WHAT WORKS FOR US

SECTION 5.

YOUTH-LED ADVOCACY ON DSD

Section 5.1 FOR YOUTH, BY YOUTH: WHY THIS CHAPTER?

Section objective

The objective is to understand why interventions must renew their focus on young people living with HIV (YPLHIV) and to make clear the unique challenges faced by individuals at this stage of life.

Young people living with HIV: What are the facts?

"Reaching YPLHIV with better information, improved services and innovative approaches that can address our specific health needs is of paramount importance. Available evidence shows that we are still not having our needs met by current services and that, globally, compared to adults, we have worse access to and coverage of ART, higher follow-up loss rates and poorer adherence to treatment."

WHO defines "adolescents" as individuals in the 10-19 years age group and "youth" as the 15-24 year age group. The term "young people" covers the age range 10-24 years.

1 IAS, CIPHER and WHO. Research for an Aids Free Generation: A Global Research Agenda for Adolescents Living With HIV.
An estimated 1.8 million adolescents (aged 10-19) globally are living with HIV. 90% of these are in sub-Saharan Africa.

In Asia, young people from key populations make up 95% of young people diagnosed with HIV. (www.avert.org)

37% of new infections are among young people aged 15-24, 22% among young women, and 15% among young men.

New infections among 15-19 year olds have declined, but more slowly than children under 15 years of age.

Adolescents and young people living with HIV are the only age group where mortality from AIDS-related conditions has not decreased.

What are our needs?

Adolescence is a transitional stage between childhood and adulthood and a time of extreme social, physical and emotional development and change. As adolescents, we all face challenges related to changes in our bodies, increasing independence, development of our sexuality, peer pressure and exploration of new experiences and ideas.

Throughout adolescence and beyond, as YPLHIV, we face additional challenges that include accessing treatment and care, following a regime of lifelong medication, dealing with issues around disclosure to family, peers and potential sexual partners, worrying about the future and facing stigma and discrimination.

I would rather miss my appointment than another test at school. My friends are asking questions about where I go every month.

Sticking to a routine where we have to take a particular pill every day is frustrating. And there are side-effects. I don’t want to take something that will change how I look and feel.

What happens when I fall in love or want to have sex with someone? Do I have to tell them my status? What if they reject me?

This phase of life also tends to be accompanied by an increase in risk-taking behaviour, which may involve pushing boundaries established by authority figures and trying things that could be harmful. Many scientists now suggest that this might be a normal and, indeed, necessary part of growing up and preparing for adulthood. However, this tendency has an effect on the way we think about health, how we look after ourselves and our perception of risk when it comes to non-adherence to treatment regimens.

YPLHIV are a diverse group and come from many backgrounds and walks of life. We may have been born with HIV or we may have acquired it through our lives. We may be in school or college, employed, looking after siblings, living in poverty or wealthy, using drugs, selling sex, pregnant, married or unmarried. The challenges we face will be experienced and navigated differently depending on some of these factors.

Section objective

The objective is to understand the technical aspects of DSD, who can benefit from it and how YPLHIV would like to receive their care.

The building blocks of DSD for adolescents and young people: What does WHO say?

Useful resources to read and watch

UNAIDS. Ending the AIDS epidemic for adolescents, with adolescents (http://www.unaids.org/sites/default/files/media_asset/ending-AIDS-epidemic-adolescents_en.pdf)
**What WHO says**

Who
Non-medical staff can provide us our ART refills, as well as other support, and this could include caregivers or even our peers.

What
Psychological and adherence support must be included for us.

Where
We can collect ART refills at community venues or at group meetings, which don’t have to be held at the facility.

**What young people say**

When
We should have access to longer ART refills (3-6 months) and we only need to go for a full clinical consultation every six months.

Who
We want to receive our care from both clinicians and peers through peer mentoring in group models.

What
We don’t want everything separate - combine HIV care with other things, including services for sexual and reproductive health. We would like more access to counselling and support, including from communities and peers.

Where
We need places that are easily accessible and located close to schools and homes. It would be good if HIV clinics were not easily identifiable as HIV-only services because many of us fear that our friends, family and community may find out about our status accidentally.

We want operating hours outside of school time.

We want to have more gatherings with like-minded people in a space where we can talk and share ideas.

**The building blocks of DSD for YPLHIV: What do young people say?**

"In order to learn from and boost our peers’ voices, five of us Youth Advocates have done some research amongst YPLHIV in five countries. We talked to 393 YPLHIV about their experiences, needs and expectations, and they told us how they wanted to receive their HIV care and how this would look for them."5

**Healthcare worker-managed group model: South Africa’s youth clubs, Cape Town**

Who:
Lay healthcare workers manage groups of up to 20 young people (ages 12-25 years) and groups are divided into older and younger as their needs are different. A nurse provides support for clinical aspects.

What:
ART refills, symptom checks, viral load monitoring and SRHR services are provided. Interactive activity sessions and discussions also help with adherence and create peer networks for sharing and support.

When:
Every month for the first six months and then every two months at the clinic.

Where:
Primary care clinic with a separate area for young people.

"A viral load test measures the amount of HIV in a sample of blood. This is the most effective way to learn if HIV treatment is working for someone. This is an important tool because it shows if a person is failing in their treatment or is having problems with their adherence. As we can see from the WHO guidance, a low viral load can be used to support YPLHIV’s demands for DSD.

For a lot more information on this and on why we should demand routine viral load monitoring, please see Section 2.3 of the toolkit. Also take a look at: [ITPC Activist Toolkit: Campaigning for Routine Viral Load Monitoring. 2016](http://itpcglobal.org/resources/community-demand-creation-model-routine-viral-load-testing)"

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According to WHO, DSD models are suggested for adolescents who are “clinically stable”, which means those:

- Who have received ART for at least one year and have no adverse drug reactions that require regular monitoring
- Who have no current illnesses
- Who have good understanding of lifelong adherence and evidence of treatment success (i.e., two consecutive viral load measurements below 1,000 copies/ml)
- Who have access to psychosocial support.

Young people from key populations include:

- Young people who sell sex
- Young men who have sex with men (MSM)
- Young transgender persons
- Young people who inject drugs

However, it is important to note that other groups also have different needs, such as pregnant young people or those living with disabilities. YKP face greater obstacles in terms of access to HIV-related care and treatment than other YPLHIV.

These obstacles may include:

- Being alienated from family and friends
- Challenges in terms of access to education, housing or healthcare
- Fear of discrimination and legal consequences in environments where certain behaviours are criminalized
- Stigma and discrimination in healthcare settings
- Ignorance within health systems about gender variance
- Lack of understanding and knowledge of their rights
- Not identifying as being from a group at risk and therefore not seeking care.

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**WHO can benefit from DSD models?**

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**WHAT DO YOUNG PEOPLE FROM KEY POPULATIONS NEED?**

**CAN DSD HELP?**

**HOW?**

<table>
<thead>
<tr>
<th>WHAT DO YOUNG PEOPLE FROM KEY POPULATIONS NEED?</th>
<th>CAN DSD HELP?</th>
<th>HOW?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Integrated HIV and SRHR services, as well as those that focus on specific social, emotional, physical and legal needs faced by specific groups</td>
<td>Yes</td>
<td>A DSD approach can involve adding services for YKP to existing youth-friendly services.</td>
</tr>
<tr>
<td>Prioritizing building of trust with young stigmatized groups</td>
<td>Yes</td>
<td>Reach out through peers, including those from key populations themselves, who can approach marginalized groups with user-friendly information.</td>
</tr>
<tr>
<td>Community-based services using peer outreach and support</td>
<td>Yes</td>
<td>Reach out through peers who can accompany adolescents from key populations to access services delivered in “hotspots” where specific groups gather or work.</td>
</tr>
<tr>
<td>Easy access and safe impartial settings</td>
<td>Yes</td>
<td>Delivery through existing key population-focused community-based organizations.</td>
</tr>
<tr>
<td>Use of social media to promote services</td>
<td>Yes</td>
<td>Use apps and sites that YKP can access confidentially to get information and treatment.</td>
</tr>
</tbody>
</table>

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In Chiang Mai, Thailand, Save the Children is running a programme that focuses on HIV prevention outreach among YKP, specifically young MSM and young transgender people.

- HIV outreach is conducted through mobile apps with project staff promoting Mplus Chat, which is used to establish relationships.
- Outreach workers meet in person in safe areas that are frequented by these young people, such as bars and clubs. Tablets are used to make communication easier.
- The tablet is used to show the project website, to provide content for discussion and to record contact details for later follow up. After initial contact is established, online platforms are used to provide information on HIV prevention, treatment, care and support.
- Young people are offered accompanied referrals to free HIV testing, treatment and care services.
- Online counselling services since young MSM and transgender people sometimes prefer to have more privacy.
Section 5.3 OVERCOMING BARRIERS: IMPLEMENTING DSD MODELS FOR ADOLESCENTS AND YOUNG PEOPLE

Section objective

The objective is to highlight barriers to accessing HIV services and to effective DSD implementation, as well as examples of how these difficulties are being overcome by young people.

What barriers do we face in accessing HIV services?

“As we all know, there are many barriers that may prevent us from accessing the HIV-related services that we really need.”
How can DSD address these barriers?

“DSD can address these barriers by delivering services differently - the building blocks shown previously (Who, Where, When, What) can be adapted to reflect our needs and address the barriers that we face. Let’s meet Teleza, who will give us an example of how this is being done in Malawi.”

So, we have heard of “teen clubs” in Malawi. It seems this is a great example of DSD on the ground. Who runs these clubs?

Yes, I attend a teen club. They are run by club mentors who are especially trained in teen issues since it’s for adolescents aged 10-19. And there is also support from a nurse for the health aspects.

So, when do you go?

The great thing is that the club is held every month on Saturdays or Sundays - so we don’t have to miss school. I only need to go once every two months. But I go every month because I like the support and the activities. It’s good to have a special time and a special space for us. Also, there is always music on. We dance and laugh. So the atmosphere is friendly and fun.

But I guess it still takes time to get there?

It’s about an hour on the bus. We do have to go to the health facility in the next town, but it’s fine because we also get a bit of money to help with transport.

That makes sense. What happens there?

Well, a nurse checks us and makes sure that we are on track. We also get our ART refills and, twice a year, we have viral load checks. The thing I like best is that we get information that we need on other things like relationships and birth control, sex, STIs ... we can discuss, ask questions and share problems. Pregnant girls can get antenatal care, as well. And we get to do it all in one place.

A DSD model for young people must include:

- Options for how support is given
- Clear information on what is available
- Safe and confidential peer counselling support groups run by peers who are also HIV positive
- Adolescent days/times at facilities, and information and sharing sessions at a clinical level
- Multi-month ART prescriptions
- Comprehensive services, including information and counselling on SRHR, harm reduction, drug use, PMTCT
- Convenient hours for young people
- New and innovative approaches to share information and support participation and adherence using social networks like WhatsApp, Twitter and Facebook.

“I have been working as a youth facilitator for youth clubs that are running for YPLHIV. We prepare the medication for our club members. They come straight to the club room when they get to the clinic. They have a health screening and then those who are adhering just take their meds and go home after the club meeting. They don’t have to stand in lines or anything. In our programme, YPLHIV services are provided mostly by other young people, who are trained and understand young people’s problems.”

(Tumie, Youth champion, South Africa)

What are the barriers to implementing DSD models?

“When fully implemented, DSD can address many of these. However, we also need to understand some of the obstacles to delivering DSD for YPLHIV in our countries. Feedback from healthcare workers, ministry officials and youth activists from all over the world at a meeting in New York suggests that there are some significant barriers at the local level to putting DSD into place for YPLHIV.”

Below are some ideas of how to overcome these barriers from Youth Advocates working in different countries.

Useful resources to read and watch

http://www.differentiatedcare.org/Models/TeenClub

Namusoke from Kampala. DSD for Adolescents https://www.youtube.com/watch?v=5OVBBbHb7_Bs


12 Interviews with Youth Advocates in October 2018.
BEST PRACTICE: Zvandiri programme, Africaid, Zimbabwe

A key feature of this DSD programme is the community adolescent treatment supporters (CATS), trained HIV-positive young people who provide support to children, adolescent and young people living with HIV. Advocacy point: CATS are integrated within the health facilities supervised by the Ministry of Health and therefore their role is recognized and supported. CATS work between clinics and the community, encouraging and supporting YPLHIV to access the services they need. Clinical staff and social workers refer YPLHIV to the CATS for necessary peer support and follow up.

- CATS do community outreach going door to door linking YPLHIV to HIV-related services and providing advice and support on adherence issues.
- CATS, supervised by clinical staff, also work within the health facilities at clinic-based Zvandiri centres, which are safe spaces to link YPLHIV to clinical and social services, including SRHR services, mental health and socio-economic services, as well as PMTCT services for pregnant individuals.
- CATS run monthly community support groups with planned activities that develop skills and awareness, promote adherence and improve sexual and reproductive health. These groups also provide a chance for YPLHIV to meet others in a similar situation, make friends and share troubles.
- As of September 2017, a team of 860 CATS were actively providing adherence support for more than 45,000 HIV-positive children, adolescents and young people in Zimbabwe.

For more information on this programme, see:

Video: Zvandiri - Peer to Peer Support with HIV Positive Adolescents (https://www.youtube.com/watch?v=zfLCl4_Up2s)


Section 5.4 YOUTH-LED ADVOCACY ON DSD

Section objective

The objective is to help and empower youth activists to advocate and demand DSD.

What do we have to do?

“As Youth Advocates, we have many tasks. We have to:

- Examine and understand the challenges and barriers so that we know what to address and what to ask our governments for.
- Do the research so that we know what our peers want and need.
- Spread awareness within our communities about what is available and what we can ask for.
- Find ways to raise community demand – so that adolescents and young people are gathering and raising their voice and asking for what they need.”

YPLHIV are an essential part of leading advocacy around improved HIV-related services that meet our diverse and specific needs. Youth activists are working within communities, inside clinical facilities and outside in different spaces as advocates, facilitators and peer educators. Our work includes going door to door within communities to speak to young people about the services that our local facilities are offering, hosting meetings, handling referrals within clinics, providing counselling and support at adolescent groups and meetings and following up with peers to make sure that they are not lost to follow up.

“At the facility, we do one-on-one adherence counselling and provide support, helping young people address their obstacles. We do home visits to see what support they have at home. And we do peer-to-peer engagement. My main work, though, is helping young people and service providers have a dialogue, creating links between them. This is an important part of helping adolescents access DSD services. One of the other ways we help them access DSD is home visits, where we are able to tell young people about the diverse services that are available in their facilities and in their community. We are also able to provide some of these services. So, if they cannot reach the facility, they know that a peer supporter is close by and can be reached for counselling and support.”

(Phakamani, Youth Champion, Zimbabwe)

So how do we do advocacy?

“Chapter 4 of this toolkit has information on how to conduct advocacy and looks at issues like how to make an advocacy plan, what is an advocacy cycle, suggested questions for baseline research on DSD and other useful information. However, some of the basics from the chapter are adapted in the picture below.”

1. Gather evidence
   Find out all you can about DSD in your area and about what your peers want and need.

2. Decide on strategy
   What should we focus on? Raising awareness? Linkages with the community? Strengthening peer engagement? Why?

3. Make a plan!
   How will we carry out the advocacy? To whom? With what resources? What tools? Social media? Outreach campaigns?

4. Implement and monitor
   What have we done? How is it going?

5. Evaluate
   Is the plan working? Are YPLHIV becoming more aware of DSD? What questions can we ask to measure if it’s working?”
"I advocate on differentiated care amongst YPLHIV. I do demand creation sessions online and in and out of schools and these are effective because YPLHIV are getting the information they need about all the types of services (ARV collection, SRH, nutrition, economic) that they can access in one place."
(Gladwell, Youth Champion, Kenya)

How can we measure the impact of our advocacy?

It's important for us to examine whether what we are doing is working. Below is a simple checklist of questions that we can use to help us decide if the goal of increasing demand for and provision of DSD services is being met.

Some questions you can ask:

- Do more YPLHIV in your area know what DSD is?
- Do more local community health workers know what DSD is?
- Are options available for YPLHIV, for example, fast track at the clinic/community group closer to home?
- Can YPLHIV get ART refills for longer periods of time, at least two months?
- Can YPLHIV get ART refills from a community-based group, from trained peers?
- If peer-facilitated community groups exist, are more people approaching and accessing the services?
- During clinical checks, do the nurses and doctors show increased understanding of young people's needs and issues?
- Can YPLHIV go for a check-up and ART refills and also access other relevant services at the same time and place?

"Depending on the tools and tactics that you are using within your advocacy, you might measure things differently. For example, if you are using social media to spread awareness, you might be looking at how many people are looking at and liking your informative posts. However, simple questions like the ones above or any that make sense in your community context are useful to see if practical changes are happening on the ground."

What do we need?

"It’s not easy being a Youth Advocate and getting our voices heard where the decisions are being made - at national and regional levels, and also within our local communities. Read on to see what Youth Advocates in different countries have to say about what they need to support their work as they advocate for DSD."

The following are some important areas of support:

- Technical: support on knowledge around issues, guidelines and protocols, participation in forums with diverse stakeholders, training on skills and management
- Financial: support of running of campaigns, gathering supporters, transport, materials for campaigning
- Emotional: including assistance with resilience, trauma and security threats when operating in unstable political environments
- Political: supporting linkages between national and district-level implementation.

Useful resources to read and watch

Chapter 4 of the DSD Toolkit, What Works for Me!
IAS, The Young HIV Advocates’ Cookbook
(https://www.iasociety.org/Web/WebContent/File/IAS_Yong_HIV_Advocates_Cookbook.pdf)
IAS Youth Voices videos
(https://www.iasociety.org/HIV-Programmes/Campaigns/Youth-Voices/Multimedia)
Module 7 of the ITPC ACT 2.0 Advocacy for Community Treatment
Community Toolbox, Developing a Plan for Advocacy
"Youth advocacy is not known. We need buy-in from the Department of Health (DOH). This is the support we need, recognition so that the health centres know what we are doing and then allowing us to do our work with adolescents in the facilities. I have to tell the clinic staff, ‘This is what I am supposed to do.’ It’s much easier for us when the DOH buys in because they are the ones who are heard.”
(Tumie, Youth Champion, South Africa)

"We need more financial resources so that we can meet with key stakeholders, like community healthcare workers on the ground, and run big campaigns to raise awareness in rural areas. Policies about DSD are on the books, but there is a gap between national policy and things happening at the local community level. The message doesn’t go to those people who can actually make the changes.”
(Tanaka, Youth Champion, Malawi)

"When you’re an activist or an advocate, there are times when things are just not working out. But we still keep on going and keep on trying. You need to keep going to help other young people. But that’s where emotion comes in - we need some ways to get support. You can be the shepherd, but the shepherd also needs help.”
(Kelvin, Youth Advocate, Zimbabwe)

"The important thing to remember is that, as YPLHIV, we understand the needs of our peers better than anyone else. If we aren’t involved, programmes and services won’t meet our needs. If we stay informed and continue to demand services and information that works for our community, our peers will be encouraged to do the same. Don’t stop learning, don’t stop talking and don’t stop demanding what works for you.”