy   |                 |   |         | slight improvement  |
| 55. Thomas et al 2006       | School-based programmes for preventing smoking.   | 23              |   | x       | Mixed   |
| 56. Torgerson, et al 2002   | Reading support by volunteers on reading performance  | 7               |   | x       | Mixed—volunteering had a small effect on reading outcomes   |
| 57. Valle et al             | Nutritional interventions and child growth  | 14              | x |         | Yes, nutritional counselling improves child growth  |
| 58. van Sleuwen et al       | Linking social welfare development with cash transfers and education to promote child wellbeing | 8               |   | x       | Yes—beneficial effects on children  |
| 59. van Sleuwen, et al 2007 | Swaddling   | 78              | x |         | Yes for excessive crying but carries risks  |
| 60. Vreeman et al 2007      | School-Based Interventions to Prevent Bullying  | 26              |   | x       | Yes, multiple disciplines interventions reduce bullying   |
| 61. Waddell et al 2007      | Preventing Mental disorder in children.   | 15              |   | x       | Yes—psychosocial interventions can prevent depression, anxiety and conduct disorder                               |
| 62. Wainwright et al 2000.  | Health promotion interventions by school nurses   | 0               |   |         |   |
| 63. Wethington et al 2008   | Reduce psychological harm from traumatic events   | 30              |   | x       | Yes individual and group cognitive therapy help trauma exposed children   |
| 64. Wiener et al            | Disclosure of an HIV diagnosis to children:   | 1               |   | x       | Inconclusive due to lack of comparison group  |
| 65. Zoritch et al           | Day Care  | 8               | x |         | Yes – positive effects on children's development  |