



A para-social discusses adherence and regular PCR testing with a young mother during a home visit.



REACHING BEYOND THE CLINIC: IMPROVING TREATMENT OUTCOMES FOR HIV-EXPOSED INFANTS

Though Uganda has made major progress in reducing mother-to-child HIV transmission, diagnosis and care for infants exposed to HIV remains a major challenge. Intersecting issues include non-disclosure, stigma, transport costs for clinic appointments, and poor coordination across multiple clinic departments and community follow up. Together, these have contributed to poor retention in care, with highest attrition occurring in the child's first six months of life.

Completion of the Early Infant Diagnosis (EID) cascade — identification of HIV-exposed infants (HEI), diagnosing HIV infection, and initiating and retaining HIV-positive infants in treatment — requires a well-coordinated and sustained response.

As the OVC technical lead for the **USAID Integrated Child and Youth Development (ICYD) Activity**, World Education's Bantwana Initiative delivers comprehensive HIV and social protection services to mitigate the impacts of HIV and violence on children, in close coordination with clinical partners

In the first two years of the program, ICYD has strengthened the capacity of seven Ugandan implementing partners to deliver integrated services to 70,000 families across 44 districts, including **22,317** HIV-exposed infants and their mothers. The overall ICYD Activity is primed by the Education Development Center.

APPLYING A COMMUNITY CASE MANAGEMENT APPROACH: In line with national priorities, ICYD extends the continuity of care through a responsive clinic-community referral network, using a structured case management approach to track and support children and caregivers from intake through to care plan achievement. Working with clinic partners, ICYD's **Community OVC Teams** (linkage facilitators, social workers, and para-social workers) enroll children, coordinate and deliver services, and continuously monitor progress during home visits. Community case managers ensure that children are able to access all needed services across the continuum of care. In this way, ICYD supports the Government of Uganda's nascent national case management system and advances its 95-95-95 HIV epidemic control goals.

Uganda's community child protection workforce, upskilled as community HIV case managers, can play an important role in addressing gaps in Early Infant Diagnosis (EID) cascade by extending the continuum of care to HIV-exposed babies and their mothers at household level through case management.

ICYD APPROACH: Clinic coordination and community monitoring

ICYD has intensified coordination at facility level to ensure mother-baby pairs are followed across different EMTCT (ART) and mother-baby care points and linked to ICYD social workers (SWs) or para-social workers (PSWs) for community follow up. The social worker cadres holistically identify barriers to treatment which inform tailored case plans. Community teams coordinate service delivery for disclosure to husbands/partners, stigma reduction, food security and nutrition, treatment adherence, and PCR testing and immunization schedules for babies. Mothers can enroll in ICYD's early childhood development (ECD), economic strengthening, and parenting programs to address socio-economic barriers to health and well-being. PSWs track and monitor progress across the continuum of care during case management home visits.



“ Intentional coordination across clinic ART and mother-baby care points [has been] essential for following mother-baby pairs through delivery. Continuous community monitoring through case management expanded access to essential supports like emergency food, kitchen gardens, savings groups, and ECD while also following up PCR and immunization schedules.”

- Mildmay Uganda ICYD OVC partner

ICYD KEY STRATEGIES for ACHIEVING 95-95-95 GOALS

CHALLENGES

Low enrollment of HEI-exposed infants and mothers in available ICYD OVC program

High attrition of HEI mothers within the first two months of care

High attrition due to non-disclosure between HEI mothers' and their partners/ husbands

Treatment interruptions due to missed appointments and/or community stigma

Limited understanding of importance of adherence and regular PCR testing among young mothers

STRATEGIC ADAPTATIONS



Intensified coordination between EMTCT clinics and mother-baby care points to enroll mothers before and after delivery and ensure follow up and monitoring by community-based ICYD social workers and PSWs



Developed and integrated an HEI tracker into community case management and ECD platforms for active community tracking of PCR testing, immunizations, and mothers' adherence



Identified non-disclosure at enrollment and coordinated joint home visits with clinic partners to support safe disclosure and provide ongoing post-disclosure support



Supported home delivery of HIV services (e.g. PCR and VL testing and counseling for disclosure, stigma reduction, nutrition, and adherence) and linked mothers to emergency transport and savings groups for longer term sustainability



Expanded enrollment of HEI mother-baby pairs into early childhood development (ECD) package layered with PCR and immunization schedule reminders and support for exclusive breast-feeding and adherence



“I have been living with HIV since I was born . When I got pregnant from defilement [sexual assault] at age 15, I was so ashamed ... Martha [the ICYD-trained para-social worker] has given me and my family so much support! She checks in on me and my baby and helps me cope with shame and stigma. As a mother living with HIV herself, Martha knows what I am going through. After a very dark period, I now have hope!”

– Adolescent mother living with HIV

RESULTS AND IMPACT ON THE EID CASCADE

IMPROVED enrollment of HEI mother-baby pairs on the OVC program



22,317 HEI mother-baby pairs accessed health and social protection services



100% mother-baby pairs retained in care at two months.

EXPANDED community delivery of layered HIV and social protection services



100% of HEI mother-baby pairs attached to PSWs at mother-baby clinic care points



3,433 HEI mother-baby pairs enrolled in ICYD ECD programming

COMPLETED the EID cascade and remained HIV negative



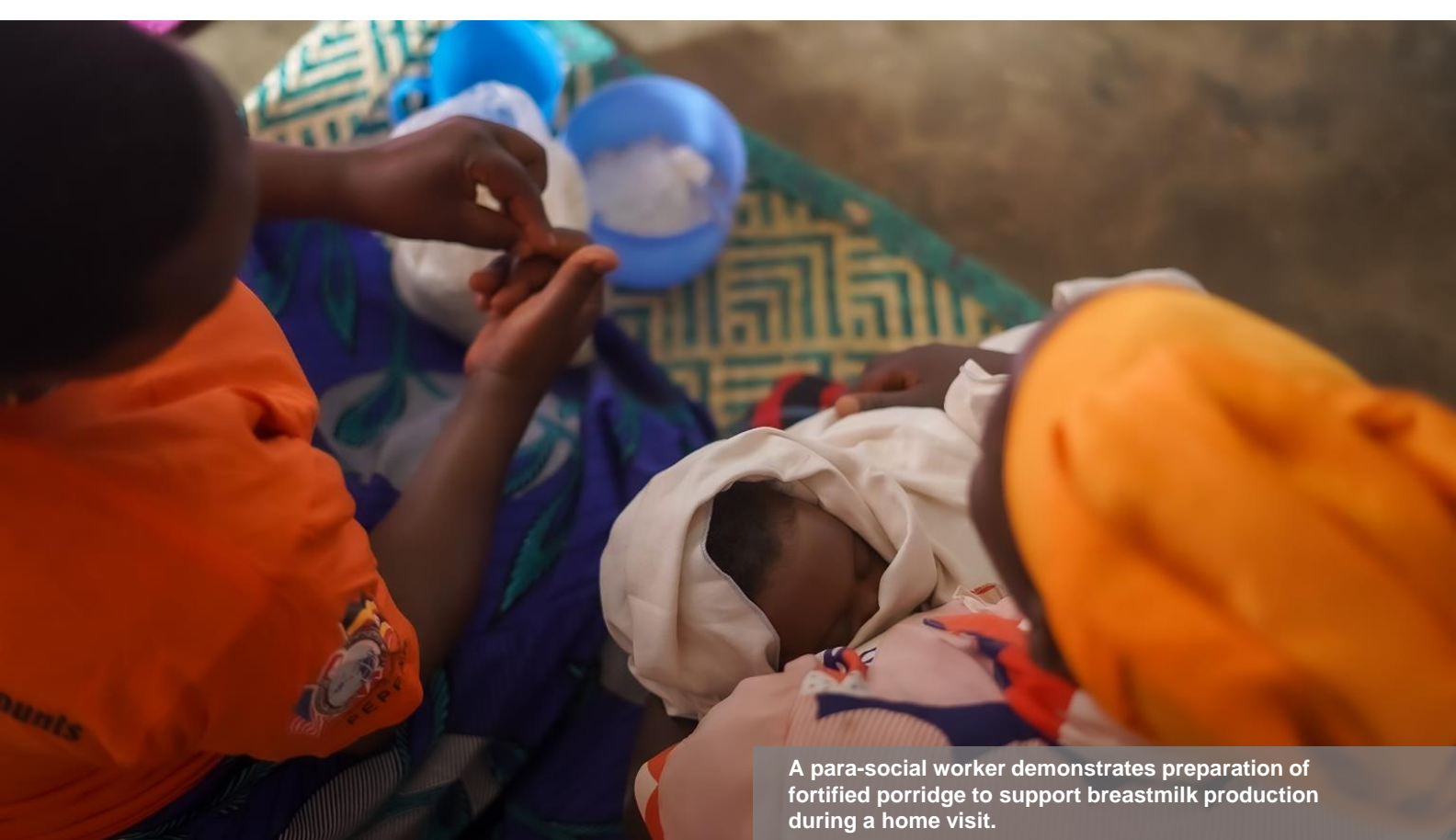
5,929 HEI mother-baby pairs completed PCR 1&2 (no positive results)



778 HEI mother-baby pairs completed the EID cascade (no positive results)

LASTING INNOVATIONS

- **Training peer mothers as para-social workers (PSWs)** to leverage lived experience and familiarity with facility care points to rapidly build trust with mothers and foster cooperation with clinic staff
- **Introducing an HEI tracking tool** into community case management to streamline all relevant information in community and clinic case files for improved EID management
- **Conducting joint home visits by trained clinic staff and PSWs** to combine the strengths and knowledge of both to enhance access to layered clinical and social protection services at community level



A para-social worker demonstrates preparation of fortified porridge to support breastmilk production during a home visit.

LOOKING AHEAD: The Way Forward

ICYD will continue to work closely with clinical partners to close gaps by doing the following:

- ✓ **Harmonizing and streamlining data management across EMTCT (ART) and mother-baby care points:** This is an essential strategy for improving enrollment, monitoring, and completion of the EID cascade for mother-baby pairs. ICYD will expand placement of community structures (e.g. linkage facilitators or mentor mothers) at mother-baby care points and consolidate HEI mother-baby treatment data in one clinic case file to ease EID management.
- ✓ **Leveraging social protection platforms to encourage disclosure and reduce stigma facing HEI mothers:** Non-disclosure to partners/husbands and family as well as community stigma significantly contribute to poor retention in treatment and care by HEI mothers. ICYD will intensify upskilling of social protection facilitators to safely leverage savings groups and parenting and ECD platforms to plan supportive disclosure and address stigma.
- ✓ **Engaging male partners in supporting HEI mother-baby pairs:** Mothers living with HIV face multiple stressors and challenges related to their own health and fears of transmitting HIV to their babies. Programming evidence shows that OVC social protection platforms can be effective entry points for engaging men to improve family communication, especially around sensitive issues like disclosure, allocation of resources, and necessary financial and emotional support for children's health and wellbeing. ICYD will intensify efforts to encourage male participation and track and monitor how these platforms can be used to promote disclosure, adherence, and gender equity in decision making.

To learn more, go to
<https://bantwana.org>



This brief is made possible by the generous support of the American people through the United States Agency for International Development (USAID). The contents are the responsibility of the Bantwana Initiative of World Education, Inc., a subcontractor under the USAID ICYD Activity, and do not necessarily reflect the views of USAID or the United States Government.