

Young people's participation in community-based responses to HIV

From passive beneficiaries to active agents of change



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Key messages

The key messages in this report are:

- Barriers, challenges and leadership roles experienced by young people vary according to the different legal, cultural and structural contexts of communities and countries around the world. Context makes a difference for the role of young people in community-based responses to HIV.
- Young people should not only be seen as beneficiaries of services; they should be meaningfully involved as collaborators and leaders from the beginning of policy and programme design, development, implementation, and monitoring and evaluation.
- It is essential to consider the diversity of young people, not only when determining appropriate models of service delivery, but also in acknowledging different perspectives of young people to lead and steer HIV responses.
- Both adults and young people need to be trained about what is involved in enabling meaningful youth participation in the HIV response.
- Renewal, representation and encouragement of new leadership committed to a diversity of young people and their participation in community responses to HIV—as well as how they do so—is critical to ensure young people’s participation in community responses.
- The support provided by young people living with HIV to their peers makes a real difference in antiretroviral therapy adherence, navigating disclosure and living positively with HIV.
- Remuneration for the role of young people in service delivery, providing peer support and training, demand creation and enabling linkages to care is critical for sustaining and enabling effective and meaningful involvement of young people in community-based responses to HIV.

Introduction

The following report is based on research that was undertaken as part of a series of projects commissioned by UNAIDS to support the #Uproot agenda.¹

The objective of this research was to better understand and document community-led interventions that aim to strengthen demand creation and uptake of HIV and sexual and reproductive health services, with a focus on engaging young people as beneficiaries, partners and implementers.

The primary audience of this report are donors, technical cooperation agencies and government authorities.

Background

Young people (between the ages of 10 and 24) are not a homogenous group, and interventions often fail to affirm that young people in all their diversity have the right to access comprehensive and evidence-informed information to make autonomous decisions regarding their own health, including their sexual and reproductive health, free from coercion and violence (1).

Differentiated services in the context of HIV should consider age, evolving capacities of children to exercise rights on their own behalf, and the importance of social determinants of health among young people associated with key population groups.² This includes young people who may still be understanding their sexuality and gender identity, or those who are exploring transactional sex and experimenting with drug use (2).

A literature review was undertaken to gain a deeper understanding of how young people are engaged as beneficiaries, partners and implementers in the HIV response, and this was used to inform a survey and interview questions. The data from the survey and interviews form the basis of this report. Using the UNAIDS Community Responses to HIV Framework and a three-lens approach to understanding youth participation in development, this report assesses how effectively young people are engaging and being engaged in the different levels of community-based responses to HIV (3, 4).

1 #Uproot is a youth-led political agenda to end AIDS by 2030. It focuses on challenging harmful laws and policies that pose barriers for young people's access to HIV and sexual and reproductive health services; supporting youth participation in decision-making spaces that affect their health and community responses to HIV; building and strengthening ongoing partnerships with lawmakers and health-care professionals; and scaling up access to youth-friendly HIV and sexual and reproductive health services. For more information, please visit <https://www.theyouthpact.org/uproot>

2 "The social determinants of health are the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries." Available at https://www.who.int/social_determinants/sdh_definition/en/

About this report

Watipa is a social enterprise that provides ethical consultancy services and supports a youth development program. Watipa (www.watipa.org) was commissioned by UNAIDS to conduct this research and deliver this report. The process was overseen—and technical guidance was provided—by UNAIDS, with contribution from the #Uproot team and the PACT. The research took place between October 2017 and February 2018.

Methods

Using the UNAIDS Community Responses to HIV Framework and the three-lens approach to understanding youth participation in development, this report assesses how effectively young people are engaging and being engaged in the different levels of community-based responses to HIV (3, 4).

Primary data was collected through three methods:

1. An online quantitative survey with 32 questions that was offered in five languages (Arabic, English, French, Russian and Spanish).
2. Peer interviews, which were semi-structured qualitative interviews conducted by young people in either English or their local language in six different countries.
3. Key informant³ interviews, which were semi-structured qualitative interviews conducted in English via Skype by two of the young consultants leading the research team.

The analysis draws on all three datasets: the online survey (74 participants), peer interviews (59 participants) and key informant interviews (10 participants). The total number of participants was 143.

Most participants were young people under the age of 30 years, with the majority being between 20 and 29 years of age.

The 143 participants in the research were from 42 countries. In terms of regional representation, almost half of the participants indicated that they were based in Africa, with 22% in eastern and southern Africa and 21% in West and central Africa. The regions with the lowest representation were eastern and central Europe (5%) and the Middle East and North Africa (7%).

The online surveys were quantitative in nature to ensure that responses in the different languages could be compared directly. The peer interviews and key informant interviews were qualitative, semi-structured interviews that included guiding questions.

³ As there were only 10 key informants in this research project, their country, age and gender could identify them. As such, we assured all research participants of confidentiality and have therefore listed them by continent only.

Figure 1. Percentage of participants who self-identified as one or more of following: person living with HIV; lesbian, gay, bisexual, and/or transgender; sex worker; and person who injects drugs (total number of people who took part = 143)

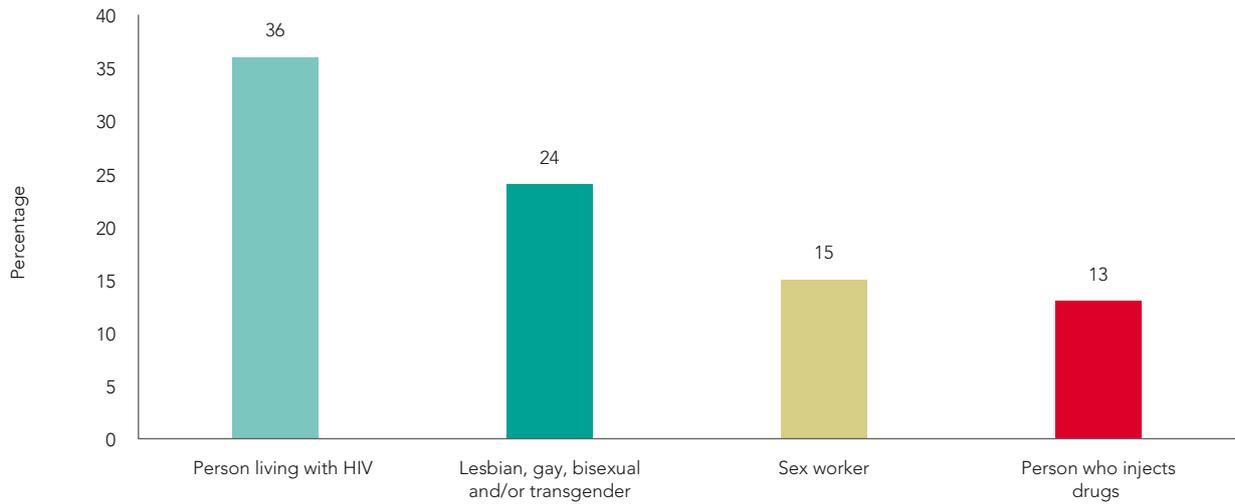
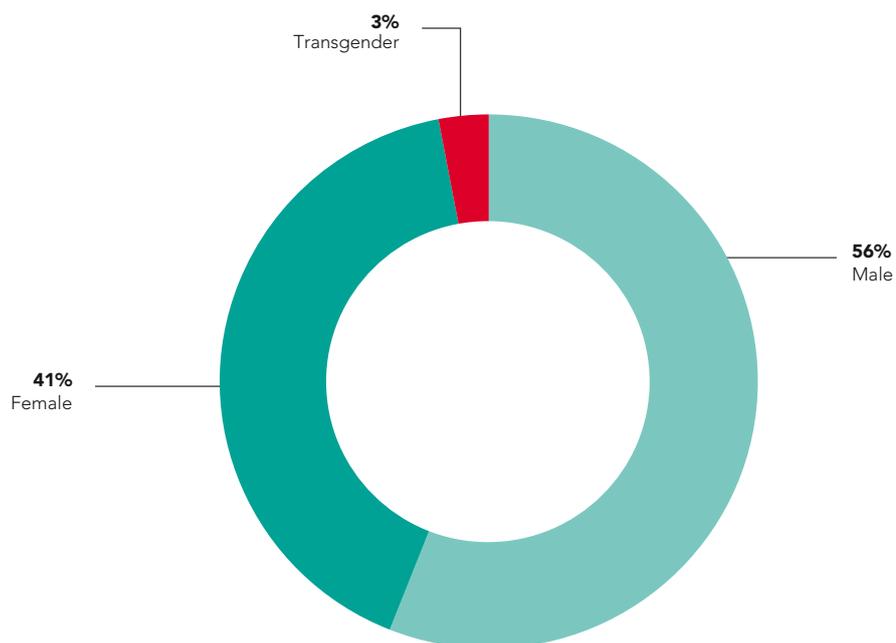


Figure 2. Percentage of participants who self-identified as male, female or transgender (n = 143)



The analytical approach used for the qualitative interviews was inductive, reading through all the responses alongside each other to identify recurring themes and extract indicative quotations.

Verbal consent was recorded for all peer and key informant interviews at both the beginning and the end of each interview. Confidentiality for all participants has been assured, and identifying places and other names have been changed or omitted.

A purposive sampling approach was adopted for all methods. Participants in the online survey were self-selecting, having received information disseminated through networks of young key populations, young people living with HIV and youth-led organizations. They included representatives from networks and organizations that were both youth-led and youth-serving in order to garner a variety of responses. The peer interviewers selected their participants from within their local community, and the focus was on young advocates, young people involved in the response to HIV and local health service providers. The key informants were identified by UNAIDS and the lead consultants for the research, prioritizing the perspective of youth advocates in global movements and representation from constituency-led organizations.

Limitations

The combination of research methods sought to engage a wide variety of participants. The translation of the online survey into five languages was an attempt to reach as many people as possible across all regions of the world. Some delays in the translation process meant that some translations of the online survey were not open for as long as other versions. This may have influenced the responsiveness of participants from the relevant regions and language groups.

The sampling approach meant that key informants and targeted participants were reached, but the regional distribution of responses reflects the networks and reach of the lead consultants and peer interviewers conducting this research.

The peer interviewers were based in six countries (Ghana, Kenya, Malawi, Nepal, Uganda and Zambia), which enhanced participation from those countries. It also meant that there was a greater representation of perspectives from across Africa, as the majority of the peer interviewers were based in African countries.

The work with the Watipa scholars as peer interviewers meant that a broad range of perspectives of young people and participants have been included in this research. Some—but not all—of the Watipa scholars are involved in their local response to HIV, and they are all young leaders within their communities.

Findings and analysis

The results indicated that young people play an essential role in demand creation, linkages to care and uptake of services for HIV and sexual and reproductive health and rights. They are the backbone of community-based demand creation, and the results showed that this effect was twofold: it enhances the overall response to HIV and benefits the young people themselves.

Young people, particularly role models and leaders who are living with HIV, play a critical part in enabling access to HIV treatment and retention in care. The results showed that the support provided by young people to their peers has a positive effect on antiretroviral therapy adherence, navigating disclosure and living positively with HIV. Details of the types of support show that young people are actively involved in peer psychosocial support, peer-to-peer consultations, policy engagement processes, peer mobilization around specific campaigns and projects, and peer-supported hospital and care access.

Young people, including young key populations and young people living with HIV, also play a key role in primary HIV prevention, early testing and diagnosis. Peer education, outreach and community engagement are all areas where young people are informing and influencing their peers. In some examples, young people working as peer supporters and volunteers provided HIV testing and counselling services, distributed condoms or worked alongside community-based health assistants.

Newer prevention technologies, such as pre-exposure prophylaxis (PrEP) and topical gels, did not feature in the kind of information sharing work done by the young people surveyed and interviewed, but information about regular testing, delaying sexual debut, preventing early marriage, avoiding early pregnancy and enjoying healthy relationships did feature across most settings.

The role of young people in advocacy was apparent in both current HIV responses and historical ones. However, the opinions and perspectives of young people are not consistently present in some decision-making fora, and the extent to which the opinions of young people are taken seriously and respected seems questionable and context-specific. This is in line with a recent report by UNAIDS highlighting the results from the 2017 National Commitments and Policy Instrument that found that “while young people participate in the development, consultation, validation or review of strategic documents that guide the HIV response at the country level, they participate much less frequently in spaces where decisions are made about the policy framework or resources invested in the HIV response” (12).

Increased attention has been given to the need to disaggregate data to reflect the diversity of young people and the important role they play in gathering data to inform nuanced policies. Factors to note include the following: (a) age and the different life stages of young people in terms of their sexual and reproductive health and rights and needs; (b) geography and the differences faced by young people in rural communities and

urban settings when accessing HIV services; and (c) the layers of complexity experienced by young people who identify with one or more key population groups, including gay men and other men who have sex with men, transgender people, sex workers and drug users.

The three-lens approach calls attention to the participation of young people as beneficiaries, collaborators and leaders in facilitating the effectiveness of the HIV continuum of care.

The three-lens approach to youth participation was introduced in 2010 by the Department for International Development (DFID) in the United Kingdom of Great Britain and Northern Ireland, adapted from the 2007 World Bank Development Report. This approach views young people's participation in development, acknowledging their agency, capacities and skills to transform their lives.

In line with this approach, the research findings raise several key points. This research found that there is a perceived value in young people's participation in all stages of programme and policy design, implementation, and monitoring and evaluation. Despite this, young people are often seen as being passive in the process and participating only as beneficiaries; their role as implementers was either overlooked or taken for granted.

The role of young people as collaborators or partners in the HIV response was valued, but it was simultaneously identified as an ambition rather than a reality in most contexts. Having meaningful youth participation in policy-making and programme delivery was the exception and not the norm.

The qualitative interviews added nuance to the kind of information on sexual and reproductive health and rights and HIV prevention that young people would like, indicating that it was not only about protecting themselves and their peers, but also having greater knowledge to be able to participate effectively in decision-making spaces. Examples were given in relation to acronyms, global targets and national policy jargon that can at times appear to be a language unto itself. Capacity development and support for young people to gain the appropriate knowledge to participate effectively in those spaces would also be advantageous in strengthening the community-based response for young people and enhancing their access to HIV services.

Participants in the peer interviews also encouraged donors to resource the time and involvement of young people so that they could be paid for their role in service delivery and not only be considered as volunteers. Concrete suggestions were given to donors to provide core funding to enable organizations run by and for young people to have some funding sustainability and support in setting up governance and organizational structures to facilitate a stronger and more long-term engagement in the local HIV response. This included things such as formal organizational registration, Internet access and communication tools to facilitate communication within the organization and with the young people in the communities they represent and serve.

“In many countries, English is the operating language in the HIV response. Being a good leader and not knowing English gets you excluded.”

KEY INFORMANT, AFRICA

The findings point to a vast variation in how young people are involved in advocacy and policy discussions. At times, they are not involved at all; at other times, they create spaces for themselves to speak out. In some instances, they speak out and are heard, and in others, they are being invited, consulted and valued for their essential role in demand creation, linkages to care and uptake of services for HIV and sexual and reproductive health and rights.

Donor leadership has created space for young people to participate in global meetings and/or in the design and development of international guidelines. Ring-fenced funding for young people’s participation in such global fora—as well as their participation in designated spaces in national fora, such as the Country Coordinating Mechanism of the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund)—would help ensure that young people are involved, and that political, technical and financial resources are made available to support their participation. Just as in national decision-making spaces, the capacity of young people to participate effectively in global fora needs support to ensure that they are equipped with the appropriate knowledge, language and background resources. Advocacy tools, translation and guidance can help facilitate the meaningful participation of young people.

Making space for new voices to represent young people while also providing support and mentorship was cited as a challenge for ensuring continuity and renewal within community-based responses to HIV.

It is important to enable opportunities for the participation of young people from a variety of backgrounds (including rural communities) in community-based responses. Project discussion fora, youth-friendly service access and policy engagement processes often are limited to major cities and can leave behind young people in rural or hard-to-reach areas.

It seems that young people’s involvement in the HIV response is primarily siloed, and more could be done for young people working on HIV to engage with movements working towards other aspects of the Sustainable Development Goals (SDGs). There were notable examples where innovative and cross-thematic partnerships were identified, but these appeared to be exceptions rather than the norm. At the strategic level, few approaches seemed to place the complex and holistic needs of the young person first; rather, they focused on one aspect, such as sexual health, the uptake of HIV services or another specific factor.

Community-based responses to HIV are critical for ensuring that the supply of (and demand for) services are reaching young people in all their diversity. The following section looks at the findings from the research in greater depth by applying a three-lens approach for the participation of young people as beneficiaries (target groups), partners (collaborators) and leaders (youth initiators) in community-based responses to HIV, with a focus on demand creation and uptake of HIV and sexual and reproductive health services (4).

Lens 1: seeing and working with and for young people as beneficiaries

“Young people are often considered passive beneficiaries, and they don’t even have a voice as beneficiaries.”

KEY INFORMANT, ASIA

Globally, young people between the ages of 10 and 24, including girls, young key populations and young people living with HIV are still among the most affected in the context of new HIV infections, AIDS related deaths and stigma and discrimination. Globally, there are approximately 1600 new HIV infections among young people between the ages of 15 and 24 per day. Although AIDS-related deaths have declined over the past 15 years, adolescents living with HIV, and particularly those who were born with HIV still struggle with treatment adherence, and a young person dies because of AIDS every 10 minutes around the world. In many countries there are laws that require adolescents to have the consent of their parents or guardians to access HIV testing and treatment services, discouraging adolescents from accessing the life-saving services that they need. Globally, adolescent girls and young women, young gay men, transgender people, sex workers and drug users continue to experience from discrimination, stigma, violence and gross violations of human rights. It is imperative that young people in all their diversity remain a priority for the HIV response, and that programmes effectively address their needs.

Having a voice as beneficiaries gives young people an impact on the effectiveness of policies and programmes. “When young people participate meaningfully in the development and implementation of policies and programmes that affect their health, services are more effectively tailored to their needs and their health outcomes improve” (12). All the key informants said that young people were seen as beneficiaries in the response to HIV. However, more efforts are needed to listen and take young people’s specific needs and recommendations on board to ensure that services effectively reach them.

For example, time-bound interventions were given as examples of taking young people’s specific needs into account by using a specific place and time to reach young people and provide information, referrals and even specific HIV services. Examples given included a Wednesday “youth corner” in a local health facility or a Thursday meeting of a youth organization in a community centre. For example, one young woman from Uganda said that “[an example of good practice in Uganda is] Thursday conferences on sharing experiences and information new and old on the HIV response as a way of coping with positive living and supporting each other, [particularly] considering that Thursday is when the youth come to pick [up] their medication.”

Lens 2: seeing young people as collaborators and engaging with youth as partners

Almost all participants in qualitative interviews who described young people as being seen primarily as the beneficiaries of HIV interventions also expressed a desire for young people to be involved as partners and implementers from the beginning of the process.

The role of allies in the form of “adults” or established professionals within larger national and international organizations was cited by a few of the key informants as important for generating change and trust in the capability of young people. Others spoke of the role of “old people” as blockers of the participation of young people or as gatekeepers who were unwilling to yield space for meaningful participation of young people in the response to HIV.

A few interviewees stressed the need for greater collaboration between young people in the HIV response and other civil society partners and movements, particularly in order to address some of the structural barriers that deter many young people from accessing services (such as age of consent, cultural values that silence young people, poverty or gender inequality).

Participants also indicated that young people are more open-minded, friendly and willing to collaborate with others, and that they therefore bring a positive and collegial energy to the national response to HIV.

However, it was noted that it is not usually the case for young people to be listened to or influence decisions, and that this was to the detriment of the policies. It also decreased any motivation for young people to participate. In words of one participant, *“young find that majority of policy-making is done by people who are not youths: the older generation that is.”* A young man from Nepal said that *“if you have [the] will, energy and idea, but you’re not heard, then you lose your interest.”*

Lens 3: seeing young people as initiators and supporting youth as leaders

“Most young people undertake to be their own leaders in their capacities. That is, they may spot a problem as an individual and attend to it or be asked by the management to attend to a social problem . . . so they are leaders in one way or another. They are leaders as volunteers, teachers and mentors and in offering their skills.”

MALE, AGED 25, KENYA

Several participants gave specific examples of how young people are involved as implementers in the provision of HIV services in their communities, but all participants indicated that young people are not usually in positions of leadership or decision-making regarding the models of service delivery or the strategic management of different programmes. For example, a young man from Nepal said that *“young people mostly work on the field rather than making decisions.”* A young female health-care worker from Malawi said that *“Young people are involved in HIV response as volunteers or peer workers, but not as decision-makers.”*

The most common examples related to the role of young people as implementers were in the areas of information, education and communication. In terms of health services, 62% of surveyed individuals who were members of a youth-led or youth-serving organization in the HIV response indicated that they themselves provide HIV services directly to young people. These were services designed to benefit and reach young people as the focus groups. The provided services include information about sexual and reproductive health and rights (51%), peer support (50%), psychosocial support (42%), condom promotion and distribution (41%), antiretroviral therapy adherence support (32%) and HIV counselling and testing (30%). Many of the organizations surveyed offered integrated services, including referrals, prevention, and testing and treatment of other sexually transmitted infections (STIs) (38%), tuberculosis (28%) and/or hepatitis B and C (22%).

Some participants described how young people in their communities were involved in door-to-door outreach and offering HIV testing and counselling services, general health screening and/or home-based care. One participant indicated that young people had a critical role as champions in the local voluntary medical male circumcision (VMMC) programme. The important role of university students in educating themselves and their peers in HIV prevention was also cited in the peer and key informant interviews as an avenue for reaching a wide audience.

Participants described the role of young people in peer education and outreach services to other young people through school talks, community theatre and songs. One participant described how a young person was involved as an artist in creating images for a pamphlet about local HIV services. In the words of one participant: *“It’s easy to disseminate the knowledge among ourselves, because if [I] am part of it, then it’s easier to talk to somebody of my age about it.”*

Participants also described significant services provided by young people living with HIV for other young people living with HIV, such as support for “positive living,” adhering to antiretroviral therapy, confronting stigma, challenging discrimination and providing

support for disclosure-related changes. Twenty-four per cent reported enabling access to antiretroviral medicines and providing treatment adherence support for adolescents and young people. A further 16% reported providing referrals for antiretroviral medicines.

The peer interviews revealed a number of key points in relation to funding and the challenges of providing HIV services by and for young people. Remuneration to young people for their role in providing services was identified as a challenge, as was the sustainability of service provision beyond the life cycle of specific project-based funding. Some participants in the peer interviews raised concerns relating to allocation, indicating that youth-oriented or youth-implemented services were overlooked for receiving funds directly.

Almost half (49%) of surveyed individuals who are members of a youth-led or youth-serving organization in the HIV response indicated that their organizations compensated young people for the services provided. The compensation models varied, with some reimbursing transportation costs (41%), providing t-shirts (35%) or covering meal expenses (32%). Fifteen percent of organizations actually paid young people for their role in providing services to other young people, but most respondents across all three datasets indicated that they thought young people should receive greater compensation for their work and contribution to enabling young people to access HIV services (82%). *"We need to take it more seriously to pay young people for the work they do"*, said a key informant from Africa.

In terms of informing policies, an additional point that emerged from the qualitative interviews was the role of young people in gathering information and evidence to inform local programming and national policies. As one participant in the peer interviews explained, young people in Uganda have an essential role in monitoring service delivery and improving quality: *"We formed a group of advocates who carry out research on access, utilization and availability of services [for] adolescent girls and young women in health facilities. It's a good practice [and] we shared the findings with the district officials, and the issues which were realized are being worked upon: for example, less staffing, discrimination, drug stock-outs and putting up friendly corners."*

The role of mentorship was raised by several key informants as particularly important for ensuring the renewal and sustainability of the leadership of young people. The challenge of "aging out" or "retiring" as a young leader was noted by some, who felt they needed to step aside at age 30 as they would no longer be considered "young." Doing so creates space for new leaders and perspectives to shape the response, but it also risks decreasing momentum and jeopardizing sustainability if adequate mentorship processes, handover and adequate governance systems for leadership transition are not in place.

Other participants spoke of the initiative taken by young people in setting up their own organizations or clubs to respond to HIV and other cross-cutting community concerns. In Malawi, for example: *"The young people are involved in positions of leadership in the community. The clubs and the groups are governed by youth themselves, [and] they share the responsibilities among them"*, said a young woman from Malawi.

One key informant spoke of concepts around youth organizing and the importance of shifting from "youth mobilizing" to "youth organizing." In other words, it was necessary to adopt a long-term and more in-depth understanding of the complex and evolving needs of young people based on an approach generated from the community itself.

Several participants spoke of the need for young people to be taken more seriously in the decision-making process. A key informant from Europe said that *"there is a tendency to make youth-led organizations seem like they do not know what they are doing . . . there needs to be a shift from just being partners to leading projects."*

Participants described the importance of role models and service provision provided by young people living with HIV to their peers, particularly in the context of peer support by and for young people living with HIV. A young transgender woman from Uganda said that *"some young people are in position to lead. For example, we have a youth councilor at the district level [who] handles all issues [that] affect the youths. Groups of young [HIV-positive people] are led by young people."*

One key informant stressed the leadership of young people living with HIV in responses to HIV, and how they are responsible for the very success or failure of the HIV response now and in the future. *"Young people living with HIV are changing the game in the community. They are peer educators, mentors . . . they support other young people at health facilities to direct them about services to make the process swifter for them while receiving services. Many young people are involved in advocacy where they speak for the voices of [the] young."*

The greater and more meaningful involvement of young people in the response to HIV

The main reasons for the greater and more meaningful involvement of young people in the response to HIV that emerged in this research can be grouped under two main themes: (1) the enhancement of the response to HIV; and (2) the benefit of the young people themselves.

In terms of the first theme, several participants indicated that young people bring creativity, energy and an important perspective to responding to the current (rather

than historical) community priorities of the local HIV response. In Malawi, for example, one participant described the benefits of youth participation for health outcomes. *“Participation of the youth in the response to HIV is a tool for enhancement of the health of young people. Therefore, governments and institutions should emphasize the need for active involvement of young people in the response to HIV, as it is a means that can help to improve service delivery by allowing [the] appropriate authorities to respond accordingly to the specific needs and concerns of the youth”,* he said.

Other participants also specifically stressed the benefits for policy-making: *“It is important to involve the youth, because when the youth are involved in policy-making, it is easy for them to implement their own policies. But when the policies are made by others, the youth may feel that they are left out”,* said a young woman from Malawi.

Regarding the second theme (the benefit of the young people themselves), many participants stressed that young people must be responsible for their own health, and that they are the generations of the future. Therefore, young people need to be involved actively in the HIV response for their own benefit and for the benefit of the future development of the nation. *“I firmly believe that we youths do not consider the sensitivity of HIV and AIDS as much as we must, and this must be changed. Youths are the ones to change the future”,* said an adolescent girl from Nepal.

The role of young people in community HIV responses was seen as critical to working towards promoting health and well-being and preventing HIV among adolescents and young people.

Barriers that continue to limit young people’s access to services and meaningful youth participation and leadership in community-based responses to HIV

Participants in the research identified barriers that inhibit the uptake of HIV and sexual and reproductive health and rights services among young people, and their meaningful participation and leadership in community-based responses. These included factors that centred on both the young people themselves and society as a whole.

A lack of interest or motivation among some young people regarding HIV—combined with a perception in some contexts that HIV is no longer a priority concern for young people—deters access to services. Young people also indicated a fear of stigma or discrimination that may arise from being involved in the HIV response. There also was a lack of trust that young people’s sexual history would be kept confidential by health-care providers. Language, access to information and educational levels also were cited as

factors affecting a young person's choices about their sexual health and their ability to make informed decisions.

Other barriers that young people face in accessing HIV services include the anticipated stigma and/or discrimination associated with HIV, sexual experiences before the age of consent or marriage, and other behaviours (such as same-sex attraction). The perceived lack of quality (including a lack of confidentiality) in the provision of youth-friendly services—and a need for capacity development of health-care workers in the provision of accessible and appropriate services—were also identified as factors. Traditional authorities, religious leaders, parents and peers are sources of influence that affect a young person's access and openness to HIV services.

Structural barriers highlighted in the key informant interviews included laws and policies that criminalize or marginalize certain young people, such as young gay men and other men who have sex with men, young sex workers and/or young drug users. These laws and policies create barriers to health service access for young people associated with key population groups. They also make it more difficult for a young person to be fully open with a health-care worker during a consultation, therefore compromising the quality of care provided and limiting the opportunity for the young person to receive the comprehensive package of services that they need.⁴

Several of the key informants also identified structural barriers that prevent the participation of young people in programming and hinder their access to health services, such as the age of consent and/or activities that require parental permission. In both key informant and peer interviews, the anticipated stigma of being associated with either HIV and/or same-sex attraction was seen as a barrier for many young people to engage fully in local HIV programmes.

The importance of disaggregated data and understanding the nuanced community needs of different young people was cited as an essential component of any effectively focused HIV response. However, it was mentioned that such precise data is rarely available, and that gathering it should be a key role for young people going forward in HIV responses.

The lack of appropriate or proportional remuneration for the role of young people in demand creation and enabling linkages to care seems to be a critical barrier to the sustained, effective and meaningful involvement of young people. Other barriers inhibiting their participation included a lack of funding for institutional support, a lack of capacity or support for the knowledge necessary to participate fully in technical discussions, and a lack of tailored tools and resources to support participation in different processes and mechanisms.

⁴ For more information related to laws and policies, including age of consent requirements to access HIV services, availability of comprehensive sexuality education and youth participation in the HIV response, please refer to UNAIDS report "Youth and HIV: mainstreaming a three-lens approach to youth participation", available at www.unaids.org.

Recommendations

The essentials to strengthen young people's participation in community responses

The following 12 recommendations come from the experiences of young people who participated in this research, and are aimed at government authorities, United Nations entities, donors, civil society organizations and other stakeholders in the HIV response. They have emerged from this research to strengthen young people's participation in community responses, particularly demand creation and service uptake in the HIV response.

1. Take young people seriously. Trust their contributions and value the benefit of including their perspectives.
2. Involve young people from the very beginning, including in design, fundraising, planning, delivery, and the monitoring and evaluation of policies, programmes and services.
3. Recognize the essential role that young people have in implementing service delivery to their peers, and do not consider young people as only passive beneficiaries.
4. Compensate young people for their role in creating demand and providing services.
5. Promote inclusiveness. Consider the involvement of young people from rural areas, representatives from different constituencies (such as key population groups, including young gay men and other men who have sex with men, transgender people, sex workers and drug users), adolescents, older young people, and/or young people living with HIV.
6. Ensure young people are invited and taken seriously in decision-making spaces, including deciding budgets and setting priorities.
7. Be informed by disaggregated data (e.g., by age, gender, geography or key population groups) so that the HIV response matches the evolving dynamics and complexity of the lived experiences of diverse young people. Take into account research materials produced by young people themselves and strengthen the capacity of young people to perform research.
8. Provide translation so that young leaders whose language is not English can also shape programme and policy discussions.
9. Be open-minded about new communication channels for policy dialogues—such as through social media—that are familiar and accessible to young people but that may represent a new or different way of doing things in policy processes.

10. Resource youth-led organizations so that they can register, establish systems and work on long-term cycles rather than relying on funds on a project-to-project basis.
11. Develop tools to give practical guidance about meaningful youth participation for young people and “adults” partnering with youth-led organizations.
12. Support youth-led organizations in processes of democratic governance and leadership development and renewal so they can maintain continuity while also mentoring new leaders. This will help them represent (and stay relevant to) the changing perspectives of young people.
13. Challenge harmful laws and policies that restrict young people’s participation, ability to organize, and access to HIV and sexual and reproductive health services.

Annex

Annex 1. Practical examples to inspire

This section provides select examples of good practices in youth-led community-based responses to HIV that were cited by research participants.

ACT!2030 (global) is a youth-led movement that supports young people to hold their governments accountable for promises made in the SDGs regarding HIV and sexual and reproductive health and rights. It is a collaboration between UNAIDS, the International Planned Parenthood Federation (IPPF) and the PACT, a global coalition of youth organizations working on HIV and sexual and reproductive health and rights. ACT!2030 is implemented by youth alliances in 12 focus countries: Algeria, Bulgaria, India, Jamaica, Kenya, Mexico, Nigeria, Philippines, South Africa, Uganda, Zambia and Zimbabwe. The project began in 2013 and is currently in its fourth and final phase, focused on establishing national youth-led and data-driven accountability mechanisms for the SDGs and the 2016 Political Declaration on Ending AIDS (5).

Teenergizer (Ukraine and eastern Europe and central Asia) is a youth organization and online platform that was created by teens for teens. It was started by three people (two adults and a young person living with HIV) in December 2015 with the following vision: (a) a world where every teenager can realize her or his potential; (b) a world free from discrimination in all areas, including HIV; and (c) a world where the rights of teenagers and youth do not have to be defended because they are fully respected. It works on two levels: one in Ukraine and one for the region of eastern Europe and central Asia. Young coordinators work alongside adults to monitor the quality of HIV testing services via an online website. Teenergizer has also developed a phone application to support adherence to HIV treatment for young people living with HIV, and it performs advocacy work that includes an application to the Global Fund that enables young people to get involved in the Country Coordinating Mechanisms. Teenergizer shows that young people are strong in advocacy and can inform, interact and engage community members in an innovative way to improve access to services like HIV testing and counselling (6).

Go Sisters! (Zambia) is a programme in Lusaka that was launched in 2001 to encourage the empowerment of girls through sport. It aims to allow girls to play, learn, exercise leadership roles, develop, discuss and participate in decision-making spaces. The programme is run by, for and with girls. They also try to incorporate boys as a way of influencing their peers and creating a generation that will appreciate and respect each other. Through sport, the program aims to empower girls by building physical resources, providing social recognition and challenging some traditional gender myths. The approach is based on the peer leader approach, building a sustainable network of young role models who lead and inspire the next generation of leaders. Peer leaders are trained in facilitation, gender assertiveness, human rights, health, sexual and

reproductive issues, event organization, sports, HIV and leadership skills. In addition, peer leaders are trained in income-generating activities, fundraising and entrepreneurial skills through sustainability workshops (7).

Haus of Khameleon (Fiji) is a social justice organization devoted to ending discrimination and violence against transgender people through education and advocacy on national, regional and global issues of importance to transgender people. By empowering transgender people and allies to educate and influence policy-makers and others, Haus of Khameleon facilitates a strong and clear voice for transgender equality. Haus of Khameleon is a movement that is led by young transgender women who are lobbying, campaigning, organizing, researching, training and advocating for transgender equality in Fiji and the Pacific. Its work is framed around feminism, using human rights-based and evidence-informed approaches to address transgender issues covering gender-based violence, access to transgender-friendly services and resources, sexual and reproductive health and rights, peace and security, legal gender recognition, housing, employment, ecological justice and good governance. Some of its core work involves documenting and reporting transgender-specific violence and implementing research on the sexual and gender-based violence experienced by transgender and gender nonconforming people (8).

READY! (Burundi, Eswatini, Ethiopia, Mozambique, Uganda, United Republic of Tanzania and Zimbabwe) stands for resilient and empowered adolescents and young people. READY seeks to ensure that adolescents and young people are resilient, empowered and knowledgeable, and that they have the freedom to make healthier choices and access services and commodities related to their sexual and reproductive health and rights. A five-year project, READY is funded by the Netherlands Ministry of Foreign Affairs and implemented by a consortium led by the International HIV/AIDS Alliance with Paediatric-Adolescent Treatment Africa (PATA), Regional Psychosocial Support Initiative (REPSSI), M&C Saatchi World Services, the Global Network of Young People Living with HIV, and additional technical resource partners and in-country implementing partners. The first three READY projects—READY+, READY Teens and READY to Lead—are under way in East, central and southern Africa. The goals of READY+ are as follows: (a) for adolescents and young people living with HIV to become ready to make informed decisions about their health and rights; (b) for parents and caregivers to be ready to support young people to talk about sexuality; (c) for service providers to be ready to provide youth-friendly services; and (d) for decision-makers to be ready to champion access to information, services and commodities. The READY project supports eight youth-led organizations in seven countries where young people manage their own funds and are compensated to carry out activities that affect the project. READY has community adolescent treatment supporters, adolescents living with HIV who are informed and empowered to support others through mobilization for HIV testing and counselling services, linkages to HIV-related services, community counselling and monitoring support,

child protection and mental health support. They also support each other in disclosure and adherence to treatment. READY trusts young people to make their own work plans, direct and control the level of their activities and manage their own funds in determining what is needed and what should be prioritized (9).

La Red Argentina de Jóvenes y Adolescentes Positivos (RAJAP) (Argentina) is a national network of young people and adolescents aged 14 to 30 years who are living with and affected by HIV. It was created in 2010 and consolidated with its first national meeting in 2011, which was attended by more than 40 young people. Tapping into a need for a safe space created by and for young people living with HIV, RAJAP provides support, peer discussions, training and opportunities for involvement in local community HIV responses. By the fourth national meeting in 2014, the group had grown to almost 100 young people and adolescents from 15 provinces across Argentina. At the most recent gathering in Rosario in 2017, more than 230 young people from 24 districts came together to empower themselves and make it known that they are not alone. The meeting was a space for exchange and training through workshops on topics such as human rights, HIV prevention, healthy eating and harm reduction associated with the use of drugs (10).

The **Y+ Beauty Pageant** (Uganda) is an annual event by, for and with young people living with and affected by HIV that challenges stigma by celebrating beauty, life and togetherness. The Uganda Network of Young People Living with HIV/AIDS (UNYPA) created the initiative in 2014 after a girl was rejected from attending a beauty contest due to her HIV status. Every year, young people aged 15–24 years participate in the pageant, where they are judged by a panel for their knowledge of sexual and reproductive health and rights and HIV as well as their personality traits and talents. Since 2015, UNYPA has held regional auditions where young men and women between the ages of 16 and 25 from partner organizations or health centres in the districts take part. Every year, the auditions travel to new districts to encourage participation and reach new groups of young people. After the auditions, a “boot camp” is held that brings together the final 30 contestants to help them be prepared for the main pageant. A “flash mob” is also held that is aimed at mobilizing the community for free and integrated services, such as HIV counselling and testing, cancer screening, tuberculosis testing and VMMC (11).

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