

# PROMISING PRACTICES

"I can't take it when someone who is older than my mom is talking to me about sex. I need to go to someone my age, a peer, and talk about sex. Honestly me, I am a patient at (clinic name), when the nurse asks me if I use protection, I tell her yes. But when I go to (peer supporter), I tell her the truth, that I don't use condoms. We can speak freely as young people."

> - Peer supporter, PATA 2016 Youth Summit

# Promising practices in peer support for adolescents and young people living with HIV

"If you trust us, help us to do it by ourselves"

#### BACKGROUND

The HIV response has long recognised the importance of peer-led interventions in supporting the health and wellbeing of people living with HIV (PLHIV). Such interventions draw on the knowledge and lived expertise of PLHIV to plan, deliver and monitor HIV services. Reported benefits of meaningfully engaging peers as frontline supporters include improved health, wellbeing and health facility cost savings.

More recently, the principles of peer engagement are increasingly being applied to support populations of adolescents and young people living with HIV (AYPLHIV). As a critical key population of people living with, and at risk of HIV in sub-Saharan Africa, a focus on peer support is timely. AIDS-related illnesses are the leading cause of death amongst adolescents in the region, with AIDS-related mortality in this age group tripling since 2000 while declining in all other age

groups<sup>1</sup>. Strategies and programmes that support AYPLHIV to adhere to antiretroviral therapy (ART) and clinic appointments achieve viral suppression, good psychosocial and health outcomes, and are crucial not only for individual patient benefit, but also to stem onwards transmission.

Equipped with first-hand experience of the socio-cultural challenges of living with HIV, AYPLHIV are well-placed to understand, support and respond to the needs of other adolescents and young people in their communities<sup>2</sup>. Evidence shows that that peers are often the primary source of information about sex and HIV<sup>3,4</sup> and that young people's sexual decision-making is often highly influenced by peers<sup>5,6</sup> positioning peer-to-peer dialogue and engagement as both a significant challenge (for instance, where peers are poorly informed) and a powerful opportunity. When their unique skills are harnessed, HIV-infected adolescents and youth come to serve as positive role models for accessing and remaining in care<sup>7</sup>.

Emerging evidence demonstrates that peer-led interventions may have potential to deliver high-quality and context-specific services to support ART adherence, retention in care, virological suppression and psychosocial wellbeing, although more rigorous data is needed<sup>2</sup>. Peer education services have been documented to be effective in improving individual and social-level sexual health and risk outcomes, including increased condom use, delayed sexual debut and fewer multiple concurrent partnerships<sup>8-11</sup>. Peer-led support has been shown to positively impact acceptance of HIV status, self-esteem and psychosocial support 12,13, as well as a sense of worth, social connectedness and group belonging 13,14. Young peer-led services have been documented to offer value through allowing for the provision of highly relevant and context-specific services, while also providing peer service providers with opportunities to develop new skills which can improve future career prospects, self-esteem and resilience<sup>2</sup>. Peers are considered to be more credible, influential and accessible when they share similar socio-economic and contextual circumstances with service recipients. while challenging stereotype norms<sup>15,4,16</sup>.

"I am more than my HIV, and I have a life beyond being a peer supporter. I have other dreams too, and much more to contribute."

- Peer supporter, PATA 2016 Youth Summit



Advocacy messages at the PATA 2016 Youth Summit A recent review of social protection interventions for adolescents living with HIV (ALHIV) found evidence of effectiveness of peer support for HIV-related outcomes for adolescents in Eastern and Southern Africa (ESA)2. For example, a pilot intervention of HIV-specific peer support<sup>17</sup> found improved linkages in care for ALHIV, while a peer-education and care intervention found improved adherence support<sup>18</sup>. The Africaid Zvandiri Programme in Zimbabwe<sup>19</sup> (documented as a spotlight on page 4) has demonstrated remarkable improvements in health and psychosocial outcomes for AYPLHIV. PATA has also documented promising peer-led programmes in a series of promising practice briefs, including an out-of-school programme for ALHIV in the Western Cape of South Africa<sup>20</sup>, and a 'One-stop adolescent shop' that engages ALHIV in Kafue, Zambia as peer supporters<sup>21</sup>.

The involvement of peers in the design, implementation and evaluation of services is emerging as a key element of many adolescent- and youth-friendly service strategies<sup>2</sup>. This approach recognises adolescents as experts in their own context, and that through including them as service providers, facilities and patients can benefit greatly from this expertise. Additionally, engaging adolescent peer supporters as catalysts for effective linkage to care and the delivery of childand adolescent-focused activities provides much-needed human resource capacity to over-stretched health facilities<sup>7</sup>.

While the contributions of AYLHIV peer supporters are increasingly acknowledged, their voices too often go unheard and their efforts unrecognised<sup>7</sup>. This promising practice brief was developed in acknowledgement of the urgent need for further operational evidence and practical examples and models of peer-led interventions at health facility level, as well as to

better consider how peer supporters can be fully integrated into adolescent- and youth-friendly health services (AYFHS)7. This brief draws on data and reports emerging from a call for promising models of practice in AYPLHIV peer support within the PATA network of health providers and partners. In-depth surveys (n=14, six countries), each documenting a particular model were received, and 12 were ultimately included and analysed thematically. Survey findings were complemented by focus group discussions and surveys from adolescent peer supporters and their supervisors (n=94) attending PATA's recent youth summit.

Young peer supporters act out their dream consultation at the PATA 2016 Youth Summit



# Partnership between Africaid's Zvandiri Programme & PATA and the One to One Children's Fund's Expert Patient Programme

Programme implementer: Africaid Zvandiri

Programme location: Bulawayo, Harare and Kwekwe, Zimbabwe



#### CONTEXT:

Zimbabwe has a generalised HIV epidemic, with an adult prevalence estimated at 14%<sup>22</sup>. Despite recent successes in ART provision and uptake which have reduced adult HIV-related mortality, poor HIV outcomes amongst young people remain a concern. Young adults have the highest HIV incidence of any group in Zimbabwe, and prevalence actually increased in 2014<sup>23</sup>. Rates of retention in care 24 months post ART initiation are only 26% amongst young adults, compared with over 80% in all age other groups<sup>24</sup>. Viral load suppression among young people living with HIV on ART is low, with 48.6 percent of females and 40.2 percent of males between the ages of 15 and 24 being virally suppressed<sup>22</sup>. Paediatric ART coverage is also a challenge, which - despite recent improvements remains low, with only 47% of children accessing ART in 2013<sup>25</sup>.

#### AIM:

The project aims to improve the quality of HIV treatment, care and support services for children, adolescents and young people (age 5-24 years) living with HIV, so that they can live happy, healthy, safe and fulfilled lives.

#### APPROACH:

The Zvandiri model was developed to respond to poor adherence, retention in care, psychosocial wellbeing and sexual and reproductive health (SRH) outcomes amongst children, adolescents and young people in Zimbabwe. Prior to implementation of the Zvandiri model, children and adolescents were receiving care from adult-focused health facilities and were seen by service providers and caregivers who did not understand their unique and dynamic needs. In contrast, this project is implemented by young HIV-positive peer

"There has been a noted decline in children and young people loss-to-follow up as a result of the communitybased follow-up."

> - Africaid Zvandiri programme implementer



Emily, a peer supporter, conducting adherence counselling with a fellow adolescent supporters between the ages of 18 and 24 years, with support from health workers and Africaid staff. Funded independently by the programme, Zvandiri peer supporters work within the urban healthcare centres of United Bulawayo Hospital, Harare Hospital and Kwekwe General Hospital, with an aim to support the clinical and psychosocial wellbeing of children, adolescents and young people living with HIV, while alleviating some of the burden of staff shortages. These facilities serve as the primary health service providers and referral centres for local urban residents, as well as adjoining rural areas.

Peer supporter responsibilities include peer counselling and support, pill counting in the pharmacy and providing childcare for young patients. They also facilitate SRH talks for young people to provide them with knowledge and a platform to interact with one another. When young patients are facing adherence challenges or are lost to follow-up, peer supporters facilitate home visit referrals to Zvandiri Community Adolescent Treatment Supporters (CATS), who are also young HIVpositive peers who work in the communities in which they live. CATS conduct home visits to young people and caregivers of children and adolescents living with HIV, and provide a range of services which include community-based counselling, disclosure facilitation, ART initiation and adherence support, support group referrals, and support for young people to deal with relationship challenges, stigma and discrimination.

Peer supporters are actively involved in project design, implementation and evaluation to ensure that the intervention is tailored to young people. They are recruited from Africaid Zvandiri support groups and once trained, join staff case management as well as weekly referral meetings. They are supported with a vocational skills training programme, on-going counselling training, psychosocial support from staff counsellors or psychologists and mentorship by a peer support clinic supervisor and a Zvandiri mentor. They also receive a stipend for transport.

"I am a girl aged 16. I could not believe (that I was HIV positive) and I struggled to come to terms with it. My caregiver then referred me to the peer supporter at the hospital. They gave me counselling and I now understand about my status and I know that HIV cannot define me. Now I am a happy person who is taking medication well."

- Africaid Zvandiri programme participant



Peer supporters are integrated into clinic teams at Kwekwe General Hospital.

#### **KEY RESULTS:**

- High uptake of peer counselling services –
  between 80 120 children and adolescents
  attend counselling sessions per week. This
  success is in part attributed to attaching counselling appointments to treatment collection so
  that AYPLHIV can collect medicine and receive
  psychosocial support in one visit. This approach
  has been especially helpful to newly-diagnosed
  patients as the counselling helps them to accept
  and cope with their HIV status as well as remain
  in care.
- Improved HIV and SRH knowledge amongst AYPLHIV service users, through well-attended SRH talks and group discussions.
- Improved access to services for AYPLHIV, as a result of strong referrals and linkages to care.
- Improved retention and re-enrollment in care, due to combining the CATS home visits model with clinic-based peer support. This approach has also improved linkages between the health facility and community as well as reduced service-delivery bottlenecks.
- Reduced burden of staff workload, as a result
  of peer supporters conducting activities such as
  pill counting and clinic filing. This allows facility
  staff more time to attend to patients.
- Improved adherence to ART, due to improved psychosocial support and increased engagement with the health facility.
- Improved knowledge, skills, psychosocial wellbeing and confidence of young people providing peer services, which not only allows them to better support other young people living with HIV, but also improves their own quality of life and career prospects.

- "There is a great value in the peerto-peer support as before many of the children were unwilling to open up and talk to an older healthcare worker."
  - Africaid Zvandiri programme implementer
- "...peer supporters help to relieve pressure so that the healthcare workers can care for patients with more time and increased quality."
  - Africaid Zvandiri programme implementer

For more information:

www.africaid-zvandiri.org

# **Sunburst Projects**

**Programme implementer**: Sunburst Projects and Family AIDS Care and Education Services (FACES)

Programme location: Nyanza Region, Kenya

#### CONTEXT:

Sunburst Projects is located in three of the highest HIV prevalence zones in Kenya's Nyanza Region. Homabay, Kisumu and Migori counties have prevalences of 27%, 19% and 14% respectively, all significantly higher than the national average. These areas contribute to 65% of new HIV infections, and are made up of both rural and urban areas. As in other parts of ESA, children and ALHIV experience poor HIV-related outcomes, including poor adherence to ART, retention in care, and psychosocial wellbeing.

#### AIM:

This project was developed in response to the need to improve child and ALHIV psychosocial wellbeing, ART adherence, and linkage to and retention in care in order to achieve optimal viral suppression. It strives to build supportive, stigma-free communities for children and teens (age 6-19 years) through developing positive relationships, increasing self-esteem and reinforcing positive behaviours. The project's ultimate aim is for children and ALHIV to transition healthily into adulthood and reach their highest potential. In addition, it aims to improve youth employability, decrease stigma, reduce HIV risk and improve HIV knowledge amongst children and ALHIV, their families and communities.

#### APPROACH:

The project engages five main strategies in order to achieve its aims:

- Recruit young peer leaders to run project activities. Two peer leaders per site (ideally one male and one female) are recruited from FACES-supported health facilities through a competitive interview process. The programme prioritises unemployed high school graduates age 18-24 years living with HIV. They are provided with detailed job descriptions and dedicated supervision by both health facility and FACES staff.
- Provide peer leaders with a twoweek induction training to build their capacity to provide psychosocial support to children and ALHIV. They are trained in support group facilitation, communication, public speaking and computer skills, as well as HIV and SRH counselling – including risk reduction, ART adherence and positive living.





"Months ago, I was not taking my medication properly and most of the time I was getting bored in taking my medicines. For the last 3 months. I have diligently taken my drugs well and I feel energetic and full of life. Thank you all for giving me a second chance. Never give up on us."

Sunburst Projects participant

- Implement a peer leadership programme. The purpose of the programme is to implement services and activities to address the psychosocial needs of children and adolescents age 6-18 years living with HIV. Activities include:
  - » A 5-day residential camp programme that aims to support young people to build positive relationships, improve self-esteem and self-confidence, and acquire life skills through recreational and educational activities. At the end of the camp, participants are invited to provide peer support to fellow peer leaders.
  - » Support groups and caregiver sessions run bi-weekly by peer leaders. Support groups require a three-month commitment from participants and consist of group gatherings of a maximum of 40 participants. Sessions blend education, art therapy, games and role-play. At the end of each three-month block, the impact of the programme is evaluated with a survey that includes indicators of behaviour change, school performance, ART adherence, and the ability to overcome challenges such as stigma and discrimination.
  - » Family gathering and social event at the end of each support group cycle, aimed at promoting family communication and connection. Family activities are directed by peer leaders and include sports, games, art therapy, songs, dance and drama. Parents and caregivers are also given opportunities to meet counsellors to discuss disclosure and related challenges.

- » Monthly community outreach sessions run by peers, which aim to create stigma-free and supportive environments for ALHIV within schools.
- Continuously evaluate the programme. Using standardised questionnaires, Sunburst Projects staff, FACES medical staff and peer leaders work closely together to evaluate programme results, such as changes in the attitudes, beliefs, and behaviours of participants. Three primary indicators are used to measure health outcomes and success: health and ART adherence, psychological wellbeing, and knowledge about HIV. The evaluation includes viral load count to determine young patient's adherence and health outcomes. Surveys provide valuable information as to whether a child's attitudes toward adherence has improved and whether they are more or less willing to attend clinic visits. Caregiver surveys also provide information about the child's psychological wellbeing and school performance. Pre- and post-programme tests are administered by peer leaders to determine participant knowledge about HIV and risk behaviours.
- Offer capacity-building and prioritise programme development. The programme is continuously adjusted based on performance and implementation gaps, with the aim of improving programme outcomes.

Sunburst projects programme activities



Peer leaders are integrated into all department activities, including staff and departmental meetings. They receive mentorship from peer leader mentors, as well as psychosocial support from supervisors and on-site counsellors. They are also enrolled in a scholarship programme to pursue courses of their choice at institutions of higher learning. Project investments include wages for peer leader mentors (two per clinic – one male and one female) as well as a programmes coordinator, assistant programmes coordinator and peer leader mentors. Transport is also provided for peers conducting home visits.

**KEY RESULTS:** 

- The programme has employed 18 youth as peer leaders and engaged over 100 youth as volunteer counsellors in the annual camps programmes. It has served over 2000 ALHIV enrolled within the FACES Programme and approximately 3000 youth within the community.
- Pre-and post-test surveys demonstrate significant positive change in attitudes towards medication, clinic and school attendance.
   Post-programme surveys demonstrate reduced stigma, guilt and secrecy, as well as increased disclosure. In addition, ALHIV knowledge about HIV transmission and health improved following the programme.
- The programme led to increased communication between young people and their health providers. In addition, after the programme, young people report feeling less isolated, and gave feedback on the benefits of age-appropriate peer support. At the end of the support group block, most adolescents (85%) report having hope for their future.

"The Teachers of Sunburst have helped me appreciate myself the way I am, and equally to appreciate others the way they are. When I finish school, I want to help teach people the importance of knowing their status and those who don't know their status to know their status. I also want to help and support children who are HIV-positive to feel loved and appreciated in society."

- Sunburst Projects participant

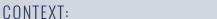
For more information:

www.faces-kenya.org/ www.sunburstprojects.org

### **Peer Educator Programme**

Programme implementer: Baylor College of Medicine Children's Foundation - Tanzania

**Programme location:** Mwanza, Tanzania



An estimated 6% of adolescents (aged 10-19 years) in Tanzania were living with HIV in 2014<sup>26</sup>. Like other countries in the region, Tanzania sees high attrition of AYPLHIV who have enrolled in HIV care, and it has been suggested that peer education may be effective in addressing this issue<sup>27</sup>. The programme is located in the Baylor College of Medicine Children's Fund - Tanzania, Centre of Excellence (COE) in the Mwanza region of Northern Tanzania, which has a population of approximately 2,773,000<sup>28</sup>, including 1,472,613 under the age of 18.

#### AIM:

COE Mwanza provides medical and psychosocial support to ALHIV. The Peer Educator Programme was developed in acknowledgement of the fact that there are certain struggles and challenges that AYPLHIV may feel most comfortable sharing with their peers, and that peers will be better placed to understand age-related challenges, struggles, and pressures. The programme seeks to create an approachable and accessible space, with the aim of improving young people's adherence to ART and overall wellbeing. It also aims to provide young peer educators with skills that can support their education and future professional endeavors.

#### APPROACH:

Peer educators provide various education and support services, including:

- Peer counselling sessions: Peer educators
  provide counselling to their peers at the clinic.
   Sessions are one-on-one, and frequently focus on
  ART adherence, clinic attendance and disclosure.
   A drop-in service is also available so that young
  people can receive psychosocial services without
  an appointment.
- "Teen Talk": The clinic has a designated weekly adolescent-focused day, where peer educators conduct 'Teen Talk', a group counselling session focused on topics such as peer pressure, nutrition, and stigma and discrimination.

  Peer educators facilitate the discussion and encourage adolescents to interact with one another, and share their experiences.
- Pre-Teen Club: Peer educators assist with coordination and preparation of monthly Pre-Teen
  Club meetings and help to brainstorm themes,
  icebreakers, lecture topics and strategies to
  engage participants.
- Teen Club: Peer educators assist in the implementation of Teen Club, a monthly psychosocial support group. They coordinate the introduction of club events, perform educational skits, lead icebreakers and discussions, and encourage active participation

"Let's support each other to combat HIV."

- Peer Educator Programme implementer

Tuesday 'teen talk'

- Home visits: Peer educators conduct home visits to young patients that have been identified as requiring additional support and follow-up.
- SRH Counselling: Peer educators
   provide education around adolescent
   SRH for peers at the clinic. Female
   peer educators also provide counselling about hygiene and pregnancy for
   adolescent girls.

Peer educators are very involved in clinic programmes, and have full opportunity to provide their own perspectives and ideas. As a result, they have spearheaded innovative support services, such as the development of a psychosocial support group specifically for older ALHIV and young adults as well as an income-generation programme. They also participate in meetings with the Adolescent Programme Coordinator to voice their needs, concerns, and ideas for improving the programme.

Peer educators are recruited from the cohort of ALHIV patients attending the clinic, and provided with a one-year contract. They undergo a one-week induction training, and are then linked with counsellors and social workers for on-the-job training. Peer educators are trained by and work alongside clinicians and counsellors within the clinic. They participate in a variety of activities alongside clinic staff, such as social service rounds, continuing medical education, and staff meetings. They receive job descriptions and meet with the managerial staff to review their performance and express their needs. Through the programme, peer educators build their own skills in counselling, working with technology, communication,

leadership, time management, SRH, and HIV management. As their skills improve, they are assigned additional responsibilities and more patients. They have also begun assisting with various other activities around the clinic, such as front-desk duties and supporting clinic administration.

Peer educators are able to access support from clinic counsellors if they have experienced issues or require guidance in addressing patient challenges. They receive a stipend to support their nutrition and transportation.

#### **KEY RESULTS:**

Despite being newly initiated, the programme has begun to see **improvements** in adolescent adherence as a result of peer counselling. The programme has seen considerable growth in peer educator confidence in their ability to support peers, address issues arising in counselling and facilitate group discussions.

In the project's first year of operation, 112 adolescents received peer counselling, six (6) teen and 11 pre-teen meetings were held and two SRH and family planning education sessions were conducted. In addition, nine 'Teen Talks' were held, reaching a total of 83 participants.

"If you trust us, help us to do it by ourselves."

> - Peer Educator Programme participant

For more information:

http://bipai.org



Crafts with peer educators

# **REACH (Re-Engage Adolescents and Children with HIV)**

Programme implementer: PATA

Programme locations: Ethiopia, Uganda, Malawi, Cameroon, Kenya and Zambia

Partners: ViiV Healthcare - Positive Action for Adolescents Programme. Previously funded by One to One Children's Fund

#### CONTEXT

PATA's partnerships at the frontline create a powerful platform to deliver capacity-building and technical input while facilitating peer-to-peer exchange, shared learning and dissemination of promising practices.

REACH (Re-Engage Adolescents and Children with HIV) is a peer support model which integrates young people living with HIV (YPLHIV) as peer supporters within health facilities in order to improve HIV treatment and care services for, and treatment outcomes in, their adolescent peers age 10-19 years, while providing AYPLHIV themselves with skills and training opportunities for their career development. REACH's main goal is to improve HIV treatment and care services for, and treatment outcomes in, adolescents aged 10-19 years.

Launched in 2015, the programme has completed a successful 22-month pilot, with 59 YPLHIV peer supporters across 20 health facilities in Ethiopia, Uganda, Malawi, DRC and Cameroon. The pilot phase was implemented in partnership with One to One Children's Fund. PATA has now entered into a new partnership with ViiV Healthcare through the Positive Action for Adolescents Programme to develop REACH beyond its pilot phase to form a cohesive implementation model for evaluation.

Its sister programme, the Expert Patient Programme (EPP), has been supporting a further 62 community health workers in Zambia and Zimbabwe. Together, REACH and EPP facilities care for 21,440 ALHIV in urban (81%) and rural (19%) settings. One of the key lessons from the programmes is that whilst community models importantly drive demand, sensitise communities and link to care, facility-based models like REACH and the EPP are best situated to improve health services, sensitise health providers and engage adolescents accessing care, assisting them to navigate the health system and providing safe and supportive facility-situated spaces.

Since its inception, REACH has demonstrated the critical role that facility-based peer supporters can play in addressing critical gaps in AFHS and improving outcomes. In particular, peer supporters have empowered adolescents through disclosure support (95%), defaulter tracing (90%), adherence counselling (85%), support groups (75%), dedicated spaces or times (75%), and teen camps or clubs (75%). Over the past 12 months, the paediatric and adolescent patient base at participating facilities has increased by 34%, and retention increased by 1%. All facilities added at least one new adolescent-focused service, with peer supporters instrumentally contributing to such expansion. Ninety-five percent of facilities include peer supporters in staff meetings; of these, 85% reported that peer supporter contribution at these meetings has resulted in programmatic change.







Key intended outcomes and implementation strategies for the REACH programme include:

- Improved adolescent-friendly health services and adolescent-orientation with increased service engagement and retention in care, through integrating YPLHIV within health facilities to deliver peer-led AFHS and expose and sensitise health providers to adolescent needs; and creating flexible, adolescent-oriented environments to increase service engagement and improve retention in care.
- Strengthened peer support capacity and resilience through the creation of channels for skills transfer and facilitation of new peer support leaders into YPLHIV networks and country-level structures, through: (1) providing school-leaving YPLHIV an opportunity to gain work experience, learn new skills and receive psychosocial support to improve their own health, wellbeing, self-esteem, confidence, career and study options; (2) ensuring that peers

- earn a stipend, receive a detailed job description and close supervision, appraisal and integration support by a designated facility-based staff member; (3) training peer supporters on treatment literacy, disclosure, adherence and psychosocial support; and (4) providing practical support to YPLHIV to access and link into YPLHIV country networks.
- Shared evidence for a facility-based peer support model, generated from (1) implementation experiences of integrating peer supporters into the health system and clinic team; (2) differentiated support groups as a mechanism for psychosocial support of ALHIV and (3) outcomes associated with facility-based peer support, with a specific focus on retention in care.

For more information: http://teampata.org



Young peer supporters place their votes on accessible services at the PATA 2016 Youth Summit

#### KEY IMPLEMENTATION STRATEGIES

Across the four spotlights and other surveys, several cross-cutting principles emerged:

- Recruitment of peer supporters through facility programmes such as support groups ensures that peer supporters will have an existing relationship with the facility's services. Such a strategy allows for peer support programmes to draw on young people's expertise as service users, and also for programmes to recruit peer supporters who will fit well with the team. This method also means that selected peer supporters may already know some of their peers - which represents both an opportunity for increased connection and support, but also a challenge, as this proximity may mitigate social distance and make negotiation of support relationships more difficult.
- Provision of mentorship, skills development and psychosocial support
   by clinic or programme staff to peer supporters is a fundamental component of successful peer programming.
   Well-supported peers are more likely to be motivated, have their psychosocial needs met, and be better equipped to provide support for their peers.

- Dedicated job descriptions and induction trainings for peer supporters provide a framework for expectations and important preparation for key tasks and responsibilities.
- Implementers of peer-led models may provide different types of financial and in-kind support to peer supporters.

  The spectrum of support includes a transport or food allowance, stipend, vocational training support or a salary. Innovative types of support may also include cell phones or bicycles. Facilities should strive to support and remunerate peer work as far as possible, in acknowledgement of the value and expertise that peers offer.
- Inclusion and involvement of peer supporters in all stages of the programme, including design, implementation and evaluation, allows them to understand the project life-cycle and learn new skills, while providing highly-relevant input to ensure that the programme is best tailored to meet the needs of AYPLHIV.

We are more
than just our HIV
status, and our
holistic wellbeing
is important.
We cannot give
wellbeing if we are
not well ourselves.
We ask for positive,
supportive
and enabling
environments to
receive and deliver
healthcare.

- Call to Action - Peers to Zero Dar es Salaam Peer Supporter Declaration



Tuesday 'teen

- Common individual-level services provided by peers include psychosocial, adherence and SRH counselling and **disclosure support**. In some models (such as Baylor College of Medicine Children's Foundation-Tanzania), home visits are conducted by the peer supporters directly, whereas in other models (such as the Africaid Zvandiri programme in Zimbabwe), peers provide home visit referrals to community peer workers. Peer supporters may also lead group activities, including planning and facilitating support groups and providing educational talks. Such peer-focused initiatives have dual benefit - they allow for peer supporters to develop new skills, while providing highly-relevant support to young people who are likely to better understand each other's challenges and needs.
- Many peer models have similar overarching objectives related to improved wellbeing, adherence and retention of children, adolescents and young people living with HIV. To meet these, standard activities and services are often led by peers such as support groups, counselling and education. In addition, based on the nature of the clinic or programme operations, there are often context-specific roles and responsibilities. For example, Matero Main Clinic in Zambia, another survey respondent, involves peers in delivering HIV testing and counselling, and within Sunburst Projects, peers conduct outreach with school teachers and facilitate day camps.

Peer supporter needs as brain-

stormed at the

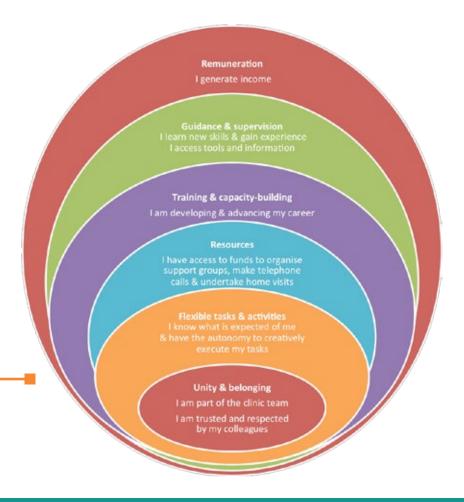
Summit

PATA 2016 Youth

- As a strategy to reduce clinic and programme-staff workload and support skills-development of young peers, other tasks based on clinic needs and peer interests such as data entry, case management, reception, pill counting and pharmacy duties can be supported.
- Several successful models
  include at least two peers
  per facility. This allows peer
  supporters to work together,
  and task-share based on
  individual skills, interests,
  abilities and workloads. Aiming
  to have both male and female
  peer supporters allows young
  people to receive peer services
  from a gender-concordant peer
  if they desire.

We must be genuinely involved and at the forefront of developing, implementing, monitoring and evaluating services that affect us and organisations that seek to represent us. Our voices count and must be heard.

 Call to Action - Peers to Zero Dar es Salaam Peer Supporter Declaration



# **Support groups**

A recent review of evidence on social protection for HIV-related outcomes in ESA amongst children and adolescents has demonstrated the potential of interventions that provide psychosocial care and support<sup>2</sup>. Such documented interventions include activities that peers can provide, such as community-and home-based care<sup>29,30</sup>, adherence support and individual counselling<sup>31,32</sup>, family-based psychosocial interventions<sup>33</sup> and structured support groups<sup>17,19,34,35</sup>. Emergent PATA evidence demonstrates that leadership of support groups by AYPLHIV is a key strategy in many of the varied models of peer support and engagement from a variety of PATA network facilities in different countries.

Support groups and teen clubs are critical services to widen the circle of support for AYPLHIV<sup>7</sup>. PATA findings have demonstrated the importance of creating safe spaces, such as support groups, in order to offer AYPLHIV opportunities to meet and engage with peers who are facing similar challenges, speak openly about sex and sexuality without fear of being judged, access factual and up-to-date information, and be alerted to relevant upcoming events, including social gatherings<sup>7</sup>. Emergent research in South Africa has found higher ART adherence amongst ALHIV attending support groups<sup>36</sup>, while evidence from 66 PATA peer supporters representing 28 health

facilities in nine countries has revealed the needs and challenges of young people attending such groups. Support groups should be motivating, inspiring and dynamic spaces with flexible content and programming in order to meet the changing needs of group members<sup>7</sup>. They should include a variety of activities such as crafts, music, drama, writing, sports and social events and cover topics of interest to young people beyond HIV and ART adherence<sup>7</sup>. Many young people feel that support groups are poorly planned and managed, and may become stale and tedious over time<sup>7</sup>.

The location of a support group (for instance, health facility- or community-based) is a key consideration. Adolescents may fear stigma and discrimination they may face attending community-based support groups, and feel safer attending support groups that are based in clinics. However, a documented challenge of clinic-based support groups is that adolescents may feel pressure by health facility staff to 'perform to adherence and sexual relationship scripts'2 by staying silent or hiding behaviours they understand to be unwanted. This represents an opportunity for involving sensitised peers to design and run support groups so that adolescents may receive non-judgemental support from people close to their own age.

Community-based support groups may face different issues, including securing space and resources to ensure continuity.

Regardless of their location, support groups may require differentiation, depending on participant needs. For example, an adolescent who has recently tested positive may have different needs from an adolescent who has known about their status for years, and younger adolescents may face different challenges to their older peers.

Support group

#### CHALLENGES

Despite the many successes and benefits of peer support reported across the spotlights and surveys, several challenges emerged as common themes:

- Adolescents and young people are a critical population to identify, reach and provide services for. Unfortunately, few peer models are targeted specifically to young key populations such as young men who have sex with men, young sex workers, young transgender and gender non-conforming key populations, and young people who inject drugs. UNAIDS technical briefs provide more details about some of the critical challenges and strategies for working with young key populations<sup>37</sup>. Many countries have restrictive legal and policy environments for identifying and providing services for young key populations. Even when laws are not restrictive, stigma, discrimination, lack of awareness and inadequate funding make service provision for these groups challenging.
- As with many programmes within the paediatric and adolescent HIV sectors, resources can be a major implementation challenge. Specifically:
  - » Despite the highly cost-effective nature of peer programme considering their positive outcomes, funds for programme activities and financially supporting peer service providers via stipend or salary can be difficult to raise. This challenge is compounded by the semi-formal nature of this work, and the perception of care work (especially as performed by young people) as unskilled.
  - » Given that these are relatively new programmes running alongside existing clinics, finding spaces for the delivery of confidential peer services can

- be difficult. An innovative solution by MJAP Uganda, another survey respondent, was to allocate an outdoor space, protected by a shade cloth, for health education and counselling activities. The makeshift space served as a designated space for adolescents to meet and interact.
- » A significant time investment is required by clinic and programme staff to train, mentor and provide on-the-job and psychosocial support for young peer supporters.
- Provision of peer support is not a longterm career opportunity, and programmes must therefore manage peer supporter expectations and provide career development support and mentorship. Greater attention and investment must be made to build the resilience of peer supporters as they seek to grow and develop and live healthy, economically-active lives.

We insist on access for all, as we are! As young people, we are not all the same. We acknowledge that access may be more difficult for key and vulnerable populations, including young men who have sex with men, young women who have sex with women, transgender and intersex young people, young people who use substances, young people who sell sex, young people with disabilities, orphaned youth and pregnant/young mothers. We call for innovative and creative efforts to engage difficult-to-reach populations. Services should recognise our diversity and strive to be inclusive.

- Call to Action - Peers to Zero Dar es Salaam Peer Supporter Declaration

#### SUCCESSES AND LESSONS LEARNT

- When well designed and implemented, peer services demonstrate promise in improving ART adherence, retention in care, virological suppression and psychosocial wellbeing, while also serving as a form of social protection for young people themselves as they are provided opportunities for development and capacity-building. In addition, peer-led programmes may also attract previously unreached young people to take up services when they include community outreach and in-referral activities.
- The needs of AYPLHIV are diverse and there is no one-size-fits all model. Insofar as possible, young peer services should be differentiated to meet specific needs and target young key populations. Peer supporters, and the environments in which they are active, will also have their own strengths, abilities and challenges. Models should be adequately flexible and well-planned to adapt to these needs and draw on particular strengths.

- Beyond their daily activities, peer supporters can model positive behaviours for their peers by demonstrating positive living while still having fun and connecting with others. This can help to combat the negative effects of self-stigma and peer pressure.
- It is important to include peers within clinic staff structures and activities such as meetings and committees. This provides the opportunity for learning and integration, as well as relationship-building with staff.
- Prior to initiating any peer support programmes, existing staff should be briefed on the peer supporters' role in order to understand its value and create buy-in
- Peer models can reduce the burden on health workers by creating task-shifting opportunities.
- Peer support offers an effective launching pad for AYPLHIV to build leadership skills and participate in youth-led advocacy.

"Use of peer supporters is a good strategy to hear adolescent needs."

> -Machinga Clinic, Malawi

"Services must be taken to (children/adolescent's) point of need. They must be easily accessible and affordable. Involving peers makes this more accessible...countless times we think we know what is happening in adolescent's life, but then CATS [peer supporters] tell us what is really happening."

- RIATT-ESA Resourcing Resilience Report

"Building agency through involvement is a fundamental tenet of psychosocial support. The children and caregivers themselves are experts in their own situation. They might not realise it but they have strengths. When they start engaging with you they can appreciate their strengths and pull them out. They know what the challenges are and they can find ways of overcoming them."

- L Mudenkunye, REPSSI

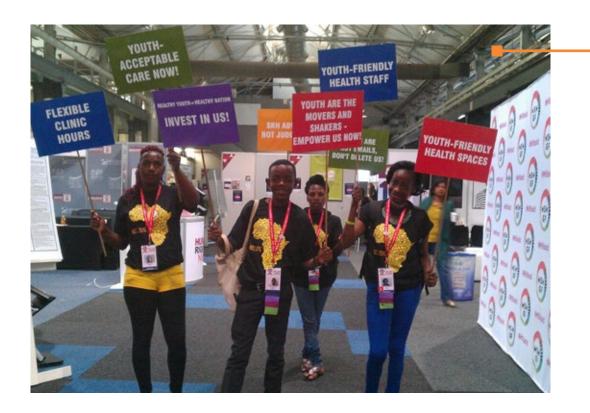
#### CONCLUSION

Involving AYPLHIV as peer supporters in the design, implementation and evaluation of HIV services for children and AYPLHIV can offer experiential opportunities for them to improve future career prospects, self-esteem and resilience. At the same time, peer service providers can support the health, wellbeing and service uptake of AYPLHIV through the provision of highly-relevant and context-specific services, while reducing staff workload. Commonly provided peer-led services include psychosocial and disclosure support, through group support and education, as well as individual adherence and SRH counselling.

Despite their potential benefits, peer-led services require careful planning and implementation to ensure that services are meaningful and effective. Requisite organisational and staff capacity and support include training, psychosocial support, and financial support. Given that peer service provision is not a long-term career opportunity, such services work best when facilities manage peer expectations while investing in their resilience. This can develop skills, build confidence and link peers to a variety of opportunities for improved personal growth, economic security and health.

Young people offer a unique voice in the global fight against HIV. We play a crucial role as peer educators and peer supporters, providing and linking youth to quality HIV and SRH services.

- Call to Action - Peers to Zero Dar es Salaam Peer Supporter Declaration



Peer supporters advocating at the AIDS 2016 conference.

### **Resources & Links**

- S2S, Psychosocial & Adherence
   Counselling Support Training Toolkit,
   2010, <a href="http://www0.sun.ac.za/southtosouth/toolkits/aps/training-material/Psychosocial%20%26%20">https://www0.sun.ac.za/southtosouth/toolkits/aps/training-material/Psychosocial%20%26%20</a>
   Adherence%20Counselling%20
   Support%20Training\_Facilitator%20
   Manual.pdf
- Museum of AIDS in Africa, <a href="http://muse-umofaidsinafrica.org/">http://muse-umofaidsinafrica.org/</a>
- The Kirkpatrick Model, <a href="http://www.kirk-patrickpartners.com/OurPhilosophy/">http://www.kirk-patrickpartners.com/OurPhilosophy/</a>
   TheKirkpatrickModel
- PATA, 2015, <a href="http://www.teampata.org/uploads/CHWToolkit\_web.pdf">http://www.teampata.org/uploads/CHWToolkit\_web.pdf</a>
- PIH, Accompagnateur's Handbook, 2012, <a href="http://www.pih.org/library/accompagnateur-training-guide">http://www.pih.org/library/accompagnateur-training-guide</a>
- TAC, HIV in Our Lives, 2007, <a href="http://www.tac.org.za/publications/">http://www.tac.org.za/publications/</a> hiv-our-lives-1

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- International HIV/AIDS Alliance,
   Community Engagement for
   Antiretroviral treatment: A training
   manual, 2006, <a href="http://www.aidsal-liance.org/assets/000/000/982/Trainers\_manual\_Community\_engagement\_for\_ART\_original.">http://www.aidsal-liance.org/assets/000/000/982/Trainers\_manual\_Community\_engagement\_for\_ART\_original.</a>
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  Adolescents: A second chance in
  the second decade, 2014, <a href="http://www.who.int/hiv/pub/prev\_care/en/HandbookAccess\_en.pdf">http://www.who.int/hiv/pub/prev\_care/en/HandbookAccess\_en.pdf</a>

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#### Special thanks to the organisations that shared their peer models and experiences:



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# SUNBURST PROJECTS / RCTP-FACES, KENYA

**FACES Website:** www.faces-kenya.org/

Sunburst Project Website: www.

sunburstprojects.org



# MACHINGA HEALTH CENTRE AND YOUTH IMPACT MALAWI

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#### UGANDA NETWORK OF YOUNG PEOPLE LIVING WITH HIV AND AIDS

Website: http://unypa.elite.ug/

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CHISOMO COMMUNITY PRO-GRAMME, ZAMBIA

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# MAKERERE UNIVERSITY JOINT AIDS PROGRAM (MJAP)

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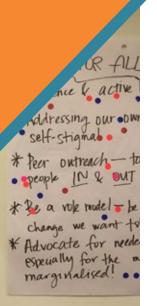
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# **Call to Action - Peers to Zero**

# The Dar es Salaam Peer Supporter Declaration













- 1. We, the peer supporters and network representatives of young people living with HIV from Cameroon, the Democratic Republic of Congo, Ethiopia, Malawi, Tanzania, Uganda, Zambia and Zimbabwe have assembled at the PATA-AY+ Youth Summit in June 2016.
- 2. We are inspired by the resilience, creativity and courage of our young African peers who have led the way before us. Many of these young people lost their lives as we waited for treatment access to be realised.
- 3. The end of AIDS is now much closer, and with enthusiasm and dedication we embrace the vision of the Fast-Track strategy to end AIDS by 2030, including 95-95-95, 200,000 new infections among adults and zero discrimination.
- 4. We are, however, dismayed and concerned that AIDS-related illness is the leading cause of death among adolescents in Africa, and that adolescents have worse treatment outcomes, higher rates of loss to follow-up and worse adherence than adults.
- 5. We call for the rapid fulfilment of international commitments to make viral load testing and free treatment available to all, including young people.
- 6. We ask for easier to-take medication; including fewer, smaller and better tasting tablets, as well access to longer-lasting treatment options.

- 7. Young people offer a unique voice in the global fight against HIV. We play a crucial role as peer educators and peer supporters, providing and linking youth to quality HIV and SRH services.
- 8. We must be genuinely involved and at the forefront of developing, implementing, monitoring and evaluating services that affect us and organisations that seek to represent us. Our voices count and must be heard.
- 9. Peer service provision is work and should be taken seriously. We call for remuneration, guidance, supervision, training, capacity-building, resources, autonomy and belonging. We also require investment in young peer supporters beyond delivering services, and request the creation of study, livelihood and income generating activities for us.
- 10. We are more than just our HIV status, and our holistic wellbeing is important. We cannot give wellbeing if we are not well ourselves. We ask for positive, supportive and enabling environments to receive and deliver healthcare.
- 11. As young people, we need HIV and SRH services that are comprehensive and integrated. A comprehensive package should include private and confidential HIV prevention, treatment and monitoring; supportive psychosocial and mental health services; and sex-positive messaging and counselling. We demand options for unwanted pregnancy and access to a range of family planning methods, including regular cervical screening.















- 12. We request friendly and sensitised healthcare workers with positive attitudes and ask that HIV and SRH services be provided to us with care, acceptance, respect and without judgement. We should be provided with comprehensive information and recognised as capable of making our own decisions. Don't lecture us, empower us!
- 13. We call for accessible adolescentand youth-friendly services. Let us move beyond a checklist and ensure that services are appropriate and context-sensitive.
- 14. We insist on access for all, as we are! As young people, we are not all the same. We acknowledge that access may be more difficult for key and vulnerable populations, including young men who have sex with men, young women who have sex with women, transgender and intersex young people, young people who use substances, young people who sell sex, young people with disabilities, orphaned youth and pregnant/young mothers. We call for innovative and creative efforts to engage difficult-to-reach populations. Services should recognise our diversity and strive to be inclusive. As peer providers, we will endeavour

- to reach these populations and ensure that all young people – including the most marginalised – receive services free from stigma and discrimination.
- 15. Transition to adult health care, as well as to tertiary education or boarding school is a time where many of us falter. We call for greater attention, strategies and services to support us in making transition safer.
- 16. We acknowledge the physical, economic, and social factors that make accessing services and staying in care difficult, and call for creative, positive and youth-sensitive responses that address the socio-economic drivers that render us vulnerable.
- 17. As young peers living with HIV, we commit to providing services as we wish to receive them. We endeavour to actively listen, understand the needs of young people, be patient and address our own stigma. We will act as positive role models to our peers and dedicate our efforts so that future generations of young people will not live with the burden of HIV and AIDS.





















# Getting to know PATA

Our MISSION is to mobilise and strengthen a network of frontline healthcare providers to improve paediatric and adolescent HIV prevention, treatment, care and support in sub-Saharan Africa.

Our VISION is that all children and adolescents living with HIV in sub-Saharan Africa receive optimal treatment, care and support and live long, healthy lives.

#### PATA's objectives are:

- 1. To improve the quality of paediatric and adolescent treatment, care and support at health facility level
- 2. To grow and deepen engagement of the PATA network and increase peer-to-peer exchange between health providers across countries and regions
- 3. To incubate, document and share promising practices in paediatric and adolescent treatment, care and support in order to effect positive change in policies, programmes and practices at national and global levels

PATA works through four activity streams: PATA Forums, PATA Incubation Projects & Programmes, PATA Practice-Based Evidence & Advocacy and PATA Connect.

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