Community solutions for promoting treatment continuity for children and adolescents living with HIV in Uganda

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Introduction

Common reasons for missed appointments:
- Poor caregiver understanding and appreciation about the importance of adherence

- Interruption in treatment, a primary cause of poor adherence; is strongly linked to missed clinic appointments

- Non disclosure of HIV status to C/ALHIV
- Pill fatigue
- Psychosocial issues related to stigma and unreliable caregivers
- Clinic travel costs

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Under the USAID/Integrated Children and Youth Development Activity (ICYD), community case managers coordinate and deliver integrated health and social protection services with clinic counterparts to improve HIV treatment outcomes for 30,098 children living with HIV (CLHIV) across 44 districts in Uganda.

During home visits, case managers observed significant treatment barriers linked to socio-economic/child protection issues.
Our Response:

- **Intensified appointment tracking** and fast-tracked joint home visits by clinic staff and case managers to minimize treatment disruption.
- **Case managers** led assessments with families to identify root causes and developed care plans to address barriers.
- **Clinic staff** delivered safe disclosure supports, and treatment literacy in clinical settings.
- **Case managers** supported disclosure at home, facilitated home ART delivery for C/ALHIV, delivered emergency transport funds and set up appointment reminders.
- **Case managers** monitored children until tasks were completed and children were stable.
Coordinated Interventions & Results*

- **Supported families** following safe disclosure during home visits for 4,294 C/ALHIV following
- **Delivered** home ART to 436 C/ALHIV
- **Provided** emergency transport to clinics for ART refills 331 C/ALHIV
- **Improved** adherence literacy for 1026 C/ALHIV and caregivers during home visits
- **Attached** treatment supporters for regular monitoring and support

4,274 C/ALHIV returned to treatment

**Daily adherence practices** improved from 77% to 97%

**Viral load suppression** (VLS) improved from 82% to 94%.

*From October 2021 – December 2022*
Lessons Learned

- **Regular review of missed appointment registers** during clinic case conferences focused timely community responses.

- **Joint household visits** by clinic and community case managers were central to swift treatment re-engagement.

- **Holistic RCA assessments** led by trained case managers ensured socio-economic and clinical treatment barriers were addressed.

- **Routine monitoring** through case management helped caregivers integrate appointment tracking into daily routines.

A parasocial worker helps an elderly caregiver and her grandson set up a regular medication schedule.
Recommendations

- **Use national and district coordination platforms** to advocate with the Ministry of Health and other key stakeholders to scale up practices proven to improve children’s adherence.

- **Leverage the capacity of case managers** to coordinate joint assessments, address socio-economic barriers to treatment, and reinforce good clinical practices during home visits.

- **Institutionalize data sharing between clinic and community partners** to minimize treatment interruption.

- **Share lessons during district and national coordination** platforms to maximize resources and strengthen coordination from community to district levels.
Thank you

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