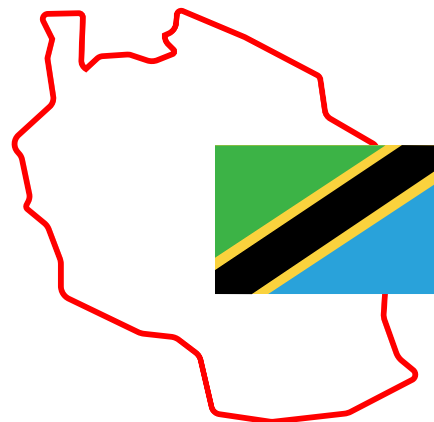
Documentation of Community Learning in the Breakthrough Partnership Pilot Project:
Action for Community Care Tanzania



Background

This short report documents the community partner learnings from ACC (Action for Community Care) from a four-month pilot phase of implementing the Paediatric Breakthrough partnership in Tanzania. There is a separate report for Cameroon. The plan is to develop a package of care for the two-year proposal and comprehensive Breakthrough plan across partners in these two countries.

Methodology

The team used the Appreciative Inquiry approach to design the interviews. We conducted a desk review of both published and grey literature, project reports and translated interviews with Community Health Workers. We spoke to health facility staff, a district official and held a group interview with ACC staff, along with feedback from Aidsfonds. ACC also gave feedback on an early draft of this report. Each of the five sections below documents the lessons learned by ACC, with the analysis and proposed strategies or interventions.

Lessons learned

1. General

ACC reported collaboration to be its most important lesson. ACC worked with all the project partners including EGPAF, PATA, UNICEF and Aidsfonds, the Ministry of Health who gave technical expertise, the Regional and District AIDS Coordinators, Regional and council health management teams, community development officers, social welfare officers, local leaders, and health care providers. Ward and village (mtaa) leaders can support HIV care and services as they have the power of gathering people and communicating information, can support implementation of community activities in their respective wards and can hold meetings. Meetings between health care providers and community volunteers are important for strengthening the community and facility collaboration.

ACC plans to meet with ward executive officers, social welfare officers, community development officers and other key personnel including health care providers to discuss about their roles in supervision of CHWs, progress in supporting the implementation of the project, share best practices and challenges. At the community level ACC will work together with CHWs, religious leaders, influential people in the community and Traditional Birth Attendants. With ACC support, the Ward Development Committee has been revived and will prioritise HIV in their meetings.

ACC advised each Council to consider the whole 'cascade' for HIV: diagnosis, enrolment into care, and retention into stable care and treatment to support underserved children with HIV. It was agreed to plan for the outreach services that would be comprehensive and integrate other health-related activities like HIV testing, family planning, and others.

ACC also learned that 'one size does not fit all' and the importance of close follow-up. Understanding an individual's needs can lead to better outcomes. ACC project staff practise active listening and not making assumptions. They will find a joint solution with the client and work out what is needed. ACC plan to take the time and resources needed to take a more personal and holistic approach, considering all aspects of the household's needs, not just considering the child's specific health issues.

2. Barriers to Paediatric HIV services

The full range of barriers to paediatric HIV services are well documented in the baseline report[1]. ACC have found that stigma remains a challenge, including self-stigma. Most women lack support from their partners and families. This means they do not access antenatal services and HIV testing during pregnancy. Stigma and discrimination and fear of losing confidentiality were noted to be one of the socio-cultural barriers faced by PMTCT.

ACC learned that most of the HIV-focused NGOs and CBOs in the region were based at health facilities with a high volume of children with HIV. This meant that children attending low-volume sites were missing out. Low volume sites have limited HIV services, mainly focused on PMTCT, with occasional outreach services. If agreed with the other programme partners, ACC hope to train and equip healthcare providers for index testing, blood collection for viral load testing, transporting the samples to the nearest Care and Treatment Centre. Low volume sites generally only have one or two healthcare providers, so this would be on-the-job training and supportive supervision.

ACC will support close follow-up for children with HIV. They will work with EGPAF and the health facility, who will share with ACC lists of children with high viral load, which they will use to make house visits. ACC will also conduct joint supportive supervision with CBO partners supporting OVCs (Orphans and Vulnerable Children). The CBO partner will share their list of children aged 0-14 who may be 'lost to follow-up' so that they can be traced back to care by ACC. They will directly advise and support the children with taking their treatment, learn what issues they are facing, (psychological or economic), and will also undertake testing of siblings and all children in the household.

3. Existing community structures that can contribute to paediatric HIV treatment and care

ACC mapped other community-based organisations, such as those supporting Orphans and Vulnerable Children (OVC), HIV Clusters, Early Childhood Development corners and children's clubs at facility level, clubs for adolescents living with HIV, Women and Children Protection Committees, as well as trained Peers and Mentor Mothers. They also mapped out the range of community volunteers under different names such as Community Health Workers (CHW), Community Case Workers (CCW), and Community-Based Health Service Providers (CBHSP).

Many of the peer supporters and mentor mothers had 'aged out', and other community structures had become dormant due to low motivation or the need for training and materials. ACC plan to recruit and train new peer supporters and mentor mothers. They plan to provide them with materials such as learning materials, training leaflets and guides. The Health Council Management Team will work with ACC to ensure effectives supervision and collaboration with the community structures and community volunteers. New committees may be established, or existing committees reminded and encouraged to meet again, and reminded and re-trained on their guidelines. ACC will attend monthly planning and coordination meetings with the Health Council Management Team.

In the pilot phase, ACC met with Traditional Birth Attendants (TBAs) and religious leaders. Through all their work, ACC have learned that the whole person needs to be supported: human beings' needs are varied. They are not just clinical, but also spiritual and emotional. Healthcare workers can attend to the clinical needs, but it is the religious leaders and the traditional birth attendants that can support the spiritual and emotional needs.

ACC learned that while TBAs are not formally recognised by the healthy system, women still go to them for advice and often choose to deliver their babies with them. They choose the comfort, reassurance and kindness they offer. ACC realised the important need for closer cooperation between TBA and CHW, and to have clarity on role division. They learnt about the limited reach of clinical ante-natal, natal and post-natal services for women who deliver at home, and the potential role of TBA in referral of pregnant women for testing. If women test HIV positive women, TBAs can support the 'referral chain' for PMTCT, care and follow-up.

ACC will continue to meet with religious leaders both Muslim and Christian. They will work together to address stigma, mobilise pregnant women and children for testing and promote PMTCT, adherence support for children and adolescents, and address wider issues such as violence against children.

[1] BKTC baseline report Tawina

4. Identification strategies

As mentioned above, ACC found that Traditional Birth Attendants were an influential and under-used community structure. ACC educated Traditional Birth Attendants (TBAs) and Community Health Workers (CHWs) to understand the importance of linking pregnant women to health facilities for HIV testing, and to also get their infant tested. TBAs now feel happy that they will support the whole cascade of care to find the underserved children. ACC plan to ensure that TBAs have education, regular supportive supervision and encouragement and access to a timely and consistent supply of referral tools. A small token of appreciation or any kind of motivation encourages TBAs to regularly visit households, identify sick persons, counsel and or refer them to health facilities for more health attention.

ACC used their knowledge of, and trusted relationship with families within communities to enable 'index' HIV testing of the siblings of HIV-positive or HIV-exposed infants. For example, in a case of an infant with HIV already in care, five further siblings, some of them not living with their biological parents, were gathered together and tested. Of these five, two were found to be living with HIV, having never been tested before. The health care provider said he would not have been able to find and test these children without the knowledge, time, skills and trusted relationship with ACC. ACC plan to continue index HIV testing.

ACC will link the community support structures mentioned above with Health Care Providers, Social Welfare Officers, and Reproductive and Child Health coordinators to work collaboratively to reach the children living with HIV, HIV Exposed Infants, and young mothers.

ACC will gather groups of young pregnant women and mothers together to educate them, and to offer them an HIV test. These monthly meetings will focus on HIV literacy and support the adolescent girls and young mothers with income generating activities.

5. Retention strategies

During the pilot phase, ACC realised one of their main roles will be adherence to HIV medication and retention especially of children and adolescents on ART, as well as pregnant and lactating mothers. They learned the importance of the following elements:

- **Disclosure** Caregivers and even some health providers do not know the best time for adolescents and school-going children to learn their HIV status. Children as young as 5 years old may start to ask why they are taking medication and others are not. Caregivers also don't know the best approach to use, to support children's mental health. Sometimes there has been great secrecy where even a few people who should know to give help are not informed about the HIV status of children and adolescents. For example, a caring grandfather was not informed and educated about a child's HIV status. Whe he found out from the child's aunt, his loving attitude changed. This could have been prevented with a good disclosure process and careful education and support. ACC will access training and use learning from other programmes such as Zoe Life, who have developed well designed approaches to disclosure for children living with HIV and their familes.

- **Support clubs for AGYW and children:** Support groups are a well-documented intervention to support adherence to HIV treatment. ACC will continue to map adolescent clubs and mobilise new groups if needed. ACC will support the meetings by providing the required education along with recreational and learning materials such as games, puzzles and sports equipment.

- Also conduct **home visits** for individual support based on their needs. Adolescents who are 'unstable' and struggling to adhere to their treatment will be visited at home, and advised, along with their caregivers, on medication, healthcare and overall welfare. Each month the groups will meet to get HIV treatment literacy support and encouragement to establish economic related activities for income generation.

- **Financial support for caregivers:** ACC has learned that having a secure financial situation is essential for caregivers to keep their children on HIV treatment. ACC have also learned that there is a barrier to access treatment of other infections for CLHIV and their caregivers, since these are not offered for free. Lack of money or health insurance limits the client's access to treatment. ACC will support caregivers, adolescents and young mothers to take part in economic empowerment interventions They will give them financial literacy and business development skills. Some caregivers will be gathered in groups, some at health facilities, and others will be visited at home.

- Most of the families experience **food insecurity** which affects taking of HIV treatment. Therefore, it is important to also integrate nutrition education and Nutrition Assessment, Counselling and Support (NACS). In collaboration with Extension and Agricultural Officer, ACC also intends to support home gardens to meet family micronutrient needs, and a further income-generating activity.

- **Mentor mothers** are very effective in supporting younger mothers and pregnant and lactating young women. It was observed that most of the peers and mentor mothers have aged out. It was agreed with RHMT and CHMT to recruit new ones. ACC will support further recruitment and training of the new mentor mothers.

- **Ward and village (mtaa) leaders** can support HIV care and services as they have the power of gathering people and communicating information, can support implementation of community activities in their respective wards and can hold meetings. With ACC support, the Ward Development Committee has been revived and will prioritise HIV in their meetings. In the pilot, ward leaders enabled joint introduction meetings between healthcare workers, community volunteers, and lower-level government authorities. The topics discussed were collaboration in identifying and supporting CLHIV, and the gaps that exist in the identification and retention of care. The meetings were used as the platform to continue mapping other stakeholders involved in the HIV/AIDS programs as well as identification of Traditional Birth Attendants (TBAs).

- Through planning meetings with Council staff, ACC has learned of the vital role played by **teachers or school matrons**, to support children to access medication and HIV services when in school. Every school has at least one member of staff who is responsible for students' welfare. These roles can be sensitised and educated to support children with HIV with adherence and more general welfare. They will be trained to maintain confidentiality, and to support children to take their medication, and to be released from school, when need be, for clinic appointments and viral load testing.

- **Community ART refill strategy:** ACC learned that in Chamwino and Mpwapwa, some people with HIV have formed groups and organised themselves to take turns collecting ART. Sometimes they face challenges due to economic constraints or issues related to confidentiality, as people may see them meeting and make assumptions about their HIV status. ACC will encourage the groups to have an income-generating activity, which has the dual effect of raising income, and providing a reason for the group to meet.

- **Support for adolescent and child-friendly clinics and provide adolescent and child- friendly health services**
Adolescent clients, especially young pregnant women and lactating mothers living with HIV, can get judged at the health facility, and so they may turn instead to religious leaders and traditional birth attendants. ACC have found that friendly, high-quality services are essential: a non-judgmental approach is vital for those who are not adhering to their HIV treatment. Health service providers should understand, counsel and motivate. ACC learned that specialised adolescent clinics at health facilities have the potential to educate adolescents on HIV and sexual health, to motivate them to remain on HIV treatment, and to understand the challenges they may be facing. For the clinics to be effective, they need recreational and educational learning materials. Adolescents will be motivated to attend, and to wait for services, if they are able to watch TV, play sports, games and puzzles and read educational materials. ACC will advocate for friendly and high-quality services for their clients, including the provision of educational and recreational materials. They will train health care providers on how to provide child- and adolescentt friendly services, including on the Kids-2Care model.

ACTION for COMMUNITY CARE aidsfonds POSITIVE ACTION ViiV