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# The Impact of Increased Availability of Antiretroviral Therapy on Programmes Responding to People Living with HIV and AIDS

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# The impact of increased availability of antiretroviral therapy (ART) on programmes responding to people living with HIV and AIDS

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# 1. Summary of key issues and recommendations

## Issues raised by the research

The expectations of clients have changed, and in largely a positive direction. Most obviously the life-extending impact of ART means that clients and programmes are now no longer preparing for death after their HIV positive diagnosis.

The long term sustainability of both the programmes and clients has become a prominent issue because of the lifelong nature of ART treatment.

Three key areas of programme development were identified:
- ART support services
- Economic empowerment
- Advocacy

Gender issues continue to abound, particularly communication between couples, violence against women and stigma barring men from accessing treatment.

Opportunities have been created: resources for services that are in less demand can instead be redirected to new initiatives

New services and treatments bring with them solutions but also new challenges such as managing demand for HIV testing and at the same time resisting coercion to test, marriage guidance and reproductive advice for HIV positive couples, and managing the potentially overwhelming demands of ART provision alongside, or instead of, other services provided up to now.

The experience of programmes in Brazil gives insight into the long-term effects of ART use:
- While the ART medications are always available, the treatment for opportunistic infections and ART side effects are not.
- The availability of ART can be seen as the complete solution to HIV and AIDS negatively affecting donor funding and government support.

Organisations requested:
- Financial and directional support to develop strategic plans and manage processes of organisational change
- Training in positive prevention, and sexual and reproductive health issues for people living with HIV
- Opportunities to learn through programme knowledge exchange, including across continents
- Support to develop HIV workplace policies and critical illness provisions
- Skills development in psychosocial support, advocacy economic strengthening, and supporting people to return to work

**CAFOD's role in supporting its partner organisation's programmatic development**

CAFOD has a significant role in supporting its partner organisations to through:
- Providing financial and technical expertise for strategy development including facilitating programme reviews with organisations
- Facilitating programmatic sharing and learning through partner meetings, exchange visits and sharing of printed resources
- Skilling its own staff in strategy development, advocacy, and economic empowerment
- Linking with other international organisations to learn from their approaches
- Encouraging programmes to implement the good practice recommendations listed above
- Supporting partners to diversify their funding and donor base

## 2. Acknowledgements

The author would like to thank the participating organisations for their willingness to share information on their programmes, their successes and concerns. Participants combine a number of CAFOD partners organisations (indicated with an * below) and other NGOs also surveyed. Their contributions provided a rich diversity of experiences and lessons from Africa, Asia, Europe and Latin America. An excel spreadsheet with the detailed responses accompanies this report, which can isolate information based on organisation name, country and region, and by a number of classifications based on organisational data gathered: CAFOD partner, type of organisation, type of community served, whether directly delivering HIV treatment, clients' ages etc.

### The participating organisations

| Organisation | Country/region |
|---|---|
| ActionAid | *Uganda* |
| Baby Milk Action | *Africa region* |
| CAMP (Centro de Atendimento Médico e Psicológico – Medical and Psychological Care Centre)* | *Brazil* |
| CHEC (Cambodian HIV/AIDS Education and Care)* | *Cambodia* |
| Christian Aid | *Global* |
| Concern Worldwide | *Cambodia, Bangladesh, India, Lao PDR, Nepal, Pakistan, Timor Leste* |
| Crescent Support Group | *UK* |
| Eurasian Harm Reduction Network | *Central and Eastern Europe & Central Asia* |
| HACC (HIV/AIDS Coordinating Committee)* | *Cambodia* |
| Interact Worldwide | *Ethiopia, Malawi, Uganda, Bangladesh, India, Lao PDR, Nepal, Pakistan, Timor Leste* |
| ICW (International Community of Women Living with HIV/AIDS) | *UK, Botswana, Kenya, Namibia, South Africa, Tanzania, Uganda* |
| Karol & Setha* | *Cambodia* |
| Maryknoll HIV Programme, Little Sprouts* | *Cambodia* |
| Mbala Households In Distress* | *Zambia* |
| MEXFAM | *Mexico* |
| MMM Counselling and Social Services Center* | *Ethiopia* |
| Pela Vidda* | *Brazil* |
| Projeto Esperança* | *Brazil* |
| SACBC (South Africa Catholic Bishops Conference) AIDS Desk* | *South Africa* |
| SAfAIDS (Southern Africa AIDS Information Dissemination Service) | *Southern Africa* |
| Samaritan's Purse UK | *Ethiopia, Kenya, Mozambique, Rwanda, Swaziland, Uganda, Zimbabwe, Ukraine* |
| Sarva Seva Sangh | *India* |
| SCC (Salvation Centre Cambodia)* | *Cambodia* |
| Seedling of Hope & Bridges of Hope* | *Cambodia* |
| SSOPO (Southern Sudan Older People's Organisation) | *Sudan* |
| St Francis Community Care Programme, Livingstone* | *Zambia* |
| St Francis Hospital, Katete | *Zambia* |
| St Theresa Mission Hospital* | *Zambia* |
| WOFAK (Women Fighting AIDS in Kenya) | *Kenya* |
| Youth Alive* | *Zambia* |

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## 3. Introduction

This report is the result of research commissioned by CAFOD into the impact that antiretroviral therapy (ART) has on programmes responding to HIV and AIDS. As ART becomes increasingly available, affordable and accessible it brings undeniable benefits to those served by programme partners in many countries. People accessing treatment are enjoying improved health, sustained -or a return to- employment, renewed ability to become active members of their society and overall improved quality of life for themselves and those dependent on them. With these benefits come new aspirations in people living with HIV and therefore different expectations by them of the programmes that support them. Where such programmes have been focused on providing health care and psycho-social-spiritual support to people who were sick, this same client group now seeks earning opportunities, work skills, opportunity to continue their education and the possibility of enjoying a renewed social life and community involvement.

These new expectations fall broadly into three categories – ART support services, economic empowerment and advocacy – placing new demands on the skills base of programmes. Questions have risen about how to respond, and, in the case of HIV-focussed organisations, perhaps whether to respond to the economic empowerment needs. Given the insights into the Brazil experience where ART has been accessible for 12 years, these agencies may want to be prepared for the long term impacts of HIV treatment rather than divert their resources to income generation. However, the retaining HIV expertise and developing economic empowerment components may not be mutually exclusive. CAFOD partner organisations in different countries are at different points in the process of encountering, confronting and responding to the challenges and this research offers a valuable opportunity to learn from experiences emerging across a wide span of geographical locations, cultures and HIV epidemiologies, and to share this learning more widely.

## 4. Methodology and data

This report summarises research which explored the issues described above and serves as a starting point to facilitate the sharing of partner experience in responding effectively to this challenge. Contributions were sought from organisations that either deliver ARVs, or are providing other services to people living with HIV and AIDS who are accessing ARVs by other routes. In total 30 diverse organisations, including 14 CAFOD partners, with experience drawn from 26 countries took part. Organisations or networks with regional remits included Central and Eastern Europe, Central Asia and Southern Africa, and one global membership network.

Information was gathered through 14 structured interviews, 15 questionnaires and one case study. All of the organisations surveyed work with people on ART. Four organisations directly deliver ART, three of which included in their services the delivery of ART to pregnant women to prevent vertical transmission of HIV.

An excel spreadsheet with the detailed responses is available to accompany this report, which can isolate interview and questionnaire responses based on the variables collected which describe the organisations and the people they work with. Many of the organisations described themselves as faith-based (33%), community-based (20%), non-governmental (33%) and/or international non-governmental (27%). St Francis Hospital in Katete, Zambia (distinct from St Francis Community Care Programme in Livingstone, Zambia) categorised itself as both 'hospital-based' and 'government-based'. Three networks and a human rights organisation also participated. The majority of respondents worked in urban (63%), rural (53%), and semi-urban areas (43%), many working with communities in all three. Three organisations had national coverage.

Programmes worked mostly with children, women up to the age of 64 and men aged up to 54. However people of all ages from 0 to 85+ were reached by the programmes collectively with the youngest clients on ART being boys and girls under 12 months old, and the oldest person on ART being a 78 year old

woman. Organisations in Africa and Asia had been working with people on ART for between 1 and 8 years, while UK and Latin American organisations had been working with people on ART for 11-15 years.

## 5. Overall trends

Analysis so far indicates that the experiences and challenges are similar for many organisations and there is no discernable difference between either CAFOD partners and non-CAFOD partners, or between faith-based and secular organisations. A distinction was noted in that HIV specific programmes seemed able to develop ART related services such as counselling and adherence support with relative ease. Introducing a programmatic focus on economic empowerment has proved much more challenging for organisations with little or no background in livelihoods approaches. Most of the organisations surveyed recognised the changing environment described in the introduction and had either adapted or expressed a strong desire to adapt their programme to respond to both ART support services and economic empowerment.

Prior to treatment being available there seemed to be a great deal of difference between the African and Asian contexts as the pandemic was perceived to be at different stages. Now that treatment is available, however, it seems that there is more symmetry in the experiences of programmes in both continents. The long term sustainability of the programmes and clients has become a prominent issue because of the lifelong nature of ART treatment. The research participants from Brazil, where the government has been providing ART for 12 years, can offer both African and Asian programmes an insight into the potential challenges ahead. The long term effects of the treatment, and diminished donor support are just two of the issues that the Brazilian programmes are dealing with.

## 6. The changing needs and expectations of clients

The research hypothesis was found to be correct, that ART has had a significant impact on the needs of clients. Their expectations of themselves and the programmes have changed, and mainly in a positive direction. Most obviously the life-extending impact of ART means that clients and programmes are now no longer preparing for death after their HIV positive diagnosis. Instead they are looking to the future and for strategies to sustain themselves and their families. Life however does not return automatically to the normality before individuals and families were affected by HIV and AIDS. Economic and health stability is seriously undermined by increased poverty. In many cases, the return to health on ART was preceded by a period of illness and anxiety in which clients stopped working and sold their assets for basic needs and the search for treatment. Emotional strength has also been tested to the limit. Family relationships and those with the wider community were broken down because of fear, blame and misunderstanding.

The wider availability of ART has provided new hope for clients and families. Access to the drugs means a chance of recovering from illness. The treatment's presence means greater community awareness and discussion of HIV and AIDS, often resulting in dissipating negative attitudes. Much has changed in the context of HIV and AIDS and the rebuilding of lives begins in this new and complex environment. Clients ask programmes to help them manage these new social challenge and opportunities.

Three key areas of programme development were identified: ART support services, economic empowerment and advocacy:

### i) ART Support Services

In addition to the changing social environment, ART also brings with it a host of related support issues which programmes are evolving to support. The first priority is for the efficacy and adherence of the regimens. Adequate food intake is vital in this respect and therefore the most commonly cited concern. Financial support for transport to access treatment and related services was the second most important

need expressed. The following list illustrates the wide variety of needs that clients want in addition to food and transport:

- Adherence information and training
- Support around disclosure, relationships, confidentiality, stigma and discrimination
- Financial support for second line treatment
- Equitable access to treatment
- ART support services outside working hours
- Flexibility from employers for time off
- Regime advice during pregnancy
- Psychosocial & psychiatric support for depression
- Marriage and sexual reproductive advice
- Succession planning for children's futures
- Unlimited access to ART
- Domestic violence issues
- Paediatric ART
- Comprehensive service that addresses treatment, prevention, care and support
- Complementary therapies, e.g. acupuncture, to assist with managing side effects of ART

The biggest challenge to programmes is to provide enough skilled staff to meet the new and changing demands of clients. Medical and non-medical staff alike require training in issues like treatment adherence and side-effects. As overall demand for services increases, programmes and government facilities are increasingly overstretched. More staff members are required to meet the increasing demands for services such as counselling and testing. Programmes have attempted to compensate for poorly resourced government facilities and equipment failures. In one Zambian hospital, community outreach has been dramatically reduced because of the demand for ART provision: St Francis Hospital, Katete (Zambia) is overwhelmed by the demand. Disappointingly, for both the staff and the community, resources for orphan support, peer-education, community care, and prevention have been entirely diverted to ART support services. Cambodian organisation Seedling of Hope faced this challenge by negotiating the handover of its home-based care programme so that it could provide new ART support and economic empowerment services.

Supporting adherence is a major area of challenge for programmes. Treatment literacy information initiatives are often not enough and there are many reasons why clients don't adhere to their regimens. Drug resistance is a serious concern for programmes such as MMM Counselling and Social Services Center (Ethiopia) who increased their ART counselling service because the overstretched hospital staff were unable to provide adherence and follow up support. Clients were switching between the ART medication and Holy Water treatment. Their religious beliefs and negative societal attitudes towards HIV hindered treatment literacy efforts.

### ii) Economic empowerment

In addition to the ART related services, the overriding change in clients' expectations from programmes is for both short term nutritional inputs and ensuring a sustainable future for themselves and their families in the long term. The new opportunity of a future as a result of ART drives the huge increase in requests for economic empowerment and income-generating activities. Clients are acutely aware of the risks inherent in charitable donations which are often time limited and don't always meet their specific needs. The desire for sustainability of treatment and economic futures, coupled with clients' new energy and motivation to be productive, is resulting in a self-initiated movement from dependency to self-reliance. At St Theresa Mission Hospital's (Zambia) programme review meeting, clients specifically requested that the budget line allocated to food supplements for immediate relief be used for investment in fertiliser and seeds for long term gains.

The impact of economic empowerment programmes can be significant. Concern Worldwide shared a case study from its partner WOFAK (Women Fighting AIDS in Kenya) which now provides certified seeds, fertiliser and extension services to clients to grow their own food. Mr. Owino is just one example of a client who was eager to return to work and rejoin his wife in small scale cultivation to once again become self-reliant and support the four orphans in his care. With training and loans from WOFAK Mr Owino has turned his life around. Having paid back the original inputs from WOFAK he has received further

financing to purchase a hand pump and hire someone to work for him. His production has increased to the point where he is relatively affluent and can share his produce with friends and neighbours in need.

But income generation, for some programmes, appears on the horizon as a completely new area of work, requiring skills and experience not previously found in HIV-focussed organisations. The majority of organisations have adapted gracefully to incorporate the other ART related services into their programmes. They have listened to the needs of the clients and increased skills and expertise gradually into the new but related areas of work. Counselling services have adapted to address depression or emerging problems between couples. ART adherence advice has taken the place of AIDS treatment advice clinics; prevention information has expanded to include positive prevention issues. It is the area of economic empowerment which is causing the most change and challenges within programmes and for this reason will be a key focus of this report. A number of programmes have introduced sophisticated programmes which integrate income generation with the broader programme, and others are at early stages of supporting their clients to become self-sufficient. The successes and challenges of all the programmes provide useful examples to learn from.

Many organisations described the challenges of two aspects of sustainability: there is the need and desire of clients to become independent of the programmes, and at the same time the organisations need the clients to become self-reliant for the programme's own sustainability. Each programme has a finite number of clients it can support at any one time. If clients become dependent on the programme, it simply cannot take on new cases. The concern for sustainability therefore is the key factor of both clients and organisations leading the impetus for income generation activities. Samarian's Purse UK summed up these challenges:

*"Medical or social professionals do not necessarily have the livelihoods skills to move into this new area. Costs to retrain can be high, and livelihoods programmes can be expensive to implement. Also the worlds of food security and HIV are separate from each other. For many of our partners, their entire world has been HIV and AIDS work, so their knowledge of organisations that work in the food security sector is limited."*

Households need skills and technical support to help them run their own business. Programmes are being asked for help with business advice, skills workshops in agriculture and handicrafts among many other things, and funds to initiate new projects. New microcredit ventures brought new challenges. For some enterprises initially had a very high failure rate and little data was captured in advance of the initiatives – there were no feasibility or market studies, no business plans or projections.

The most effective economic programmes have in some cases developed their own uniquely tailored approaches, and many have forged invaluable links with other organisations, government ministries and the private sector. HBC and HIV patient counselling programmes have been scaled down or transferred to other organisations to redirect much needed resources towards this new area of work. The Seedlings of Hope programme in Cambodia transferred its home-based care component entirely to another NGO, and developed the Bridges of Hope programme specifically to support people on ART transition into self-employment and economic security. The Southern Sudan Older People's Association previously used resources to alleviate economic shocks in households, and now see their funds directed as investment into income generating activities to facilitate their clients' transition from dependency to self-reliance.

An ActionAid initiative STAR (Societies Tackling AIDS through Rights) works with communities to set up STAR Circles. One recently visited group's focus was originally on positive living. With the introduction of ART there is now a much stronger focus on income generation and on food security, along with treatment literacy and supporting people to adhere to ART. This economic independence and treatment security has had further benefits as it has allowed group members to now also provide support for others in their community. The members visit recently diagnosed people and their families, and explaining the steps they have taken to live positively with the virus.

### iii) Advocacy

A further impact of ART has been the evolution of advocacy approaches and initiatives. It seems that once certain level of support has been, the next stage of awareness of people on treatment includes their motivation to learn about advocacy approaches demand improved or further services particularly from government providers. ActionAid and its partner organisations in Uganda noted that clients specifically request support and training in campaigning and advocacy, with a view to improving the services available to them and to tackling gender issues around HIV and AIDS in their community. CHEC (Cambodia) intends to facilitate community advocacy to empower and politicise the Cambodian people to demand their rights themselves. The director recently attended a workshop in the Philippines on community mobilisation and plans to meet with other NGOs to form a technical working group to build advocacy skills.

The organisational implications of responding to service changes among programme partners has led Interact Worldwide's policy and advocacy at national and international level to take up the sexual and reproductive health and rights of people living with HIV and AIDS and the integration and linkage of sexual & reproductive health and HIV services. Specifically, Interact Worldwide has pursued a focus within its work on health systems strengthening as health system failures clearly have a negative impact on people living with HIV and can threaten ART adherence. Coalitions of people living with HIV and AIDS are working at national level to combat efforts to criminalise HIV transmission, fight against mandatory testing, uphold access to emergency contraception and the right to marry and found a family. The Eurasian Harm Reduction Network has shifted its activities from advocacy for ARV availability in general, to activities focused on exposing good practices in ARV treatment, care and support. Advocacy for access to opiate substitution therapy, previously difficult to highlight, has also gained a higher profile since its use can be argued to support ART treatment adherence.

Advocacy is being further developed through the improved systematic collection of evidence. SAfAIDS has been monitoring who has been reached by its multi-media treatment literacy programs and reported generally high awareness levels around ART in the region and that people are demanding better access to treatment. For HACC (Cambodia), Universal Access (to HIV prevention, care and treatment services by 2010), access to ART and psycho-social support will be the key focuses over the coming period. HACC intends to hire a monitoring and evaluation adviser to facilitate the collection of a strong evidence base to inform its advocacy strategies. HACC is also developing its capacity to produce robust position papers and regional network coordination.

## 7. Gender and age

Gender issues, particularly communication between couples, continue to abound. SSOPO (Sudan) who work with older people found a culture of blame directed at older women in relationships by their male partners. Violence against women continues to be a serious problem and was cited as an issue that programmes deal with in Latin America (Projeto Esperança in Brazil), Asia (HACC in Cambodia), and Africa (SAfAIDS).

Within couples who disclose their HIV positive status to each other, Youth Alive found that men are more likely to reject their partner on discovery of their status, while women are more willing to work through their problems. SAfAIDS described stigma as a significant barrier to men accessing treatment. The consequences can be severe for women when the result is violence in the home when some men insist on sharing treatment with their female partners without going through the testing and treatment processes themselves. Mbala Households In Distress (Zambia) confirmed the trend of more women accessing testing (the programme's ratio of women to men at the time of reporting was 189:59) and sharing their treatment with their husbands.

Services are frequently not targeted at specific sectors of the community. Often both old and young people access services at the same place at the same time. Youth Alive's services are not specified and to

make its approach gender and age sensitive, the programme wants to introduce some audience segmentation to meet the different ageing and gender needs.

Economically, both men and women are equally keen to provide for themselves. A difference has been noticed (by ActionAid in Uganda and Youth Alive in Zambia) in preferred economic opportunities: women are more willing to build income generation projects for long term results while men request direct or conventional employment for more immediate remuneration.

## 8. Wider impacts of ART

The wider impacts of ART availability have been largely positive. The simple fact that they are available more easily means that they are a topic of discussion in communities. People understand more about HIV and its impact as well as the benefits of treatment. The societal level stigma around HIV and AIDS is reduced because people living with HIV are no longer seen as condemned to death. The impact at the household level is profound for each individual and their family, who can now look forward to a more secure future. An ActionAid staff member reported on a recent visit to Uganda:

*"In the family I stayed with, the fact that the mother had new life after ART had a huge impact on the way in which she could talk about HIV with her children. For example, she talked openly about her daughters having an HIV test and insisting their partners did the same."*

The broader impacts of ART treatment include the increase in demand for counselling and testing, the return of adults to productive work, the increase in food consumption and therefore economic stimulation for the food producers and more income earned for those able to return to work (ActionAid).

The emphasis on treatment by the Global Fund for AIDS TB and Malaria has provided some organisations with additional funding and contributed to their own focus on ART support. The recognition of Youth Alive's work by the Global Fund and other donors has contributed to the scaling up of the programme and strengthening the organisation. Youth Alive has been identified as a principal agency of the Global Fund and now disburses its funds to other youth-orientated groups in the area.

## 9. Opportunities created by ART

Despite the challenges, the increased availability of ART has created some important opportunities. The impact on individuals, both clients of programmes and staff, has given a new sense of hope and future that previously was lacking. In most cases their health returns and programmes see vast improvements in their clients' self-image and self-respect. In the past people admitted to the Seedling of Hope Hospice (Cambodia) had died there; but now most patients stay between two weeks and two months, and walk out with their health returned.

Another significant change for Seedling of Hope is the reduction in the number of orphaned children. Little Sprouts (Cambodia), a programme for HIV positive children, initially expected to invest energy and resources in finding foster families for children whose parents died of AIDS-related illnesses. The availability of ART has meant that HIV positive parents are returning to health and finding family placements is a relatively minor aspect of the programme. Resources instead can be redirected to other parts of the programme.

Although some organisations still struggle to meet demands, it is clear that new expertise in ART literacy has been developed. Staff, volunteer and community training have all been possible because of the introduction of new treatment literacy materials courtesy of organisations like SAfAIDS (Southern Africa AIDS Information Dissemination Service) designed to complement government treatment roll-out programs.

ART availability has also had an impact on the GIPA (greater involvement of people living with AIDS) principle, especially in terms of employment for HIV positive people. Staff members who are living with HIV are more likely to be open about their status, and at the same time more programmes have specifically sought to employ HIV positive people to provide role models for clients, benefit from their experiences and strengthen the experience and impact of the programme. Crescent Support Group (UK) encourages clients to sit on its board of trustees to facilitate appropriate decision making on how the organisation is run.

Coordination and cooperation between service providers of all kinds has been effective. Engaging in national initiatives such as the *Continuum of Care* introduced in Cambodia in 2001 has facilitated excellent coherence between diverse agencies and health providers to work towards comprehensive support to people living with HIV.

Advocacy efforts have also evolved. The Eurasian Harm Reduction Network has found that there has been a shift in activities focused on overall advocacy for ARV availability to exposing good practices in ARV treatment, care and support. Advocacy for access to opiate substitution therapy, previously difficult to highlight, has also gained a higher profile since its use can be argued to support ART treatment adherence.

The result of successful economic empowerment programmes has been astounding. Clients have returned to health, returned to work, and rebuilt previously damaged relationships with their kin. They have achieved financial independence and, while by no means completely free from the vulnerability of precarious economies, are able to provide for themselves and their families. They return to the programme for social support and financial support only in times of unexpected economic shock.

## 10. Continuing and emerging challenges

Food security was continually cited as an ongoing issue; from Samaritan's Purse in Ethiopia to Sarva Seva Sangh, in India, to Projeto Esperança in Brazil. It is this major concern that has prompted such a focus on economic empowerment for sustainability of individuals and organisations as described above.

New services and treatments bring with them solutions but also new challenges. Interact Worldwide face the new challenge of managing demand for HIV testing and at the same time resisting coercion to test. While on the whole the demand for testing has increased because of ART availability, Interact Worldwide reported that serious issues around patient confidentiality and poor quality of emotional care in many public health facilities (Interact Worldwide partners study in Malawi) lead to painful experiences in learning diagnosis, which can in fact contribute to significant *reduced* demand for voluntary testing and counselling.

Sexual health issues continue to challenge both within and outside the context of reproductive health. Informing people living with HIV about positive prevention (i.e. the risks of re-infection, drug resistance and STIs) is vital for those who may otherwise assume that sex between two HIV positive people carries no detrimental consequences. Some of Household In Distress' clients, who are recovering because of ART, want to get married without disclosing. Because of this, the programme's care supporters are all trained psychosocial counsellors and support clients to disclose through couple counselling. In Cambodia Karol & Setha specialise in sexual health education for young adults and recognise its specific relevance to HIV. Partnering with Maryknoll's Little Sprouts programme for HIV positive children, Karol & Setha will provide appropriate sexual health education programmes.

The provision of and demand for PMTCT (prevention of mother-to-child transmission) intervention is increasing, although in reality access remains very low. In 2005, the proportion of women accessing testing was estimated to be around 10 per cent and of the estimated number of infected pregnant women, only 11 per cent received PMTCT antiretroviral therapy (Source: UNICEF). In many cases HIV positive people are making informed decisions to get pregnant whether or not PMTCT interventions are available.

However, sexual and reproductive health rights are still being infringed in situations where health workers have not received any specialised training in care and treatment of HIV positive women. In these cases the general perception continues that HIV positive women should not get pregnant and coercion for contraception, sterilisation or termination may be standard (Interact Worldwide).

A newly emerging concern that SCC (Cambodia) would like to respond to is the children of people living with HIV among which there is a high dropout rate from school. Sometimes they miss school because they need to look after their parents or siblings, but often the reason is a lack of prioritisation of school by their parents. SCC is already operating a pilot community education centre in a poor area in Phnom Penh to vulnerable children. The ratio of girls to boys is 9:1, likely reflecting the gender ratio of out of school girls and boys. In poor families where resources are limited school expenses are prioritised for boys over girls. The advantage of the service being literally in the centre of the community is that it is accessible to the children, and also the parents are accessible to the school: should a problem arise or absenteeism occur, it is possible for the monks and staff to provide follow up and regular counselling. The gender balance of the community education centre for out of school children is noteworthy.

In Zambia Youth Alive have found that young people are more likely to stay at home to support their parents with ART adherence. Consequently there are fewer youth participating in the area so there are less workshops. The programme instead does much more door to door outreach to young people requiring more staff and resources.

A major challenge is to help people accept their status, their treatment and change their behaviour to stop re-infection. Overall HIV-related stigma in the community that Youth Alive work in has reduced. In general ART is now widely talked about and people are less in fear of HIV because they know treatment is available. A negative consequence of this, however, is that some people now believe there is a cure and continue behaviour that puts them at risk of infection. The link between looking healthy and being healthy remains very strong in people's minds so when someone's health returns because of access to ART they, and others, assume or believe they are not HIV positive.

Adequate funding to find and retain competent staff is a major challenge for SACBC (South Africa) in what is a highly competitive and also demanding field, which often leads to staff exhaustion.

Potentially harmful consequences have also emerged. Where the level of stigma remains high and the link between looking healthy and actually being healthy are still closely associated, those on treatment may be reluctant to disclose their status, or choose to deliberately conceal it from their partners. The issue of disclosure remains challenging between partners where one or both partners conceal their treatment for fear of rejection if their status is discovered by the other. A gender issue was highlighted by SAfAIDS (Southern Africa) who reported that stigma often bars men's to access treatment resulting in violence in the home when some men insist on sharing treatment with their wives.

## 11. Long-term ART availability: the Latin America experience

*"Access to ART has increased life expectancy, but not life quality."* CAMP, Brazil

The challenges that the Brazilian organisations are currently facing give insight into the potential future issues for programmes in Asia and Africa. The availability of ART can be seen as the complete solution to HIV and AIDS. Projeto Esperança (Brazil) describes the challenges in a country where the average standard of living has increased:

*"What happens is that poverty here [Brazil] is still a big issue. The government says that the country is, on average, better. It is true, the average is better. We have one foot in the freezer and the other in the oven, the average is good, but one side is frozen and the other burnt. The picture the government portrays*

*is one that says that having access to ART solves the problem of HIV and AIDS. It is more and more difficult for us to get funding because people think the problem in Brazil is solved."*

The funding constraints for Projeto Esperança have had serious impacts on the programme and the organisation's sustainability. The programme cannot maintain the same quality of food for its clients which affects the efficacy of the ART. They rely on more volunteers and have less support from professional paid staff such as psychologists. The women who they employ are as poor as the women clients. Projeto Esperança had to go as far as persuading its employees, including coordinators, who accepted a reduction in salary because of its current financial crisis.

Another unforeseen impact of the assumption that ART is the final word in HIV treatment is that previously allocated entitlements for people living with HIV are being withdrawn. In Brazil, people living with HIV were entitled to early retirement and receipt of a pension. Clients of Pela Vidda find that they are now no longer entitled to early retirement on discovery of the HIV positive status because ART is available. In the case of those who had already become retired because of HIV, the government is trying to revoke their retirement, claiming they are well and can go back to work. Pela Vidda claims that the government's motivation is to cut the costs of the pension system and it has not introduced any measures to help people return to work. For many people it is difficult to find a job having been retired for some years. Not every country has as developed a social protection system as Brazil, but many have introduced some sort of support for people living with HIV, for example, HIV positive people in Thailand are entitled to a modest monthly allowance. Programmes should be aware that there is a risk that any current entitlements for people living with HIV could be under threat if policy makers assume that ART is the complete answer to HIV and AIDS.

ART has been available in Brazil for 12 years. While the ART medications are always available, the treatment for opportunistic infections and ART side effects are not. For CAMP's clients in Brazil, the aggressive nature of the ART and its side effects can be psychologically devastating. Some say they cannot sleep, others that they hallucinate and are getting depressed. Once the treatment is begun, it is for life, so it takes a continuous effort, one that demands a lot of stomach and discipline.

For women, lipodystrophy has become a big issue. Lipodystrophy is a fat redistribution syndrome associated with some ART regimens, often characterised by increased fat tissue around the stomach and on the back of the neck and shoulders, and by diminishing fat around the face, arms and legs. The women's self-esteem is destroyed once their bodies start changing, especially in societies such as in Brazil where certain aesthetic expectations are imposed over the female body. Men go through this as well, but culturally, it is less of a problem for them (their biggest problem is to give up the consumption of alcohol once on treatment).Because the state does not provide the complementary psychological and emotional support for people living with HIV and AIDS, there are increasing demands on CAMP to facilitate self-help groups. In one case, a female client of CAMP became very depressed. Despite having access to medication and physicians, there was no psychological support. She simply fasted and died within a month.

MEXFAM's (Mexico) experience with male migrants demonstrates that, even with national provision of ART provided by the government, there are always individuals who slip through the net or are marginalised by mainstream services.

## 12. Two example strategies to meet the programmatic challenges

Organisations are eager to adapt to the new environment and are taking a range of approaches:

- *Scaling down activities* e.g. home-based care as demand for the service declines
- *Developing existing activities* e.g. broadening counselling on sexual health to include reproductive issues

- Redirecting resources to or *introducing new HIV treatment support activities* e.g. adherence support and treatment literacy for HIV positive clients and their families and friends
- Redirecting resources to or *introducing new economic empowerment activities* e.g. business support for self employment
- Letting go of some aspects of their work up to now, working within wider networks and referring clients to other providers for some services, or contracting these out to others.

There are important questions on this last strategy of introducing economic empowerment activities, especially for HIV focussed agencies. The economic needs of clients is clearly a pressing concern but before programmes make significant changes in this direction, they need to ask themselves if it is the best way forward to respond to the economic and self-sustainability needs of clients. The introduction of ART is still relatively new in many countries, and while the overall sentiment is one of positivity, the long term impact of ART treatment still raises many questions. Adherence to regimens, drug resistance (both the concerns of access to second line treatment and infection or re-infection with drug resistant strains of HIV), and long term side effects are all issues that organisations responding to HIV are already dealing with or will need to face in the near future. HIV focussed organisations should consider whether they risk diluting their HIV expertise by taking another direction. Is it more appropriate and potentially cost effective to make closer links with other agencies already doing income generating to provide a coherent and integrated response?

The experiences of organisations from Brazil are pertinent here as the three programmes that took part in the research have been working with clients on ART for up to 12 years. The right to ART access is enshrined in national legislation which has in some ways created problems. The guarantee of drugs was not accompanied by the necessary investment in the health system to cope with the new demands resulting from the access to treatment. CAMP (Centro de Atendimento Médico e Psicológico – Medical and Psychological Care Centre) is challenging the government to provide specialised HIV health posts and specialised hospital care for people living with HIV. Children, for example, have no specific ward in hospitals, and CAMP describes their treatment as ‘improvised’. There is also a lack of emotional and psychological support for people on ART. Most of the psychological professionals in the Brazil health service are not skilled in HIV related issues.

Change has largely occurred in the direction of the programmes from meeting the immediate needs of clients through a welfare approach to supporting longer term personal development. Gradual evolution of programme activities has been an effective strategy for some, while others have called the programme to a halt for a radical rethink of operations. All the actions of the programmes were based on feedback from clients and analysis of how the programme can meet their needs most effectively. They used the ideas of clients, volunteers and staff to reshape their responses.

For meeting the income generation and economic empowerment needs, programmes have taken a variety of approaches. Two comprehensive approaches are illustrated here, ***Bridges of Hope*** (Cambodia) and ***St Francis Community Care Programme*** (Zambia). Both start with the client’s needs at the centre, focus on ART adherence support, provide input for skills training, and then develop income generation. Both strategies encourage peer and family support but the difference in approach lies in where they focus the relationship support.

### i) Example 1: Bridges of Hope (Cambodia): Re-integration of HIV positive individuals and their families

#### Letting go, to grow

Bridges of Hope was introduced as a new programme to the Maryknoll AIDS response in Cambodia. The programme directors realised they needed to adapt to make practical responses to clients, especially in the context of extreme poverty. To meet these needs the programme negotiated the handover of the home-based care and awareness activities to other organisations and opened a building 500 metres from the hospice to begin income generating projects. The first project was making quilts and in time this was also

handed to the organisation ***Tabitha*** which specialises in high quality cottage industries. Twenty HIV positive women in line to access ART were absorbed into Tabitha where they received higher wages and were able to expand the quilt making initiative.

The programme director Fr Jim Noonan described leadership and visioning as key elements to a responsive approach to programming. Leaders of programmes must be willing to look at and understand the reality of the people they serve and ask themselves how they can make things better for the people affected. Maryknoll's philosophy and theology provided the framework for learning good leadership through the example of other people. The aim is always to respond to people living on the margin, those whose needs aren't yet being met by anyone else. The programme director isn't deterred when he finds multiple needs that cannot simultaneously. Rather than feeling overwhelmed he evaluates which most urgent needs the programme can respond to at that moment most effectively, trusting that in time the programme may evolve or new opportunities may arise in the future.

An effective strategy for successful programme management is monitoring the size of the programmes, and refraining from unrestrained growth, along with carefully planned phasing of activities. The programme director described handing over a number of programmes to other agencies in order to develop new initiatives in a process of 'letting go'. He explained "*it takes a certain amount of bravery to start something new and see where it goes, and also to live with the fact that some initiatives don't work out as intended*".

## How the programme responded

Bridges of Hope was introduced to meet the socio-economic development needs of the clients. One of the key motivations for the programme was the sustainability threat to the organisation which realised that it couldn't take on more clients if existing ones didn't graduate out of the support programme. In an environment where family ties are paramount, Bridges of Hope starts with building trust between the staff and the client, and then supports the client to rebuild relationships with their family. The client's future sustainability is developed through various support services and ultimately through a business plan based on their individual skills and aspirations. They are supported emotionally and financially to provide their own economic needs and garner the support of their extended family to increase the potential of long term success for both themselves and their family. The key elements of the programme are describes below.

- **Building an individual bridge for each client**: intensive focus on clients continues during first three months of the client's new venture into employment or small business. Cash transfers continue to be provided for food and housing support, if required during this period. Staff also make home visits to help clients address problems, and provide a safe space for clients to discuss fears, stress or any mistakes they have made so they can move on emotionally.
- **Holistic focus on the family**: Staff work hard to reunite clients with their families, even in cases of extreme family dysfunction. Stronger family ties make it easier to include family members in future business plans, which in turn increases the likelihood of success. Family reunification also helps ensure a support system for people living with HIV after they leave the programme and a sense of normality, and lays the ground for community acceptance.
- **Case management system**: Each counsellor/social worker takes responsibility for his or her own clients and also consults with colleagues at team meetings. This approach also helps the staff build capacity. Counsellor social workers refer clients to their colleagues for specialist advice in several areas, such as domestic violence, marital problems or disabilities. All clients seeking employment are referred to the job placement coordinator.
- **Home visits**: These are a critical element in building trust, so that clients can express both their hopes and fears. They also allow staff to see how each client lives, and to observe hygiene, sanitation and nutrition practices.
- **Group counselling**: These sessions allow clients to share their feelings and experiences to break through isolation caused by HIV, and see that others have similar experiences.
- **Planning for the future**: Clients attend workshops on making a plan for the future. The workshops provide structure and advice to help them decide on the best course of action.

- **Practical workshops on issues which emerge as clients reintegrate with their families**: These include a wide variety of topics such as: budgeting, the value of savings, domestic violence, health and education, HIV prevention, nutrition, hygiene and sanitation, human rights and the Cambodian HIV & AIDS Law.
- **Small grants for enterprises**: Capital is provided for activities like: small vending; market selling; food/juice preparation and selling; motorcycle repair; agriculture; animal raising; weaving; moto-taxi etc. Most clients receive a grant of up $200 provided they display the readiness, responsibility and the desire to maintain or grow the family income.
- **Job training**: the programme works with other organisations and employers in the private sector to identify vocational training and education opportunities for clients.
- **Job placement**: The Job Placement Coordinator matches clients with apprenticeships and job opportunities nearby or in the client's home village.
- **Long term support after clients have left the programme:** For longer term follow up support for clients, Bridges of Hope is developing a core group of people living with HIV to work as volunteers with former clients longer after they have graduated from the programme. Following training the volunteers will provide counselling, support for ART adherence, and help them connect with support groups.

### ii) Example 2: St Francis Community Care Programme (Zambia): Pooling the collective resources of people living with HIV

### In the hands of the volunteers

The programme directors were acutely aware that ART availability was changing the needs of the clients but also knew that they didn't have the answers to provide the most effective response. They consulted the volunteers and care supporters, many of whom were living with HIV themselves, and all in daily contact with the programme's clients, to analyse the changes in the clients' needs and design the organisation's responses.

Originally the programme was a classic home-based care model introduced in 1994, and looking after many bed-ridden patients. 18 months ago, the programme initiated a participatory workshop with the care supporters to understand their knowledge and experience of the new treatment environment. It was an opportunity to ask them how they would redesign the programme. The care supporters were quick to point out that many clients are now no longer sick and they requested that the twice weekly clinic be dramatically reduced to twice monthly. They had already had feedback from the clients who expressed their need for income generation focussed activities.

The programme was keen to learn from other experiences and visited CAFOD partner Pasada (Tanzania) who are running an income generating project centred on revolving loans. This was hugely beneficial to St Francis as they were exposed to the potential impacts and strategies for income generation. Whilst the Pasada model is sophisticated and successful, the St Francis staff were cautious in being prescriptive on their return and recommending the approach wholesale to their clients. Instead the Care Supporters consulted the clients and shared what they had learnt to find out what they wanted do and how they wanted to organise themselves. The Care Supporters visited more programmes to increase their knowledge and skills and began providing training workshops for the clients.

Although the income generation projects aren't achieving great economic impact, they do provide a small amount of funds, and more importantly are bringing people together in a constructive way. They are providing hope, solidarity and reducing stigma as they people living with HIV and the wider community see their productiveness and openness about their status.

The programme directors are also conscious of seeking out the most marginalised members of the community and are making a concerted effort to target guardians of children, especially grandparents. The programme has seen a marked change in its programme response, from a classic home-based care model to a more community orientated, and has even changed its name to reflect this (formerly St Francis

Home-Based Care Programme). To develop further and reach more people the programme has decentralised its income generating activities at zonal (village) level for people living with HIV. To strengthen the organisation's broader response, it has developed and implemented a workplace policy, introduced counselling and testing, make referrals to hospital, and provide follow up support. Monthly supervisory meetings are held with the care supporters to support them in their vital community mobilisation role.

### How the programme responded

St Francis Community Care Programme deliberately shifted its programme focus from facilitating *dying with dignity* to ART support and a key focus on income generating activities.

- **Adherence support and treatment literacy**: Clients' ART treatment is supported by care supporters who act as 'buddies' to facilitate adherence. At the same time the programme provides treatment literacy for clients, their families and the community to strengthen the client's support network.
- **Business peer support**: Whereas before ART clients came to the clinic for group counselling and to receive information, they now attend to share the management and business of income generating activities which requires proactive participation, input and decision making. An unforeseen consequence is that these shared experiences lead to much deeper support and sharing about their HIV and health concerns.
- **Pooling of resources**: The clients are supported to put themselves into groups to work together or to pool resources. In some groups the members work on individual income generating activities but come together for mutual business support. They contribute some of their income to a common fund for future investments or emergencies. Other groups work on their enterprises in partnership, again pooling some of the income into a common fund.
- **Facilitating accountability and organisation**: The income generating activities are challenging: at first there were some problems with individuals taking the group funds so security was increased. The groups meet regularly to discuss their strategies, share their opinions, work, count and contribute money. Importantly they must organise themselves with a constitution, a chairperson and a secretary so that all members are clear and agreed about the role and remit of the group.
- **Production and marketing**: The groups engage mostly in cottage industries: sewing, making door mats, children's clothes, using dry seeds to make beads and bracelets. The clients are resourceful and have ideas to put into practice but the organisation is conscious that they need to find markets for their products (e.g. with lodges where there are visitors and tourists). The programme directors are helping with this by investigating and brokering contracts with visitors' lodges.
- **Training**: St Francis Community Care Programme also offers training and skills to its volunteer Care Supporters who report that they are able to move into paid employment as a result of their training from St Francis. It would like to be able to offer larger amount of capital for its male and female clients alike who are keen to embark on more ambitious initiatives.

## 13. Further approaches to programmatic and organisational development

Among the respondents there were further examples of good practice to take forward changes in the development of both the programmes and the organisations themselves. Three are described briefly here:

#### External facilitation

Youth Alive conducted an organisational-wide capacity assessment with the support of its partner PACT. Another partner, SHARE supported an adjustment and capacity evaluation, with PEPFAR (President's Emergency Plan for AIDS Relief) funding. Both these processes highlighted areas for change, for example, building links with institutions and other organisations which directly provide ART. These partnerships have resulted in the introduction of mutual referral systems for their shared clients for

information, support and services. The review processes included the managers plus the members and volunteers, so every level of the organisation participated and was reviewed.

**Strategic plan development**
Both the MMM (Ethiopia) and CHEC (Cambodia) developed strategic plans to move their organisations and programmes forward. CHEC's director, seeing the vulnerability of the people that it supports, developed the strategic plan setting out goals and approaches to meet the challenges, and then sought funding and donor support. CHEC used its new strategic plan to ask existing donors for more funds and, perhaps more importantly, for new contacts and recommendations to gain new donor relationships. To alleviate the increased pressure on the Director, new managers were hired to line manage staff, leaving the director space to continue planning strategically and visioning the future of the organisation.

**HIV workplace policies**
A number of organisations cited the need for comprehensive workplace policies (ICW) and use it as a catalyst to develop the organisation's HIV response (Concern Worldwide). The implementation of Christian Aid's workplace policy includes a confidential counselling service (contactable via phone and email) for all staff members living with HIV who want to ask about treatment or other issues.

## 14. Support needs of organisations

Respondents requested a range of support required from local, national and funding partners. They largely centred on sharing skills and training, and support to develop specific new areas of expertise.

- Livelihoods approaches and economic strengthening skills, including strategies to manage earned income
- Counselling and psychosocial support training, including outreach for treatment literacy among family and community members
- Advocacy skills to target policy makers on HIV issues, and to broaden experience in development issues
- Support to start an employment bureau and placement agency
- Commission a study of the equity in access to ART by injecting drug users to build advocacy base for improved comprehensive services for drug users
- Create learning exchange opportunities between African, Asian and Latin American partners
- Develop critical illness provisions for partner NGO staff (in the case of international NGOs which recognise the inequity of provision between international and national staff) and comprehensive workplace policies
- Learning through exchange of publications
- Financial resources specifically for: core funding (often hard to access for network and advocacy organisations), food and medicines
- Training in positive prevention, and sexual and reproductive health issues for people living with HIV
- Support to negotiate with other organisations to take on home-based care and psychosocial support programmes to free up resources for ART and economic support initiatives
- From donors specifically, openness to good ideas and truthful feedback when presented with less feasible suggestions
- Support to secure new funding partners by making recommendations and providing contacts
- Concerted sharing of practical suggestions for programmes and experiences from their other partners, through visits by donor staff, sharing documentation and exposing partners directly through exchange visits and partner meetings
- Financial and directional support to develop strategic plans and manage processes of organisational change

## 15. Recommendations for programmatic development and CAFOD support

For programme and organisational development, there are a number of approaches that organisations have used to facilitate their adaptation to the new ART environment. The most successful programmes have implemented all of the measures:

- Getting feedback from clients
- Putting clients at the centre of response
- Facilitating peer and family support
- Linking with other organisations
- Linking with the private sector
- Developing a strategic plan
- Develop strong advocacy network with other agencies
- Develop new programme ideas and challenge donors to support them or help find alternative funding sources

CAFOD has a significant role in supporting its partner organisations to achieve appropriate change through:

- Providing financial and technical expertise for strategy development including facilitating programme reviews with organisations
- Facilitating programmatic sharing and learning through partner meetings, exchange visits and sharing of printed resources
- Skilling its own staff in strategy development, advocacy, and economic empowerment
- Linking with other international organisations to learn from their approaches
- Encouraging programmes to implement the good practice recommendations listed above
- Supporting partners to diversify their funding and donor base

## 16. Capacity or budgetary implications for CAFOD

ART has undoubtedly created sustainability issues for many of CAFOD's partners. As more people access the treatment, partners are coming under strain to respond. For the future sustainability of its partners CAFOD needs to invest now in supporting them to undertake the strategic development and decision making that will enable them to adapt their programmes. Skilling up its own staff may have low cost implications as CAFOD already has experienced programme and technical staff working in HIV and livelihoods. The main cost will be time dedicated to focussing on the needs of the programmes working with people on ART, and instituting a concerted organisational approach to ensure the sustainability of the partners. Staff visits to programmes and ongoing communication could provide programmes with the support they need to review and if appropriate change and adapt.

For meaningful learning and sharing between partner organisations, there is little substitute for bringing partners together. This will have a significant budgetary implication if there are no pre-existing or regular forums where partners meet. A three to five day meeting with opportunities for field visits would be ideal. It is costly to bring people from different countries, and even different continents together, but the benefits are potentially invaluable.

Other methods of sharing information can be simple and low-cost, for example posting printed materials and using email forums. However these are tools for information sharing not necessarily in-depth learning, and would be useful as a supplement and follow up to face to face meetings.

## 17. Emerging advocacy issues

**Improving access to ART and related services**

The main advocacy issue that respondents raised was the fact that although ART is available to many people, its *accessibility and quality are* still in question – services need to be decentralised and improved for their users. Improving access and the quality of services was raised by several programmes in Africa and Asia as their motivation for advocacy campaigns, often with their clients demanding to be skilled up to take on these issues themselves with the support of the organisation. In addition, the Brazil experience lends insight into future advocacy issues for Africa and Asia: whilst ART may be available, treatment for opportunistic infections and the potentially devastating side effects are not, particularly psychosocial support. ART services and the associated support services must accompany the provision of ART. Programmes are already stepping in to fill the gaps, but they should also be directing their advocacy efforts on these issues to government providers. CAFOD can lend the benefits of its own advocacy experience to its partners, and encourage and facilitate partners' advocacy on these areas.

**ART improves life expectancy, not necessarily life quality**
CAFOD's own advocacy must heed the lessons from Brazil, particularly about the risk of ART being perceived by governments and donors as the complete solution for HIV and AIDS. The experiences of all the respondents clearly indicate that ART alone is not the answer, and in fact, brings new challenge with it. There is also a risk that the wider public will be similarly misled, impacting on CAFOD's private, individual and community donors and campaigners, who up until now until now have been hugely supportive of CAFOD's HIV work. CAFOD's advocacy messages on HIV and AIDS to continue to highlight the complexity of HIV, poverty and gender inequality, and the new challenges that ART brings with it.