THEMATIC REVIEW: CAFOD'S INTERNATIONAL WORK IN HIV-RELATED CARE AND MITIGATION

Roger Drew
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'I was reflecting on how much the scene at the Counselling Centre and in the homes of our clients has changed since treatment for HIV became generally available here at the end of 2005. When I now arrive in the morning, instead of meeting rows of very ill people and their desperate relatives awaiting what little we could provide for them in the way of medicine and food, I now encounter clients back to normal health, meeting to discuss how best to save their money in internal lending groups. I saw two men, previously bedridden, sharing a joke as they waited for others to arrive. Instead of seeing monthly client support group meetings with their members encouraging each other to live positively until they died – usually in a year or two – every day there are two or three meetings of clients, family members, young people and others discussing topics related to behaviour change. When our nurse-counsellors and home care givers visit clients' homes they no longer come upon scenes of despair for families trying to cope with caring for their dying members. They don't meet young children, unable to attend school, caring for their ill parents and then becoming orphans. Instead of trying to cope with weekly funerals and their own burnout, counselling staff are now involved in counselling families about how to help their HIV positive members adhere to treatment and in doing pill counts. Children are now reminding their parents to take their medicines on time.'

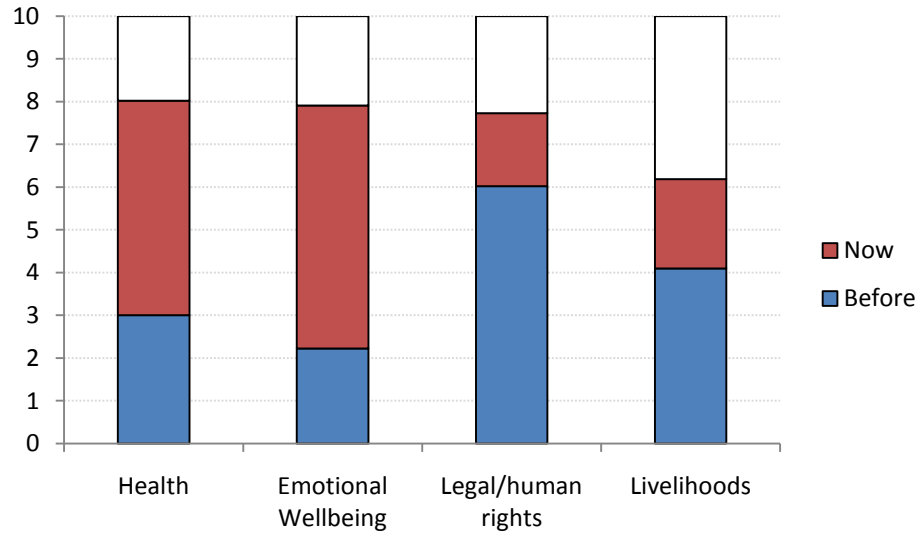
Quote from CAFOD partner, Ethiopia

SUMMARY

This document presents a thematic review of CAFOD's HIV-related care and mitigation work. It is based on consideration of relevant documentation, interviews with a range of key informants and country visits to Ethiopia and Uganda. It also involved expanded use of the CAFOD 'batteries' tool to assess the quality of life of clients of services provided by three CAFOD partners.

This review finds very strong evidence of improved quality of life of clients of services provided by CAFOD partners when comparing their situation prior to joining the programme to now. This is especially the case for people living with HIV who constituted the majority of clients consulted. This evidence comes particularly from use of CAFOD's 'batteries' tool among programme beneficiaries in Uganda and Ethiopia (see Annexes 7 and 8). Data generated through use of this tool shows that the quality of life of clients improved across a number of domains since joining a particular programme. For example, in Uganda, this improvement among people living with HIV was particularly marked in the health and emotional wellbeing domains (see Figure S1).

Figure S1: Mean batteries scores for 'people living with HIV' enrolled in Nsambya Homecare Programme, Uganda (n=55)



The tool also suggests reasons for this improvement in quality of life. For example, in Ethiopia, the reasons were multifaceted but included ART improving health, education improving social relationships and support for income generation improving livelihoods. Counselling was reported to improve both health and emotional wellbeing, while financial support was reported to have improved health, emotional wellbeing and livelihoods. These findings provide evidence of the value of CAFOD's holistic approach to care and support initiatives across a number of domains, because many different elements of care and support have positive effects on the quality of life of clients and beneficiaries.

CAFOD's approach to care and mitigation is holistic and, rightly, emphasises the need for such services to go beyond the clinical only. Partners provide a wide range of non-clinical services, with support from CAFOD, which are appreciated by clients

and which have contributed to improvements in their quality of life. This approach is similar to that supported by other international NGOs and resonates strongly with the approach of the partners interviewed. One of the most distinctive features of CAFOD's approach is its engagement with and understanding of faith-based organisations. CAFOD has excellent relationships with the partners interviewed and visited. Those partners are full of praise for the way CAFOD works as a flexible and supportive donor. This is a reputation that CAFOD will clearly wish to maintain.

CAFOD, and other organisations providing HIV-related care and mitigation services, are operating in an environment which has changed markedly since those services began. In particular, antiretroviral therapy has revolutionised the health and lives of people with HIV receiving this treatment. It has also dramatically changed the context in which care and mitigation services operate. Prior to the availability of ART, people with HIV faced chronic, deteriorating health and premature death. With ART, people living with HIV benefit from improving health and better quality of life. However, a variety of supportive services are vital to allow people living with HIV to access and adhere to ART. Some of CAFOD's partners, e.g. Nsambya in Uganda, provide ART to their clients. Others, e.g. the Lighthouse Trust in Malawi, are involved in encouraging adherence and in providing support services, e.g. food and nutrition, which contribute to the effectiveness of ART. In addition, problems of poverty and livelihoods have become of paramount importance to those restored to health through ART, a finding confirmed by data from use of CAFOD's 'batteries' tool.

CAFOD has demonstrated admirable willingness and openness to engage in discussion about controversial topics, such as the role of condoms in HIV prevention, work with key populations and institutional forms of child care. Work with key populations, such as injecting drug users, men who have sex with men and sex workers is at a relatively early stage and this is an area where activities could be expanded, particularly in countries where HIV is disproportionately concentrated among these populations. However, CAFOD faces a tension in this area, whether to significantly expand its work in these countries or to retain its current focus on Africa, where the burdens of HIV and poverty are particularly high, and where the Catholic Church has established networks working in the poorest sectors and regions.

CAFOD's policies make it very clear that the provision of institutional forms of care for children should be a last resort and highly exceptional. It is of concern that an example of institutional child care which appeared to breach this policy was featured prominently in CAFOD's domestic fundraising literature. Reference was also made to institutional child care in an application to Comic Relief for funding in Ethiopia and this was cited as one of the reasons for the application being declined.

CAFOD and its partners are clearly contributing to increasing the availability of holistic care and mitigation services. However, the extent to which this is being done maximally is difficult to determine because of limitations in the data available on the number of people reached by CAFOD partners individually and collectively. Increasing the availability of results' data will be important, not only in its own right, but also to allow CAFOD to produce more data on value for money of services it supports. Work to demonstrate the value for money of the work of CAFOD and its partners is at an early stage.

Based on the methods used in this review, CAFOD's approach and contribution to HIV-related care and mitigation appear not to be well-known outside of its circle of partners and, to some extent, the broader Catholic family. However, this may, in part, reflect the partners visited and interviewed for this review as they were mainly focused on providing services to their own clients. They appeared to have limited influence on broader HIV responses. However, CAFOD works with several partners with a reported focus on advocacy and networking and a different picture might have emerged had they been included among partners interviewed or visited.

Although HIV features in CAFOD's communications with media and communities in England and Wales, there is divergence between these and CAFOD's programmes. Communications with constituencies in England and Wales have focused on softer stories of human and developmental interest and have carefully avoided the so-called 'minefield' of sexuality. CAFOD has invested a great deal of time and effort into developing tools and training for mainstreaming its HIV work across its development portfolio. However, some of the staff interviewed expressed concern that this had had limited effect. One example was provided from an external evaluation in Ethiopia of 'mainstreaming' consisting of the addition of limited HIV awareness activities within a broader development programme.

The mapping and batteries tools developed by CAFOD are excellent resources for partners and others. The mapping tool seeks to identify the extent to which clients can access holistic care and support enabling partners and programmes to identify gaps in services. For example, Nsambya used the tool in Uganda and identified the need to link up with another organisation to provide legal advice services. In Ethiopia, use of the tool led to Mekdim being identified as a new CAFOD partner with particular expertise in supporting livelihoods of people living with HIV. The batteries tool is an excellent resource for CAFOD staff and partners to document improvements in clients' quality of life and the reasons for these. A key feature of this tool is its participatory nature. Modifications made to the tool in Ethiopia have made it even more relevant for non-literate people.

The partners visited have taken steps to involve people with HIV in their activities, for example, as volunteers and outreach workers. However, more could be done in these cases to make this involvement more meaningful. Mekdim, in Ethiopia, is an excellent of CAFOD partnering with a successful association of people living with HIV. Mekdim could be a model among CAFOD partners of involving people living with HIV in decision making.

This report makes a number of recommendations:

1. CAFOD should consider expanding its work among key populations at higher risk of HIV.

2. CAFOD's mainstream livelihood programmes are a potentially powerful way of supporting PLHIV. CAFOD needs to ensure that they include PLHIV, particularly in contexts of high HIV prevalence.

3. CAFOD should update its guidance relating to antiretroviral therapy to ensure that it reflects the current situation fully.

4. CAFOD needs to strengthen the formulation and implementation of its policy on providing care for children.

5. CAFOD and its partners need to identify ways in which they can publicise more the work they are doing in order to influence positively work being done by others.

6. The ‘batteries’ tool provides strong evidence of improvements in quality of life experienced by clients of services provided by CAFOD partners. CAFOD could write up this experience separately from this review report, e.g. as a paper in a peer-reviewed journal.

7. CAFOD should consider expanding its work with partners, such as Mekdim in Ethiopia, that are demonstrating how to involve PLHIV more meaningfully in responses to HIV.

8. CAFOD could improve its collection of results data.

9. Given resource constraints, CAFOD needs to consider prioritising its funding to care and mitigation activities which have been shown to have most benefit on clients’ quality of life, e.g. through the data generated from the batteries tool.

10. CAFOD could focus more on achieving value for money through its investments, e.g. through calculating unit costs for each of its partners. This could be nuanced by using data from use of the batteries tool and applying input costs to particular interventions. CAFOD should seek to learn lessons from others that are pioneering new approaches to monitoring value for money.