

Meaningful engagement of adolescents and young people in national and local HIV programming

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01

Rationale

Adolescents and young people (AYP) (10-24 years) are being left behind in the HIV response, with high levels of new infections, and lower levels of diagnosis and treatment coverage than adults.¹ National and local programming adapted to their specific needs is critical to ensuring their wellbeing and to reaching global targets to end AIDS by 2030.² However, AYP, including those living with HIV and from young key populations, are not just beneficiaries of programs, but are important stakeholders and agents of change. AYP leadership and partnership is an essential component of the design, delivery and evaluation of programs that affect them, leading to better decisions and policies.³ In accordance with principles of the greater involvement of people living with HIV,⁴ AYP have the capacity to identify approaches and solutions that best respond to their needs, making programs more effective and helping to ensure increased uptake of services and better outcomes.



02

Barriers and facilitators of implementation

Barriers

- Negative, judgemental or discriminatory attitudes of adults, including health workers, towards adolescent and youth sexuality in general and those living with HIV in particular
- Criminalization of and discriminatory attitudes towards young key populations (young men who have sex with men, sex workers, transgender people and people who inject drugs)
- The assumption that AYP are unable to inform programming due to their age and perceived lack of experience
- Limited institutionalized frameworks and procedures for engaging AYP in policy development
- Lack of indicators and measures of meaningful engagement of AYP in national monitoring and reporting
- The deep effects of stigma and poverty on AYP affected by HIV, which can impact on their willingness and capacity to engage



Facilitators

- Recognizing AYP as key stakeholders and partners who can take responsibility and be accountable
- Collaborating with organizations and partners that have a demonstrated track record of meaningful and sustained adolescent and youth engagement
- Creating a youth constituency and supporting youth-led structures and networks at local, national and global levels
- Taking a holistic approach to adolescent and youth engagement, recognizing the developmental stages and specific needs of different age groups, including socio-economic context and the role of education and employment in young people's lives
- Providing a safe, fun and youth-friendly context to facilitate AYP feeling comfortable sharing their thoughts and wishes

03

Policy and legal considerations

National policy frameworks must reflect the importance of meaningful engagement of AYP and AYP living with HIV (AYPLHIV) at all stages of research, as well as development, implementation and monitoring of health programs. Laws that limit access to sexual and reproductive health and HIV services, including third-party consent policies, must be removed to ensure access to non-discriminatory healthcare. Laws on drug use, sex work and sexual exploitation, and lesbian, gay, bisexual, transgender and queer identities should support an environment where AYPLHIV feel safe to engage in decision-making spaces.

04

Steps for scale-up

Several organizations have developed guidance on meaningful engagement of AYP in research and programming. The Youth Civil Society Working Group of the UK has, with partners, developed a “three lens” approach outlining how to engage with youth to ensure effective sustainable development programs.⁵ The first lens is working for youth as beneficiaries; the second is working with youth as partners; and the third is building capacity of youth to design and implement youth-led programs. The third lens includes providing both technical and financial support. Good participatory practice requires all three lenses to be present throughout the program development process.

In collaboration with youth, adolescents and children living with and affected by HIV, Oliveras and Cluver et al. (in press)⁶ set out six basic requirements, or **R.I.G.H.T.S.**, for meaningfully engaging children and youth. RIGHTS applies to a range of activities, including research prioritization, clinical trials, implementation science and policy development. According to these requirements, engagement is essential, and must be:

1. **Resourced:** Recognize that adequate time is needed for younger age groups to move at their own pace, and that training, technical support and funds should be provided, especially for those living in poverty.
2. **Impactful:** Tokenism must be avoided, with input being utilized in the development of recommendations, policies and programming. Children and youth should be informed about how their inputs have been used and, where possible, also be involved in the dissemination process.
3. **Genuine:** Children and youth must not only be informed and understand their involvement, but also have leadership roles within the processes in which they are involved. The International HIV/AIDS Alliance guidelines suggest a written agreement with clear roles and responsibilities for young people and other key partners.

4. **Harmless:** The principle, 'do no harm' in engaging youth, should be applied in a holistic manner, recognizing that children and young people require education, livelihoods and careers, and should not miss school to attend meetings, for example.
5. **Teen friendly:** Children and youth may not feel comfortable in formal groups, especially alongside adults, and may be disinclined to contribute in such settings. Different formats and activities can be developed to facilitate their full participation. Making engagement fun and linking it to the daily lives of youth are important considerations.
6. **Skills building:** Participation of children and youth should include opportunities to ensure that competencies and skills are built that can be used in future education and career opportunities.

05

Case example of successful implementation

In the Teen Advisory Group (TAG), established by Oxford University and University of Cape Town in 2008, 20-30 youth and their younger siblings (and now their children) attend an annual weekend camp, using fun activities to engage with planning, and disseminating the results of research studies. TAG has participated in disseminating information to policy makers, and government officials have even attended the camp. TAG has had major impacts on policy, including co-writing the South African National Adolescent and Youth Health Policy, and contributing towards the UNAIDS and UNICEF guidelines for social protection, care and support.

06

Tools to support implementation

CHOICE for Youth & Sexuality. The A-Z of MYP: How to integrate Meaningful Youth Participation into your organization & program; 2nd ed 2018: <http://share-netinternational.org/wp-content/uploads/2017/06/Case-CHOICE.pdf>

The Flower of Participation Narrative. <https://choiceforyouth.org/app/uploads/2018/04/20171122-Flower-of-Participation-Narrative.pdf> GNP+. Positive Health, Dignity and Prevention; 2017. https://www.gnpplus.net/assets/web_GNP-PHDP-for-networks.compressed-1.pdf

Call to Action – Peers to Zero The Dar es Salaam Peer Supporter Declaration. In PATA Youth Summit Report. PATA, 2016. <https://teampata.org/portfolio/youth-summit-report/>

Ending the AIDS epidemic for adolescents, with adolescents. A practical guide to meaningfully engage adolescents in the AIDS response. UNAIDS, 2016. http://www.unaids.org/sites/default/files/media_asset/ending-AIDS-epidemic-adolescents_en.pdf

07

Monitoring

The meaningful engagement of AYP includes involving them in the monitoring process of each stage of program development, including research priority setting and research itself. A working method developed for including children in the reporting process for the United Nations Convention on the Rights of the Child echoes these considerations. According to the method, participation should be transparent and informative, voluntary and respectful, safe and sensitive to risk, relevant and supported by training, in a child-friendly (or age-friendly) environment, and inclusive and accountable.

Meaningful engagement of AYP is a critical intervention in national and local programming. Involving AYP in developing, implementing and evaluating their own programs is essential to laying the right foundations for reaching global targets, and can help to ensure improved uptake and effectiveness of adolescent and youth interventions. Beyond monitoring outcomes, national monitoring and reporting should include indicators and measures of the meaningful engagement of AYP. It is essential to recognize the specific needs of AYP and AYPLHIV, including those from key populations, and adopt a holistic approach to programming and engagement. This engagement must be resourced, impactful, genuine, harmless, teen friendly and skills building.

References

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5. SPW/DFID-CSO Civil Society Working Group. *Youth Participation in Development – A guide for Development Agencies and Policy Makers*. 2010. http://www.youthpolicy.org/wp-content/uploads/library/2010_Youth_Participation_in_Development_Guide_Eng.pdf. Accessed May 15, 2018.
6. Oliveras C, Cluver L, Sharma A, Bernays S, Armstrong A. Nothing about us without RIGHTS: Meaningful engagement of children and youth: From research prioritization to clinical trials, implementation science and policy. *J Acquir Immune Defic Syndr*. 2018;78(suppl 1) (in press).

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