The Essential Package: An Age Appropriate Framework for Action for Young Children and their Caregivers Affected by HIV and AIDS

Highlighted in this Issue:
- Description of the Essential Package
- Findings from Literature Review
- News from the Field
- Case Study
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- Upcoming Events

BACKGROUND
Sub-Saharan Africa has the world’s highest HIV and AIDS prevalence rates and is also home to the highest number of children orphaned as a result of the epidemic. For instance, in 2008 more than 14 million children in Sub-Saharan Africa had lost one or both parents to HIV/AIDS. The literature also shows that children infected or affected by AIDS are at a distinct disadvantage in virtually all aspects of life - education, nutrition, health, safety, and development. These children are less likely to have their basic needs met or be in school, and are more likely to be sick or malnourished, suffer psychological trauma, endure abuse, and become HIV positive.

Young children are especially vulnerable to the effects of HIV and AIDS, given the critical importance of the first five years of life in providing the foundations for lifelong development. Ultimately, orphans and vulnerable children (OVC) are less able to reach their potential as productive members of society than other children and are more likely to perpetuate the cycle of illness and poverty. As the HIV pandemic puts great strains on the existing community based safety net responses, it is essential to build family resiliency. This can be done through parenting skills in the context of chronic illnesses thus strengthening the first line of response in order to build a safe and nurturing home protective environment. Although most countries with a high prevalence of HIV and AIDS have national strategies in place to support OVC, there are few programs designed specifically to meet the special needs of children under five.

THE ESSENTIAL PACKAGE
In response, CARE and Save the Children are working together, along with the Consultative Group for Early Childhood Care and Development and other partners to formulate an Essential Package to address the needs of young children and their caregivers affected by HIV/AIDS. This package addresses children’s developmental needs across the age continuum (prenatal to 8 years) with the goal of adapting the package to other vulnerable

circumstances such as conflict and emergencies. The Essential Package provides policy makers and program managers a framework for action to provide holistic and developmentally appropriate programming to improve developmental and health outcomes.

The Essential Package will consist of a six part package:

1. In-Depth Literature Review which provides the rationale for mainstreaming early childhood development (ECD) into OVC programming;
2. In-Depth Program Review which provides an overview of existing programs that address ECD and HIV;
3. Frameworks that highlight the needs of young children and their caregivers and provide the essential actions to address identified needs;
4. Tool Kit to support the Frameworks (e.g., Monitoring tools, Visual Guide, etc.);
5. Online Knowledge Management Platform to provide a centralized compendium of supporting resources; and
6. A Framework for Action Document for policy makers and program managers

**LITERATURE REVIEW**

This review provides a systematic study of elements of the published literature to guide the process and provide background detail for the Essential Package for young children affected by HIV. 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 young children and to use an evidence based approach to inform provision and shed light on the understanding of gaps. However, there is a body of wisdom on children and child related interventions from other areas which may well inform these initiatives as well. 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 were explored. There is good evidence that an ages and stages approach to children is an appropriate strategy. Young children have specific needs and may often be overshadowed in initiatives that collapse children across the ages.

**Main Findings**

- HIV exposed children are worse off than control children for mortality & health; mixed data on cognitive development
- Early childhood is a critical period for growth and development; need for interventions during this period
- HIV changes caregiving dynamics at the household level, with children taking on caretaking roles for siblings or sick adults
- Stress around providing care under adversity can have negative mental health impact
- Gender is insufficiently studied or understood in the literature
NEWS FROM THE FIELD
Findings thus far indicate that many children are cared for by the elderly; many caregivers are suffering from an acute or chronic illness; and many feel depressed and hopeless which can all lead to a lack of responsive caregiving. Additionally, the findings show that the tools used by paraprofessionals at the point of service delivery need to be user-friendly for low literacy levels but also capture key information on milestones for child development so that paraprofessionals can assess, refer, and follow up promptly. Additional feedback regarding the package is provided below from each country site.

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<th>Country Feedback</th>
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<tr>
<td><strong>Malawi</strong></td>
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<td>- Overall the Essential Package will help address holistic care for young children</td>
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<td>- The EP is a tool for engaging in dialogue about difficult issues</td>
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<td>- The tools encourage a habit of record keeping</td>
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<td>- Mobilization meetings and service mapping were beneficial activities for community members even beyond the goals of this project because they introduced community members to resources they didn’t know about</td>
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<td><strong>Mozambique</strong></td>
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<td>- Families pay more attention to their children and promote positive behavior and motivate children</td>
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<td>- Some families say that they seek relief and support from volunteers</td>
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<td>- More openness and receptiveness of families to accept messages given by volunteers</td>
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<td>- Improved hygiene in families and children</td>
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<td><strong>Zambia</strong></td>
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<td>- Community Health Promoters (CHP’s) report feelings of pride and fulfillment, as they are literally able to save lives and enhance the health and wellbeing of children</td>
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<td>- CHP’s and supervisors have provided guidance on how to improve the training for the revised training manual.</td>
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<td>- Caregivers express appreciation for the support and knowledge from the caregivers</td>
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<td>- Government stakeholders at the ministry of health and education are open to expanding the program in their areas of responsibility</td>
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Case Study from Mozambique

Maya is a 76-year-old widow who suffers from tuberculosis and is the head of a 10-person household. Ever since her husband died 32 years ago, Maya has relied on subsistence farming in order to provide for her family. In addition to subsistence farming, she supports her family by plowing neighbors’ gardens. In earlier years, Maya gave birth to 4 children, 2 sons and 2 daughters. Although her children are now all adults, none of them lend support to the household. Despite the enormous burden she carries, Maya is very warm and loving toward her family. Maya reports that visits from the volunteer have had a significant impact. In part, the visits have enabled Maya to feel less alone. The volunteer is an older female, and a friendship appears to have blossomed between the two women. This relationship seems to have increased Maya’s feeling of security, both emotionally and physically.

Moreover, it seems that volunteers might be doing more than just sharing vital information about early childhood development. The act of paying a visit seems to communicate a message of caring and concern which, in and of itself, might boost a family’s morale. For Maya, feeling cared for seems to offset some of the daily stress of survival. Aside from the emotional benefits, Maya also reports having learned a great deal from the volunteer’s visits.

There are things that changed because there are things that Ms. Alice is teaching us to do. Because, she says wash the hands of the kids, give baths to the children when they go, they want to eat, and when they come from the toilet. Wash the dishes, sweep your yard, all of those things are very important because they are changing the way we used to live.

In addition, Maya has discovered tools and resources from the Visual Reference Guide that she previously had not considered to be at her disposal.

The book is really excellent because when you look at the book it teaches you that when you are sad, go to your neighbor, and look for someone you can share with your concerns. And, it teaches us, as well, if a child has done something wrong don’t beat him. Sit with him, talk with him, and find out why he is doing what he is doing. Also, to find back the feedback of our children when they come back from school to see how did they perform.

These discoveries have reportedly resulted in some real differences in her home. Maya’s grandchildren have been so pleased by the images in the Visual Guide that they have asked Maya whether the volunteer might be able to leave the book with them so that they can have regular access to the pictures. Maya has also passed on the knowledge gained from the pictures to her neighbors and is spreading some of the recommendations made by the volunteer to other caregivers who live nearby. Even in the face of such extreme hardship, the images are salient, powerful and inspiring; for Maya and her family, they are leaving a mark.
PARTNERS SPOTLIGHT
In each newsletter we will be providing background information on the activities of Inter Agency Task Force partners. In this newsletter we are featuring REPSSI (the Regional Psychosocial Support Initiative) who will be one of our co-hosts at our October Stakeholders meeting. REPSSI acts as a regional leader in Sub-Saharan Africa to lessen the devastating social and emotional impact of HIV and AIDS, poverty and conflict among children and youth. The organization’s goal is to ensure that all children have access to quality social and emotional support. We’re excited to have their support for the coming meeting in Johannesburg this October. You can lean more about REPSSI by visiting their website at www.repssi.org.

UPCOMING EVENTS
October Stakeholders Meeting
CARE and Save the Children began working together on this Essential Package Initiative in 2008. This was done through stakeholder and working group meetings with key representatives from the HIV/AIDS, OVC, and ECD communities. Over the course of three previous meetings (September and December 2009 in Washington DC as well as June 2010 in Dar es Salaam, Tanzania) participants have provided input and guidance on specific components of the Package which have now been field tested in Malawi, Mozambique, and Zambia. Thus, we have decided to host a fourth stakeholders meeting on October 4-6, 2011 in Johannesburg, South Africa to provide partners an opportunity to hear the lessons from the field, to provide input, as well as to discuss future involvement and next steps. This meeting will be co-hosted with The Consultative Group on Early Childhood Care and Development and REPSSI. Invited guests include program implementers, regional and local government officials, U.S Government representatives, and members from the South Africa Development Community.

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