

## The Bantwana Initiative of World Education, Inc. Technical Brief

# Strengthening Caregiver Involvement to Improve ART Adherence, Retention, and Wellbeing among Adolescents Living with HIV

## BACKGROUND AND CONTEXT

Advances in HIV treatment have led to a decline in the number of people dying from AIDS-related illnesses in all age groups, except one: adolescents between the ages of 10 and 19. According to a recent UNAIDS report (2016), HIV is the second largest cause of death for young people (ages 10 to 24) worldwide and is the leading cause of death in Africa.

In Uganda, adolescents are far less likely to be on antiretroviral treatment (ART) or attain viral load suppression than adults living with HIV. At 70%, viral load suppression is lowest among young people under 20 years of age, compared to 90% of adults over 25.<sup>1</sup> Adherence and viral load suppression improvements for children and adolescents continue to lag behind those for adults due to a set of complex clinical and psychosocial issues<sup>2</sup> that require an integrated response at the family, community, facility, and school levels.

### WHAT ARE THE BARRIERS TO ART ADHERENCE AMONG ADOLESCENTS?

In Uganda, research studies have highlighted a number of complex adherence-related challenges for adolescents, including heightened stigma, psychosocial difficulties, limited financial resources, a lack of youth-friendly health services, and the absence of parental and social support. Many adolescents living with HIV (ALHIV) fall through the cracks as they move from child to adult health services, resulting in low treatment adherence. At the same time, distinct challenges related to adolescence—including rapid physical, mental, and emotional changes along with growing autonomy—make it difficult for young people to seek and access health services and to sustain healthy behaviors (Naidoo K, Munsami, et al, S Afr Med J 2015;105(11):953; Hudelson C, et al, AIDS care. 2015 Jul 3;27(7):805-16).

During a national training of trainers for Young Adolescent Peer Supporters (YAPS) in Uganda in February 2019, participants emphasized a lack of caregiver support (i.e. limited caregiver skills, changing caregivers, changes in guardianship) as one of the key barriers to adherence, viral load suppression, and retention in care. Caregiver participation in the care and treatment of children living with HIV is an important indicator of quality of care, with research showing that higher levels of caregiver involvement are associated with improved health outcomes—including psychosocial coping mechanisms, adherence, and retention.<sup>3</sup>

Within this context and following the evidence that caregivers are better equipped to assist and encourage adherence to treatment for adolescents when they are given practical knowledge, skills, and tools, WEI/Bantwana layered a tested package of supports on six existing facility-based Peer Support Groups<sup>4</sup> under the USAID/Uganda Better Outcomes for Children and Youth in Eastern and Northern Uganda program. The Peer Support Group Plus model adapts and layers parenting and economic strengthening skills on treatment literacy sessions delivered to caregivers and children together at facilities. The goal of the model is to improve the understanding and commitment of caregivers in supporting children's adherence and wellbeing while addressing the social, economic, and clinical barriers impeding retention, adherence, and viral load suppression.

1. Uganda Country Operational Plan 2019
2. COP 19 use of sub-optimal ART regimens, delays in weight-based dose adjustment, poor adherence, and HIV drug resistance
3. Mellins CA, Brackis-Cott E, Dolezal C, Abrams EJ. The role of psychosocial and family factors in adherence to antiretroviral treatment in human immunodeficiency virus-infected children. *Pediatr Infect Dis J*. 2004;23:1035-1041.
4. Led by Expert Clients trained to help ALHIV to address stigma, disclosure and other positive coping skills, BOCY supports Peer Support Groups across 65 facilities in eastern and northern Uganda. Groups meet monthly adolescent ART refill days.

Under the PEPFAR/USAID-funded Better Outcomes for Children and Youth in Eastern and Northern Uganda (BOCY) project, the Bantwana Initiative of World Education, Inc. (WEI/Bantwana) and local partners deliver differentiated services to children, youth, and caregivers across 22 districts to build resilience and mitigate the risk and impacts of HIV and violence while strengthening community and district service delivery systems.

Building on the facility-based Peer Support Groups delivered by BOCY that help HIV-positive youth increase coping skills to improve adherence, WEI/Bantwana's Peer Support Groups Plus bring caregivers and youth together to better understand the importance of adherence and viral load suppression, improve communication skills that promote bonding, and learn simple income generating skills that increase support for basic needs.

Specifically, the innovation:

1. Equips caregivers and adolescents with communication skills that increase trust, strengthen emotional bonding, and create safety and security between them;
2. Improves understanding about the importance of adherence and viral load suppression for health and wellbeing;
3. Provides space for caregivers and youth to learn simple, low-cost alternative skills that create joint opportunities and generate income to support adolescents; and
4. Offers psychosocial support and intensive counselling to caregivers that may be experiencing difficulty in handling adolescents.

## OUR INTERVENTIONS

WEI/Bantwana adopted a strategic mix of interventions that center on improving adherence, retention, and overall wellbeing while encouraging greater self-efficacy among ALHIV and strengthening family resilience. Specifically, the model aimed to ensure adolescents' and caregivers' priorities were considered and addressed and to ensure that they received coordinated, layered support through a coherent package of tailored services delivered in tandem by trained community and clinic cadres.

### **Building treatment literacy and adherence competence among caregivers and ALHIV**

Recognizing that caring for and supporting ALHIV can be a major challenge and that caregivers require guidance on the specific needs of young people living with HIV, WEI/Bantwana brought caregivers together with their children during monthly Peer Group Support meetings held on specified dates, including days when caregivers collected ART refills for themselves or children and on weekends to accommodate in-school youth. WEI/Bantwana trained 'Expert Clients' to support caregivers and ALHIV to develop knowledge and skills related to timely disclosure, treatment literacy, and intensive adherence support. Sessions also included basic information on HIV, adolescent sexual and reproductive health (ASRH), communication, and negotiation. Health workers delivered complex health or medical information (i.e. nutritional support) and psychosocial counselling. Along with their roles as facilitators, Expert Clients acted as positive role models—encouraging caregivers and adolescents to speak openly about HIV and remain on treatment. They also monitored session attendance, adherence, viral load suppression, and follow up of inactive peers, and they worked closely with para-social workers (PSWs), community resource persons, and clinic health workers to provide a comprehensive network of support.

### **Promoting positive shifts in parenting and communication practices**

Alongside treatment literacy and adherence competence, caregivers' availability to establish positive relationships with ALHIV—including developing openness and trust—is a key factor in achieving better treatment outcomes. Parenting sessions delivered by facilitators trained in the Sinovuyo Teen Caring Families Programme for Parents and Teens model provided positive messaging and skills aimed at improving caregiver involvement, parenting confidence, and communication; promoting bonding, parental care, and love between caregivers and adolescents; and supporting families to respond better to difficult situations. Sessions were designed to integrate caregiver and child communication skills and roles and included interactive activities like play therapy to cushion emotional shock and help caregivers and adolescents talk about sensitive topics without conflict. Regular opportunities to practice new skills at home coupled with coordinated follow-up and tailored supports from community structures through home visits—Expert Clients, PSWs, and economic strengthening or parenting facilitators—promoted and reinforced learning as well as adherence.

## Improving families' socio-economic resilience to HIV's impact

Economic pressures and limited financial means are known to further exacerbate the impact of HIV on families and impede access and adherence to appropriate treatment and care. In order to address this dimension, caregivers and adolescents were supported with family economic strengthening activities—including sessions on income generation, alternative skilling, entrepreneurship, and financial literacy. Access to savings and loans helped households to build a safety net, while other activities, such as backyard gardening, supported families to grow their own food, increase overall food security, and address malnutrition, which remains a significant challenge to adolescents' adherence to their medication schedules. In addition, district-based trainers utilized sessions to deliver additional information on gender-based violence (GBV), ASRH, life skills, and rights and responsibilities using evidence-based curricula.<sup>6</sup> Overall, sessions provided space for caregivers and youth to learn simple, low-cost demand- and market-driven skills, while creating joint opportunities for learning, income generation, and bonding.

## Addressing social norms and service delivery challenges

WEI/Bantwana also established a forum for service providers at the district level to improve dialogue between stakeholders, reduce stigma and discrimination, and identify potential actions to address challenges in service delivery within communities. With support from WEI/Bantwana's technical teams, peer support groups first conducted a mapping of service providers utilized by youth and located around the health facilities—including schools, community-based organizations (CBOs), churches, Community Development Offices (CDOs), the police, PSWs, and health personnel. Representatives of these organizations were then invited to monthly sensitization meetings convened to further refine options to support adolescents, discuss joint intervention strategies, and to track progress—especially related to referrals, stigma, and other emerging issues.

## OUR RESULTS

*"Before the formation of the support group, we used to lose many adolescents to non-adherence... Since the support group started, we have not lost anyone." - Expert Client, Kityerera Health Center 3*

After six months of implementation, the Peer Support Group Plus intervention has shown promising results. Specifically, pre- and post-test program data collected from participants indicate:

- Increased HIV disclosure among children to family, teachers, and friends;
- Improved understanding of the importance of adherence and viral load suppression by caregivers and children;
- Increased caregiver involvement and support to adolescents in ART adherence, nutrition, and addressing stigma and discrimination;
- Increased appointment attendance accompanied by caregivers for refills and reviews; and
- Improved positive changes in communication between adolescents and caregivers.

Key Composites	Pre-Test	Post-Test	% Change
Disclosing HIV status to children	72%	90%	↑ 25%
Positive communication between caregivers and children	27%	85%	↑ 214%
Knowledge of ART treatment literacy by caregivers	72%	100%	↑ 39%
Caregiver attendance on clinic days	62%	95%	↑ 53%

Figure 1: Positive shifts in knowledge and behavior by caregivers and adolescents

In addition, findings from qualitative interviews from caregiver and children participants indicated similar findings:

- Nearly half of the adolescents interviewed said that the level of care and support from caregivers—including support to fight stigma and discrimination—had improved.
- Nearly a quarter of adolescents interviewed said their relationships with caregivers had greatly improved as a result of the parenting skills training.
- 94% and 89.5% of interviewed ALHIV and caregivers, respectively, knew their medication time.
- 100% and 95% of ALHIV and caregivers, respectively, improved understanding about the importance of adherence for viral load suppression and wellbeing.<sup>7</sup>

6. Including the Stepping Stones and Journeys curricula

7. Adherence is a complex concept that requires ongoing sensitization for caregivers and youth as adherence related questions emerge and/or medication regimens change. With clinic partners, BOCY will continue to ensure coordinated support at the facility and community levels to address emerging adherence issues with caregivers and youth.

These results demonstrate that the model has not only exposed participants to critical information on adherence and retention—along with ASRH, communication, and life skills. It has also facilitated more trust and family cohesion between adolescents and caregivers, which may play an important role in improving ART adherence among ALHIV.

---

*“When we started, I thought this was a joke, but with time, I realized the group was serious. . . We learned about adherence, and I loved to play the games. Now, my caregiver helps me to take my medication... My viral load, which was high, has reduced to zero for the first time.”*  
-Adolescent. Bufumbo Health Center

---

## OUR LESSONS LEARNED

- Caretakers’ positive engagement in physically accompanying their children to facilities for refills improves children’s attendance at monthly support groups.
- Coordinated follow up of non-suppressing adolescents through home visits has been critical for a holistic understanding of issues contributing to non-suppression. Care plans developed at a household level address complex family issues, including nutrition, food security, transport costs, and weak understanding of adherence. PSWs and social workers facilitate follow-up visits with clinic staff to address medication issues.
- Facility-based stakeholder engagements with the CDO, police, health workers, and school head teachers, among others to address stigma, disclosure, and other adherence-related issues further create an environment at the facility, school, and community levels where adolescents and caregivers feel more empowered and are better able to negotiate for their health and social service needs.
- Alternative skilling is a critical motivator for caregiver and youth participation because of its immediate effect on boosting income to address basic needs (i.e. transport, food costs).
- Training of caregivers and adolescents in effective parenting, savings, and modern agriculture has a multiplier effect. More clients and health workers at the facility level learn from caregivers, which has, in turn, improved client-health worker relationships within health facilities.

## OUR CONCLUSIONS

Prioritizing the needs of young people—particularly adolescents—in HIV prevention, treatment, care, and support remains critical to epidemic control. This includes consideration of the vital role that caregivers play in supporting adolescents to cope with the complex psychosocial and health-related aspects of living with HIV, such as access and adherence to treatment.

The Peer Support Group Plus model has demonstrated that, given the right supports, caregivers have the potential to serve as powerful allies in supporting adolescents’ adherence to treatment and retention in care. It has also demonstrated that increased caregiver involvement has helped adolescents better navigate HIV-related stigma, while increasing young people’s sense of self-confidence during a period of rapid and complex change.

One of the most significant changes was an increase in positive communication between caregivers and adolescents. Building trust with adolescents and creating room for emotional safety through positive communication—not only with caregivers, but also with health workers who often share the responsibility of disclosing status and providing treatment support to ALHIV—proved to be an important strategy for overcoming barriers in discussing health- and HIV-related concerns. Messages were reinforced in a variety of context-specific, age-appropriate platforms to ensure that caregivers and ALHIV had ample opportunity to digest and reflect on critical and often sensitive information.

Sustaining and improving gains in adolescent adherence and viral load suppression will require even more innovation to ensure rapid adaptation and responsiveness to the clinical, psychosocial, and socioeconomic dynamics that impact disclosure, adherence, viral load suppression, and resilience. Findings from this model suggest that given the right tools, skills, and supports, caregivers can be powerful allies for supporting adherence and resilience in children under their care. WEI/Bantwana has shared these findings with the Ministry of Health for integration into the YAPS model and will continue to study the model to better understand its potential for closing gaps in ALHIV adherence and viral load suppression as Uganda nears the achievement of epidemic control.