The other 29 days:
Caregiver support for family-centred HIV services in sub-Saharan Africa

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PATA

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PHASA/UFH Conference
Children experience HIV in the context of their family and their environment

- No one knows I have HIV
- I have no one to pay for my school fees
- No one can take me to the clinic
- I forget to take medicines every day
- Other kids say mean things to me
- None of my friends have to take medicine
- My mum won’t tell me WHY I have to take medicine every day
- No one is able to draw my blood
- The clinic is too far away
- My parents are too sick to take care of me
- The medicines taste terrible
- My medicines aren’t working anymore
- My medicines make me feel bad
- My medicines aren’t working anymore
- The nurse treats my mum badly
Caregivers and families play a central role in the wellbeing of children living with HIV. A narrow paradigm of individualised care at monthly clinic visits fails to maximize the potential and responsibility of families to improve health outcomes and build resilience.
PATA 2015 Continental Summit

- 6-9 December 2015, Kenya
- 85 health providers – 29 facilities, 12 s-sA countries
- Identified **barriers to caregiver support**
- Established **implementation strategies for caregiver engagement**
- Team grids & 6-month follow-up
### Summit team grids

<table>
<thead>
<tr>
<th>Project title: IMPROVING RETENTION OF MOTHER-BABY PAIRS AT BOBI HEALTH CENTRE III, Gulu – Northern Uganda</th>
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**Priority challenge**

Bobi Health Centre III has 49% retention which is below the required National target of 100% and this is a challenge. The health facility/clinic has 115 Mothers’ Baby Pairs (MBP) currently enrolled in PMTCT. Monthly average enrollment of MBP’s ranges between 3-6 of newly exposed babies; 52% is however lost to follow up and they are at risk for acquiring new infections as they do not access the required PMTCT intervention services.

**SMART aim**

The project aims to increase retention of MBP’s from 49% to 80% at Bobi Health Centre III by August 2016.

- To address these, there is need to conduct community awareness, training of VHT’s linkage facilitators, mother-father mentors, organize point integrated out reaches, organize home visits and follow up activities, conduct coordination meeting to address gaps and progress updates of partners, organize community male meeting and dialogue sessions to address factors associated with loss to follow up of MBPs so as to increase retention and upscale enrolment of mothers, babies and male partners in the PMTCT program intervention in Gulu district, Northern Uganda.

**Beneficiaries**

<table>
<thead>
<tr>
<th>Who are the main beneficiaries?</th>
<th>Exposed infants, Mothers (Positive and breastfeeding), Male partners</th>
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<tbody>
<tr>
<td>What is the general age of the beneficiaries?</td>
<td>0 – 49 years</td>
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<tr>
<td>What do you expect the gender breakdown to be?</td>
<td>Male: 30% Female: 70%</td>
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<tr>
<td>Approximately how many beneficiaries will be reached?</td>
<td>400 beneficiaries</td>
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</table>

**Activities & outputs**

<table>
<thead>
<tr>
<th>Actions, activities, or outputs needed to achieve the project aim</th>
<th>Start-up</th>
<th>6 months from now</th>
<th>12 months from now</th>
<th>Ongoing</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Organise mapping and verification of MBP’s at facilities</td>
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<td>2 Organise project briefing at CBO/CIC/clinic</td>
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<td>3 Identification of VHT’s linkage facilitators, mentor mothers and fathers training</td>
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<td>4 Conduct community awareness on PMTCT</td>
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<td>5 Conduct follow-ups, home visits of clients at home.</td>
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<tr>
<td>6 Organise coordination meetings at facilities</td>
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**Responsibilities**

Who will be responsible for this? (Please tick)

- CBO
- CIC
- MIN (Ministry of Health)
- OUG (Office of the Governor of Gulu district)
What were the key local challenges identified?
Local challenges

- Poor caregiver involvement & commitment
- Inconsistent caregivers
- Limited caregiver treatment literacy levels
- Caregivers have insufficient parenting skills to provide care and support
- Child-headed households
- Vulnerable/elderly caregivers
- Low male caregiver involvement
- Caregiver reluctance to disclose to children
“Caregivers have highest intention but low capacity when it comes to caring for the HIV-positive child.”

St Gabriel Health Centre, Ethiopia
What were the implementation strategies identified?
Caregiver support strategies

- Caregiver educational & parenting skills-building workshops
- Caregiver support groups
- Caregiver peer mentors
- Caregiver events – family days
- Caregiver disclosure training & support

education  sensitization  mentorship
mobilisation  support
12 projects, 8 countries

Domains of support

- Education & skills-building: 7
- Support groups: 5
- Disclosure support: 2
- Peer mentors: 2
- Events: 1
What were the top implementation challenges?
Implementation challenges

• Insufficient funding and staff capacity
• Prohibitive transportation costs
• Poor caregiver uptake
• Caregiver illiteracy
• Caregiver discomfort with disclosure - stigma
BUT

overwhelming benefits
“Clinic appointment-keeping has improved greatly.”

TASO-GULU, Uganda
“When guardians are empowered through supportive trainings, adherence problems are reduced.”

Rainbow Clinic, Malawi
“The workshops have assisted in breaking the silence of HIV in the home post disclosure.”

Newlands Clinic, Zimbabwe
What works?
Recommendations from the field

• Health provider sensitization, orientation & training
• Improved caregiver counselling
• Peer models – skills building on parenting
• Caregiver economic empowerment
• Clinic attendance support (transport)
• Referral to community partners (clinic-cbo collaboration)
• Community linkage (community health)
• Engage district-level management (local coordination)
Key concepts

• Building Resilience and social protection in the family

• Caregivers are experts; are central & the gateway to positive living for children

• Children experience HIV through the lens of the family

• Caregivers need support before they can give it

• Family-centred care
Viral suppression retention

Peer relationships that are happy and healthy

Family care & connection

Access to friendly comprehensive health services

Education, training & employment opportunity

Provider support that is child-adolescent centred

Stigma-free communities

Social support and social protection

Hope for the future
“It is not adequate to always simply work with the child. There is need to strengthen the family network to maximize treatment outcomes and a child’s development.”

Newlands Clinic, Zimbabwe
Thanks

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- Summit cos-hosts: National AIDS and STIs Control Programme (NASCOP) & Family AIDS Care and Education Services (FACES)
- 29 health teams
For more information & resources

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