



Strengthening the Response for Children Affected by HIV and AIDS through Community-Based Management Information Systems

29 February 2008

Authors: Kendra Blackett-Dibinga and Linda Sussman

TABLE OF CONTENTS

Executive Summary

1. Introduction	1
2. Methodology	1
3. Background	2
A. Scale Up Hope Program	2
B. PEPFAR Data Requirements	2
4. Literature Review	3
A. Community Ownership and Action	3
B. Community Generated Data for Quality Improvement in the Health Sector	4
C. Community based Management and Information Systems within “OVC programming”	7
5. Findings	8
A. Community Level Findings – Save the Children US	8
B. National Level	15
C. Scale Up Hope Partners	17
D. Other PEPFAR Implementers	19
6. Discussion	20
7. Recommendations	23
A. Community level	23
B. Program Level	24
C. Global Level	25
8. Research Limitations	28
References	30
Appendix 1: Schedule of Field Work	31

ACRONYMS

CAC	Community Action Cycle
CBCC	Community Based Child Care Center
CBMIS	Community Based Management Information System
CB-SRS	Community-Based Health Surveillance and Response System
CHW	Community Health Worker
CLIPR	Community level program information reporting (CLPIR) system
CNCS	Conselho Nacional de Combate Ao HIV/SIDA
CRS	Catholic Relief Services
CSI	Child Status Index
CSTS	Child Survival Technical Support
FDC	Fundação para o Desenvolvimento da Comunidade
HACI	Hope for African Children Initiative
LQAS	Lot Quality Assurance Sample
MISAU	Ministry of Health (Mozambique)
MMCAS	Ministry of Women and Coordination of Social Action
MOH	Ministry of Health
OVC	Orphans and vulnerable children
PEPFAR	President's Emergency Plan for AIDS Relief
PLA	Planning, Learning and Action
PRA	Participatory Rural Appraisal
RAP	Raid Assessment Procedures
SEED	Self-Evaluation for Effective Decision-Making
SUH	Scale Up Hope
USAID	United States Agency for International Development
VHC	Village Health Committee
VHP	Village Health Promoter
WFP	World Food Programme
WRC	World Relief Corporation

EXECUTIVE SUMMARY

According to current statistics “over 14 million children have lost one or both parents to HIV/AIDS” (PEPFAR) with the majority of these children living in sub-Saharan Africa. As this epidemic claims more lives each year, it is believed that the number of orphaned and vulnerable children (OVCs) will almost double in the next ten years. (PEPFAR) Therefore, targeting and addressing the needs of these children has become an integral part of programming for international organizations. Moreover, not only are organizations responsible for addressing the diverse needs of the OVCs, they must also monitor the effectiveness of the services that are being provided to the children.

In order to monitor the effectiveness of their programs, organizations are using an approach known as community-based management information systems (CBMIS). This is an approach that strengthens community responses by allowing for decentralized decision-making at the community level. It builds on the idea that when communities are involved from the development of indicators, collection of information, and utilization of the data for decision making, it allows for a sense of ownership and more importantly, sustainability of a program. However, unlike community-based health information systems which have been successfully implemented and documented over the years, little has been studied on how CBMIS are addressing the needs of children in HIV/AIDS affected areas. Thus, this report, through an exhaustive literature review and primary data collection from various stakeholders in Mozambique including beneficiaries, OVC caretakers, community members, Scale Up Hope partners (Save the Children/UK, Save the Children/Norway, HADI), government officials, national level implementing partners and key staff of USAID, and the Ministry of Women and Social Action, attempts to address this particular question.

This study was conducted by Save the Children/US.

Key Findings

Overall, this study found five main areas that need to be addressed in order for CBMIS to be effective in countries such as Mozambique.

1. Programs should build upon the type of data collection that is already being implemented in the community. For instance, most communities and community volunteers collect data orally as oppose to writing the information on a form. This is partially due to tradition in addition to high levels of illiteracy amongst volunteers. Therefore, depending on the environment, urban or rural, a possible combination of both oral and written data collection could provide an opportunity for participation by the community itself while at the same time responding to donor requirements for information.
2. Language can create multiple barriers in the use and collection of data. Three key examples of how this can occur are (1) oral versus written; (2) final reports only written in English as oppose to the local language causing a break in the feedback loop of data back to the community; and (3) lack of familiarity by the community with specific terms

like psychosocial support and advocacy which can lead to improper reporting and in many cases underreporting of activities.

3. Data should be collected and used as part of a comprehensive and participatory process of community mobilization and action. This can be done by using approaches such as the Community Action Cycle and participatory monitoring and evaluation to help enhance community ownership.
4. By frequently changing the data collection process and the forms, additional burdens are placed on those implemented in the field. When this occurs, beneficiaries become suspicious of why the same information is being collected and can lead to distrust in the community. Additionally, valuable time and funds are spent on retraining volunteers which translates into less time for programmatic activities and the oversight of the delivery of services.
5. Linking data across sectors is essential for the wellbeing of children. One way in which this could be accomplished is by linking interventions from the education sector with child survival interventions. This will then help to decrease redundancy. At the same time, this will require significant investments in social welfare systems which have the mandate to oversee the care and support of vulnerable children and communities.

Lessons Learned

- The issue of oral versus written documentation is an area that needs consideration when deciding on the type of data that one wants to collect for programmatic purposes. Most communities visited relied mainly on oral communications due to tradition and the lack of literate volunteers.
- When developing a CBMIS, the communities/beneficiaries must be involved in every step of the process including developing indicators which they deem important and which enable them to understand their own successes and challenges.
- Community members chose not to record certain data on specific questions if they believed it might raise unrealistic expectations by the beneficiaries. Thus, programmers should be sensitive to this issue and structure data tools accordingly. A well-thought out system which does not only respond to donor reporting requirements but community sensitivities and needs may help to diminish this occurrence.
- Community leadership is a key component to any successful CBMIS. Data collected from CBMIS can be used for advocacy and fundraising purposes if those with the data understand what they are collecting. Communities that are engaged from project implementation to data collection and have strong leaders within the community can begin to leverage external funding and have greater ownership of the program's successes and challenges and use data collected to engage members for action.

Recommendations

Community Level

- Data collection forms should be simple and easy to use at the community level. This holds true even for those community volunteers who are illiterate and are unfamiliar with systematic data collection. Not only will it help to ease the burden of the few literate people in the community and will also help with ownership.
- Changes in the forms should be at a minimum in order to streamline the work of the community volunteer and gain the trust of the households participating in the project.
- Communities should have the flexibility to request the type of support that would enable them to take responsibility for their children and determine the needs of the child. If all support is coming from external organizations this can dis-empower the community and lead to dependency on donor organizations. Alternatively, support should be provided to ongoing community activities such as agriculture activities or improved technologies which enable communities to draw upon their internal resources to support vulnerable children.

Program Level

- In order for CBMIS to truly be participatory and community-owned, programs must involve communities in its development. This was shown in multiple incidents by numerous communities who did not understand the foreign term of “psychosocial support” and therefore did not know how to collect data in this area.
- Programs should ensure that data flow is not only vertical but also, that communities have an opportunity to learn from their own data and develop appropriate actions. This way the community can monitor their own successes and achieve better outcomes.
- Programs should make sure that community level data collection systems can be linked to government level systems. This will ensure sustainability by providing necessary information on OVCs to not only the donors but to their local governments as well. It will also help in the new interest to establish national MIS systems which incorporate information on vulnerable children.
- If and when programs need to collect data to fulfill donor requirements, they should consider alternatives to relying exclusively on unpaid community volunteers to collect the information. This could be accomplished by providing resources to the community volunteers and engaging them in determining their exact role in the process.
- Implementing organizations should attempt, where possible, to consolidate efforts for data collection by linking with ongoing programs in the region to minimize duplication of data and limit the burden on community volunteers.

Global Level

- Data collection and reporting should be done in such a way that it creates a balance between accountability to the donor and contributing to improved efforts at the community level.
- Programs should encourage local efforts to monitor and respond to the overall wellbeing of children by addressing not just access to services but measuring the quality of the services as well.
- Need to develop a national information system that contributes to the wellbeing of children.

Conclusion

The study showed that communities are willing to participate in their own process of development. However, external support can sometimes undermine these processes, leading to decreased ownership of community level interventions. Rigorous data collection systems which focus on more than just accountability to donors can help improve local ownership and sustainability in the future. Donors and programmers alike should consider investments in these systems so that communities are able to make the best use of external resources and provide for their own children. Furthermore, these efforts should at all levels be linked to national level systems for data capture to build government capacity to respond to the needs of vulnerable children and communities and plan their support according to felt needs of communities.