

‘Beyond the Fragments of Care’

Issues Paper for an expert meeting on Children Affected By Aids in (Sub-Sahara) Africa, in The Hague, Netherlands, Institute of Social Studies, 3 April 2008; organized by the Dutch CABA working group.

Introduction

Why yet another meeting? We want to move on with discussions (here in The Netherlands and where possible at European Union and global levels) on the best means to assist ‘Children Affected By Aids’ (also known as OVC¹) in Sub-Sahara Africa, *now* as well as in the future. In a previous meeting in 2007, we explored ‘cash transfers’ as a starter measure in a Social Protection environment and learned that such cash payments have an immediate effects on poverty. In very poor settings, however, part of this support ‘leaks away’ on Health and Education spending. We also note that globally substantial amounts are now available to combat HIV & AIDS, but this assistance is not reaching most of the vulnerable people. In fact, less than 10 percent of those in need, receive any form of external assistance and children are the last to be helped. The principle of ‘freedom from want’ – as detailed in solemn Declarations on Rights of Children and other human rights texts – is absent in the reality of HIV & AIDS in Africa. We therefore will address questions of distribution and social exclusion, in order to explore a next round of issues on outside assistance and internal organization, in the area of ‘delivery of services’ at a local (family and community) level, where up till now only ‘fragments of care’ are to be seen.

Context

We place ourselves in the mainstream international context of (UN) Agencies and Governments, which have spoken out on HIV & AIDS policies and the way in which children are affected; we refer to the ‘Framework’ on OVC (Unicef, 2004), subsequent mainstream papers and strategies and like to benefit from work done in the JLICA².

We want to benefit from work done in JLICA, in particular from the Learning Groups 1 (Strengthening Families), 2 (Strengthening Community Response) and 3 (Access to essential services). Each of these groups writes a lot of papers : LG 1 plans 14 papers, LG 2 has identified 8 subjects and LG 3 foresees 9 (LG 4, on Social & Economic Policies, is less relevant on questions at family and community level, at this moment). We will make choices in the number of subjects and limit ourselves to the region Sub-Sahara Africa.

We set up a ‘one day meeting’ on Thu. 3 April for the main group of participants (those who seek ‘information’ in the first place), but we foresee that (part of) a consecutive day will be used work on details and decide on follow-up and advocacy action with a core group.

Perspective.

As CABA working group, we have a ‘rights-based’ approach. We also take the position that working with and strengthening communities, must not be based on assumed needs, but on needs articulated by the stakeholders³ who are the primary caregivers. This implies a participatory bottom-up approach to priority setting. We can’t ignore, however that we are representing various organizations interested in ‘service delivery’ and that these organizations maybe not in design, but in effect – want our recommendations in a ‘top-down’ approach. In this expert meeting, we will have to come to terms with these approaches.

¹ OVC = Orphaned and otherwise Vulnerable Children because of HIV & AIDS; we will use CABA and OVC as synonyms

² JLICA = Joint Learning Initiative on Children & Aids

³ Stakeholders are recipients, defined in the broad sense of the communities, families and persons living with or affected by HIV & AIDS

General questions

- (1) What are the effective ways/approaches that ensure that funds and services available, do reach the communities, families and individuals, who are most in need?
- (2) What are at present the coping strategies for families and communities and how do these function? How can African governments, national and local, as well as donors⁴, work and support such strategies to ensure optimal benefits for children and families in need, so as to avoid damaging existing strategies or adding to the burden of caregivers?
- (3) Where should we look for local level analysis of coping strategies and coordination of support measures?

Issues in detail.

(A) *How strong are families and communities?*

According to the widely endorsed 'Framework' on OVC, the families and communities are the first line of response (Unicef, 2004: 10). It is believed that the community and family of (orphaned) children provide children with the best immediate and adequate care, whilst community based care is also viewed as the most effective because it assumedly has always existed in sub-Sahara Africa. A community-based approach assumes that there are working community structures. Evidence from the expert meeting in 2007 suggests that one should not assume that these structures exist or have not changed. Community- or family members may be willing and well-disposed to care for children in need, but may lack the (financial and/or physical, e.g. grandparents) means or underestimate the consequences. We need to be explicit in what we mean by 'community support', and therefore the meeting starts with *an interactive exploration of our assumptions, knowledge and views* about community care and support.

(B) *Only orphans?*

Family and community based care for children is focussed in particular on orphaned children. An important conclusion of our Social Protection meeting in 2007 was however that orphans are not necessarily more vulnerable than non-orphans. Local understandings of children's vulnerability do often not depend on orphan status, but refer to poverty, social exclusion, abuse and exploitation (see for example Mann 2002; Henderson, 2006; Meintjes & Giese, 2006), and also those children who live with disabled, chronically or terminally ill parent(s) or those whose already-poor households have expanded as a result of taking additional children in (Mann, 2002). Orphaned children are not necessarily more vulnerable than children whose parents are still alive and labelling and targeting orphan for assistance may cause further stigmatization and rather increase their vulnerability (see also: Unicef 2007: 33). We will debate the *development of the international agenda* and take a critical look at its direction.

(C) *Access to basic services?*

Many families face severe constraints in accessing basic services. Required documents, such as a birth certificate, constitute a first and major constraint in accessing many services. In the expert meeting 2007, it was suggested that birth registration should be compulsory. Families however do not refuse to register their children, the process is just too complicated or difficult (e.g. one has to travel a long distance to an office). Cultural issues that can't be ignored : in certain cultures, newly-born children are only named after so many days (or even months). On the African side, peoples' representatives (e.g. Members of Parliament) should look for ways to make the process accessible and adjusted to local circumstances (e.g. have midwives help fill in the forms). Families who care for orphaned children, meet the same and additional problems of required papers, due to the fact that many children are not formally placed in

⁴ donors to be defined in the broad sense of Donor Governments, NGOs and International Organizations

their care. Access to schools or health care – insofar as these are available in rural districts or urban slums, where the poor dwell – is again impeded by the absence of documents mentioned above. It goes without saying that children excluded from schools and health care, are highly disadvantaged. What can local authorities contribute to diminish the various problems of access? In the workshop *Access to Basic Services* we address the above discussed issues, and focus on the ways access for families can be enhanced and improved.

(D) *Sustainability and community ownership*

The 2007 expert meeting concluded that Community Based initiatives should always aim to be sustainable. All organisations in the meeting stressed the importance of participation of the local communities and connecting with existing activities to achieve this. A support program should be developed by and as much as possible, executed by community members. The link between community ownership and sustainability is also stressed by Donahue & Mwewa, (2006: 12). When programmes or activities are not connected with existing structures or coping mechanisms, they often result in the eroding of such mechanisms (Conclusions expert meeting 2007; Donahue & Mwewa, 2006: 5). This implies that insofar we truly are interested in sustainable interventions, we have to take time to work bottom up. Civil Society and NGO partner organizations have a role to play in the interaction with (inter)national institutions. Although participants in the expert meeting 2007 agreed that Community Based Organisations (CBO's) have great potential and valuable information for supporting poor (HIV & AIDS affected) households, two major constraints were identified. First, CBO's are often not recognised by official institutions and their information is consequently not used. Second, CBO's are largely run by unpaid volunteers, who are often poor themselves. These community volunteers should be remunerated and should also receive standardized training, to enhance the quality of their work. The latter is also a form of compensation, as it will improve their chances for other paying jobs. In the workshop *Community level interaction* we deal with these issues, and concentrate on ownership and participation.

(E) *Daily care and children's views*

A further conclusion of the expert meeting in 2007 was that family members are not always willing or able to care for orphans. Families which do (informally) foster children are often unprepared. Concerned relatives, even the father or other children in the household, are often not consulted; neither are children to be fostered, asked about their views. As a result, children may feel unwelcome, unhappy at the beginning of their placement and may later feel they are not always well treated; they may be at risk of being neglected or abused. Therefore, fostered children always need to be monitored. In addition, foster families may need various types of support in dealing with the difficulties of raising another child (see presentation of Njuguna, expert meeting 2007) and those needs can/should be (registered by monitors) addressed. As noted, children are often not consulted about care arrangements, although they may have well thought-through views' about these (see presentation of Mulugeta Gebru, expert meeting 2007; Mann, 2002). Mann (2002) found, in a study of care arrangements for orphans in Malawi, large discrepancies in children's and adult's views on appropriate care. Adults felt that children should play no part in decision making and emphasized the importance of material capacity to care for orphans. Children themselves stressed the wish to be cared for by adults who love them (Mann, 2002: 33).

In our view, children need to be involved about their needs and wishes in care arrangements (for themselves, as well as for their siblings). Clearly, difficulties around fostering children are not all about (a lack of) money. Nonetheless, many families are very poor, and formal assistance (grants and guidance) would make a significant difference. As many children are not formally adopted in a new household, modalities have to be found and rules must be formulated, to access formal support. In the workshop *Daily Care* we look into issues of child participation, modalities of family involvement and structure of support grants.

(F) *A fresh look*

Where does all this lead us? We hope to bring together a new look at the CABA environment, a better understanding of the interlinking of access to various services, improved insight in what can be done to support vulnerable children and how it must be done in a community context. We hope to do that with empathy, sustained by understanding of the tasks performed in daily care.

Our challenge will be to make *wise choices in recommendations and good decisions for Advocacy*. A limited number of speakers and participants will be invited for the second day, Friday April 4th, where there is time and space available to fine-tune follow-up actions and advocacy messages following the results from the first days discussion.

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