WHAT WORKS FOR US

SECTION 5.

YOUTH-LED ADVOCACY ON DSD

Section acronyms

ART	Antiretroviral therapy
ARV	Antiretroviral
CIPHER	Collaborative Initiative for Paediatric HIV Education and Research
DSD	Differentiated service delivery
HIV	Human immunodeficiency virus
IAS	International AIDS Society
ITPC	International Treatment Preparedness Coalition
MSM	Men who have sex with men
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization
IAS	International AIDS Society
YPLHIV	Young people living with HIV
PWID	People who inject drugs
RVLT	Routine viral load testing
SRHR	Sexual and reproductive health and rights
TG	Transgender
WHO	World Health Organization
YKP	Young people from key populations

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."[1]

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.

What do the numbers tell us? (UNAIDS, 2016)

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.

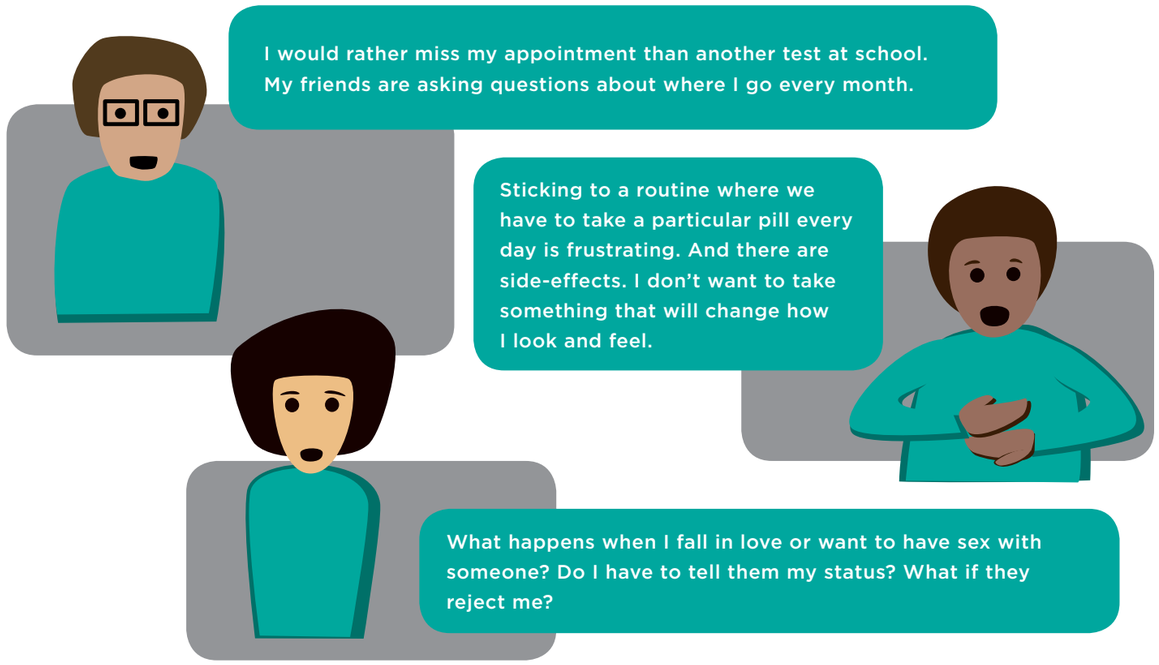
"Youth Bulge": In 2050, it is estimated that there will be 450 million young people, due in large part to the "youth bulge". On a positive note, this implies more children growing up and surviving into adolescence, but on the other hand, it also means more young people are at risk of HIV.

"So, looking at the numbers, we need to ask, why is the rate of new infections among young people (aged 10-24) still so high and what is getting in the way of our needs being met? Keep reading to understand more and to see what we can do about it. A reminder, whilst some guidance in this chapter is specifically for adolescents ((10-19 years old), most of the chapter is relevant for the overlapping age group of YPLHIV."

What are our needs?

Adolescence is a transitionary 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.

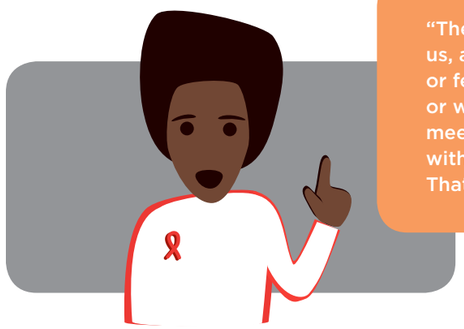
Throughout adolescence and beyond, as YPLHIV, we face additional challenges that include accessing treatment and care, following a regime of lifelong medication, dealing with issues around disclosure to family, peers and potential sexual partners, worrying about the future and facing stigma and discrimination.[2]



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.[3] 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.

[2] Paediatric Adolescent Treatment Africa (PATA). *One-Stop Adolescent Shop Delivering Adolescent-Friendly Sexual and Reproductive Health, HIV And TB Services*. Promising Practices Series. December 2015.
[3] Karaman, Neslihan Güney and Cok, Figen. *Adolescent risk-taking: comparison between adolescents' and adults' opinion. Paideia (Ribeirão Preto)* [online]. 2007, vol.17.



"The stage we are at affects how we interact with the world around us, and health services are part of this world. When we face stigma or feel misunderstood or judged by services or have to miss school or wait all day, we don't want to go back. We all want services that meet our diverse and changing needs – and that don't group us in with adults or children. So how can these needs be met? That's where differentiated service delivery, or DSD, comes in."

So, what is differentiated service delivery?

Differentiated service delivery (DSD) is a way of simplifying and adapting delivery of HIV services in a way that works for each person.

DSD works across the spectrum of HIV-related care and treatment. This means that the approach works for:

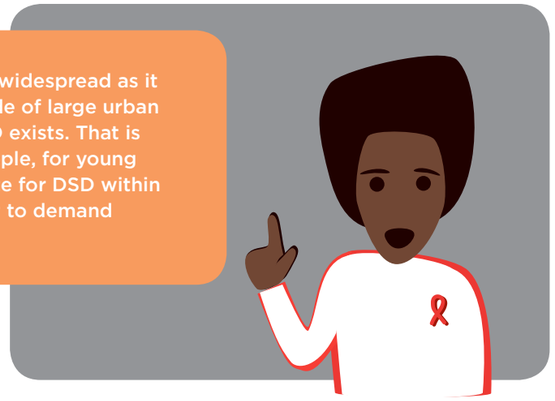
- The testing and diagnosis phase (having the test and finding out our status)
- The treatment phase (starting treatment and taking our meds regularly)
- The retention phase (staying on our treatment and keeping the virus suppressed).

Because DSD is not based on an idea of "one size fits all", it can fill some of the gaps that exist in current programmes. It can also lessen the load on the health system because it allows for new and more efficient ways of doing things. For example, if trained peers can deliver ART, it leaves clinical staff free to deal with more serious cases – that's just one example.

ADOLESCENTS are a unique group with needs different from those of children and adults.
DIFFERENTIATED SERVICE DELIVERY (DSD) is a way of providing support and services that put their needs, expectations and preferences first.
DSD MODELS have the capacity to deliver HIV services in a way that meets the unique emotional, social and medical needs of YPLHIV.
THE WORLD HEALTH ORGANIZATION (WHO) says a large body of evidence is now showing that differentiated ART delivery provides a significant opportunity to improve treatment.

"DSD really works for young people. It makes it much easier for them to access services, much more quickly and from people who actually understand them and know what they are going through."
(Tshepo, Youth advocate, South Africa)

"Unfortunately, DSD programming for YPLHIV is still not as widespread as it should be. There are big gaps in its reach – especially outside of large urban areas – and there is a continuing lack of awareness that DSD exists. That is one reason why this chapter has been written by young people, for young people, in the hope that it will inspire more of us to advocate for DSD within our communities and encourage young people from all over to demand services that work for them."



Useful resources to read and watch

UNAIDS. *Global HIV & AIDS statistics — 2018 fact sheet* (http://www.unaids.org/en/resources/fact-sheet)

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

International HIV/AIDS Alliance. *Adolescent HIV programming. Ready- Here we come!* (https://www.childrenandaids.org/sites/default/files/2017-10/Adolescent%20HIV%20Programming_1.pdf)

Section 5.2 WHAT DOES DSD LOOK LIKE FOR YOUNG PEOPLE LIVING WITH HIV?

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?

"Section 3.4 of this DSD toolkit (on page 36) talks about the building blocks (Who, Where, When, What) of differentiated ART delivery. WHO has made some additional suggestions on how the building blocks should look specifically for adolescents (ages 10-19). This is shown in the figure below."[4]

[4] International AIDS Society, United Nations Children's Fund and World Health Organization. *Providing Differentiated Delivery to Children and Adolescents.*

What WHO says

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.

Where

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

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.

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]

What young people say

When

If we are stable and on treatment, we want to see clinicians less often, like every 6 months.

If we have just been diagnosed or are experiencing clinical complications, we prefer more frequent clinical monitoring and peer support.

We want operating hours outside of school time.

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 accidentially.

Who

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

We appreciate services from peers with the same status as us. This is more comfortable for us than working with HIV-negative peers.

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.

[5] International Aids Society Policy Brief Series: *Young Lives, New Solutions.*

"We are doing research within the facilities and seeing that DSD works with diverse groups of young people, but we need to have more consultations with vulnerable groups of adolescents to understand the different priorities that they have.
(Source: Research undertaken by youth champions in Malawi, Zimbabwe, South Africa, Kenya and Tanzania. Cited in International Aids Society Policy Brief Series: *Young Lives, New Solutions*)

"Below is an example of how DSD works in practice. In Section 3.3 (page 28) of the toolkit, we described the four main models of DSD. Below is an example of how one of these models works for young people."

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)***

Who can benefit from DSD models?

According to WHO, DSD models are suggested for adolescents who are "clinically stable", which means those:[6]

- 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.**

"So, what about young people who are from key populations (YKP)?

Young people from key populations include:[7]

- 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.[8]

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.

[6] World Health Organization (WHO). *Key considerations for differentiated antiretroviral therapy delivery for specific populations: children, adolescents, pregnant and breastfeeding women and key populations.* 2017.
[7] Asia Pacific IATT on Young Key Populations (https://iatt-ykp.org/about-young-key-populations/).
[8] WHO: *Adolescent HIV Testing, Counselling and Care: Key Populations*. (http://apps.who.int/adolescent/hiv-testing-treatment/page/key_populations).

WHAT DO YOUNG PEOPLE FROM KEY POPULATIONS NEED?[9]	CAN DSD HELP?	HOW?
Integrated HIV and SRHR services, as well as those that focus on specific social, emotional, physical and legal needs faced by specific groups	Yes	A DSD approach can involve adding services for YKP to existing youth-friendly services.
Prioritizing building of trust with young stigmatized groups	Yes	Reach out through peers, including those from key populations themselves, who can approach marginalized groups with user-friendly information.
Community-based services using peer outreach and support	Yes	Reach out through peers who can accompany adolescents from key populations to access services delivered in "hotspots" where specific groups gather or work.
Easy access and safe impartial settings	Yes	Delivery through existing key population-focused community-based organizations.
Use of social media to promote services	Yes	Use apps and sites that YKP can access confidentially to get information and treatment.

"There are examples of how some of the strategies from the table above are being implemented, such as this one from Asia."

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.[10]

- 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.

[9] Ibid.
[10] WHO. Serving the needs of key populations: Case examples of innovation and good practice in HIV prevention, diagnosis, treatment and care. 2017 (https://samumsf.org/sites/default/files/2018-02/case_examples_key_populations_WHO.pdf).

Useful resources to read and watch

Section 3.3 of DSD toolkit *What Works for Me*

International HIV/AIDS Alliance. *Link Up: Key resources* – SRHR, HIV and young people (https://www.aidsalliance.org/resources/835-link-up-key-resources)

Video: *Be Healthy – Know your viral load* (https://www.youtube.com/watch?v=0VR72_lPyGo)

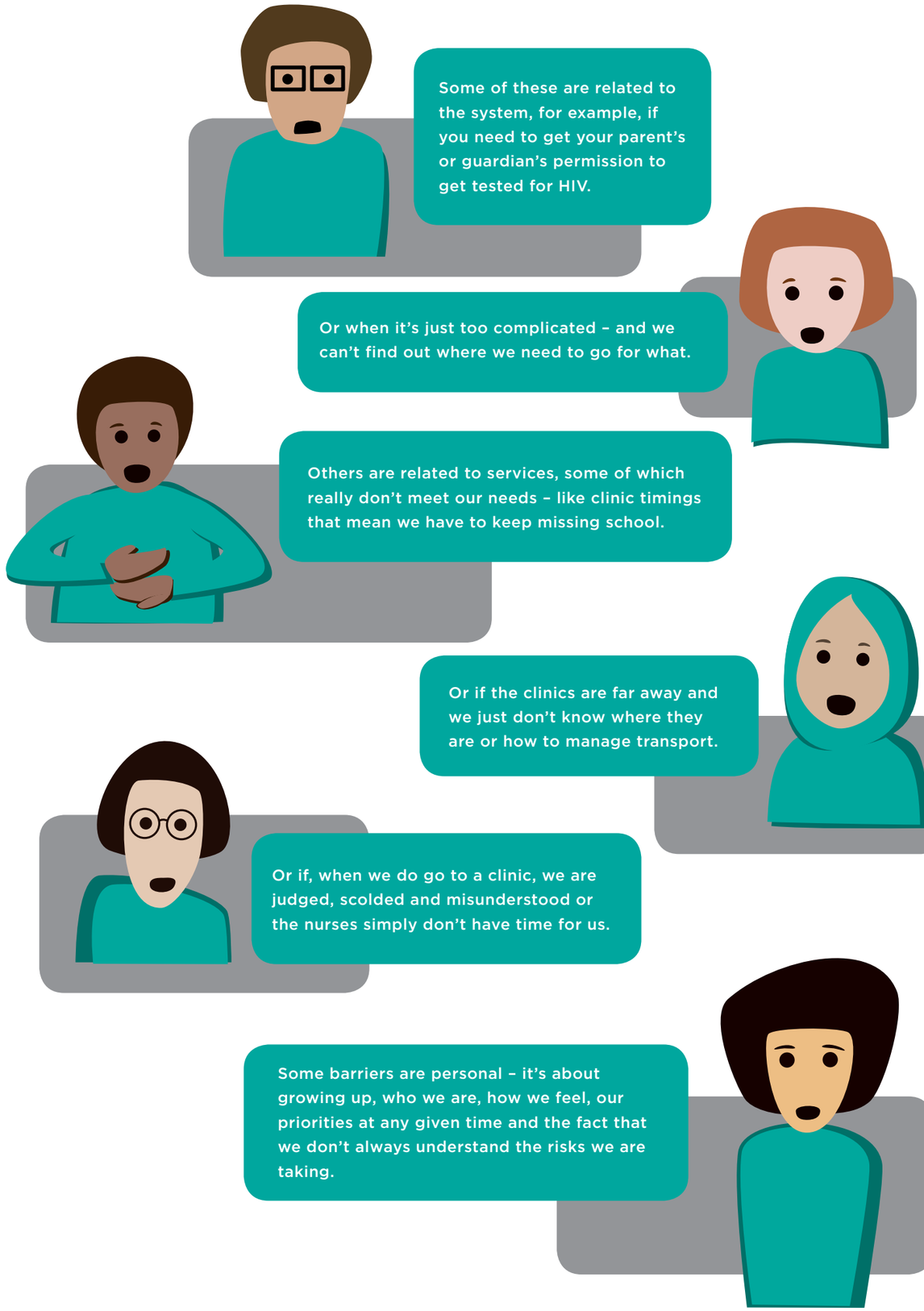
Video: IAS Youth Voices: *What is Differentiated Care?* (https://www.iasociety.org/HIV-Programmes/Campaigns/Youth-Voices/Multimedia)

Section 5.3 OVERCOMING BARRIERS: IMPLEMENTING DSD MODELS FOR ADOLESCENTS AND YOUNG PEOPLE

Section objective

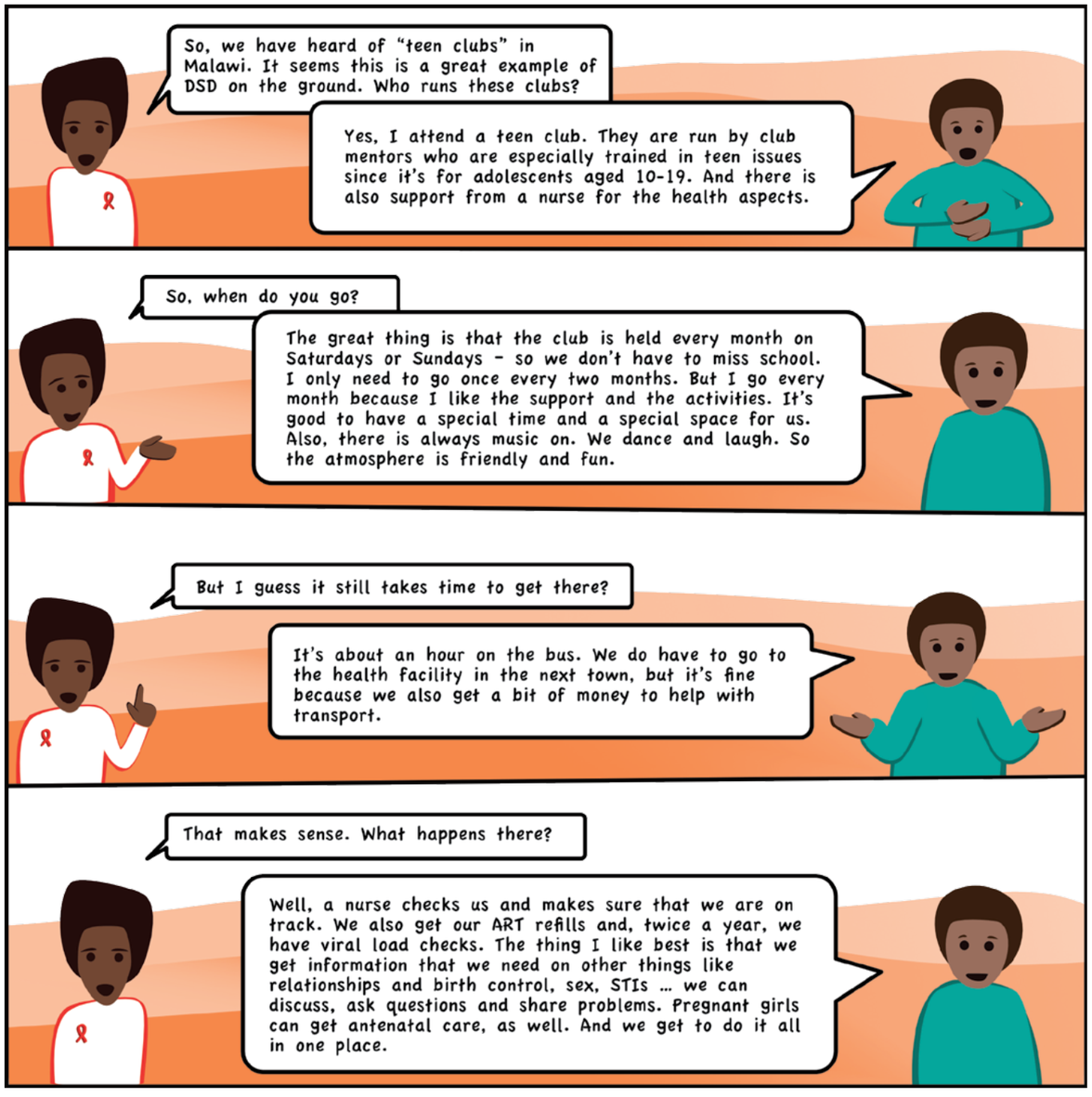
The objective is to highlight barriers to accessing HIV services and to effective DSD implementation, as well as examples of how these difficulties are being overcome by young people.

What barriers do we face in accessing HIV services?



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."



Useful resources to read and watch

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

Namusoke from Kampala. DSD for Adolescents **https://www.youtube.com/watch?v=gOVBbHb7_8s**

https://www.msh.org/resources/teen-clubs-help-retain-adolescents-in-hiv-care-and-treatment

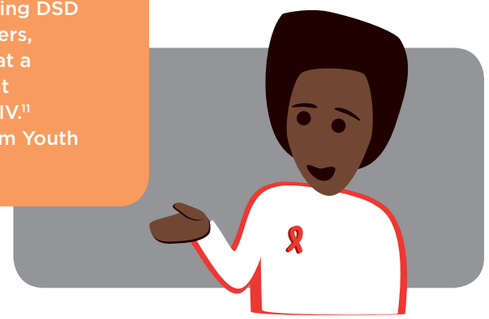
A DSD model for young people must include:

- 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.[11] Below are some ideas of how to overcome these barriers from Youth Advocates working in different countries."[12]



[11] https://cquin.icap.columbia.edu/wp-content/uploads/2018/02/ALHIV-Meeting-Report_Final.pdf.
[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=zlfCl4_Up2s)

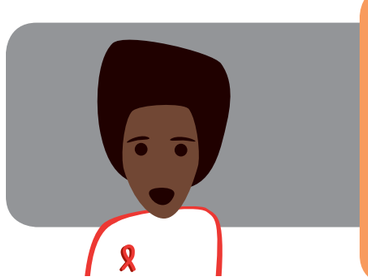
International HIV/AIDS Alliance: Supporting children, adolescents and young people living with HIV to start and stay on HIV treatment – Zvandiri Case Study (https://www.aidsalliance.org/resources/1022-supporting-children-adolescents-and-young-people-living-with-hiv-to-start-and-stay-on-hiv-treatment)

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:

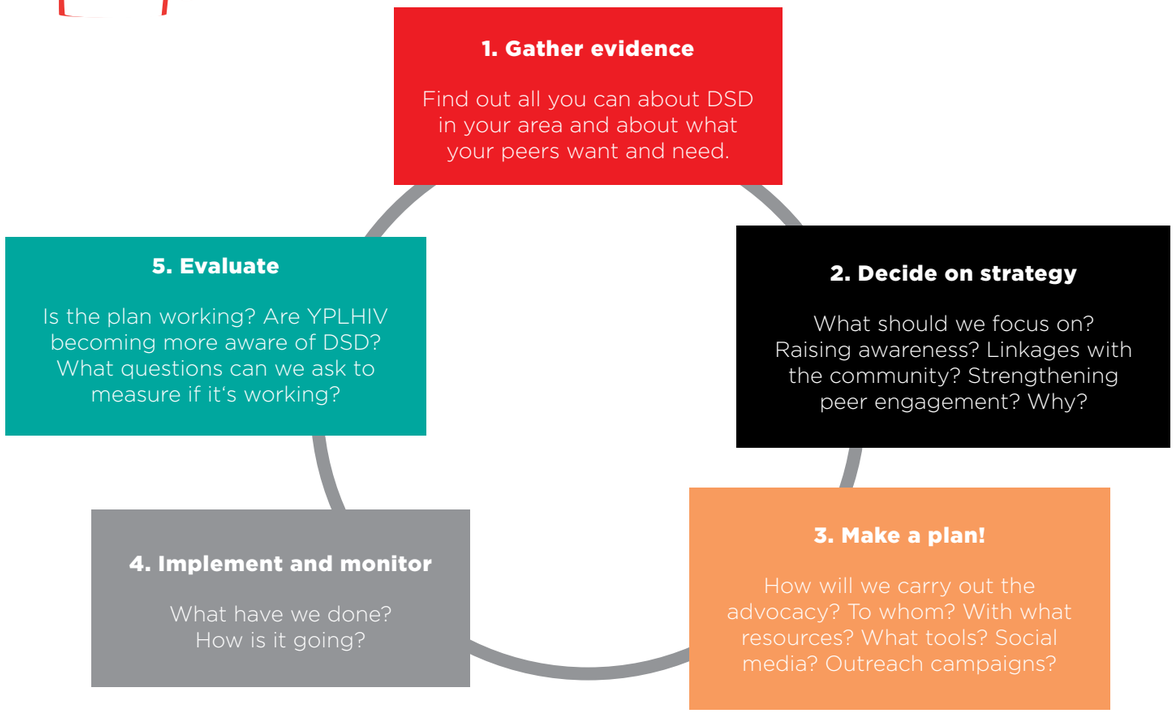
- **Examine and understand the challenges and barriers so that we know what to address and what to ask our governments for.**
- **Do the research so that we know what our peers want and need.**
- **Spread awareness within our communities about what is available and what we can ask for.**
- **Find ways 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)

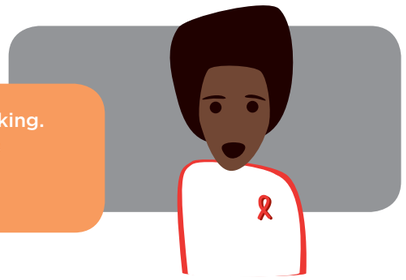
So how do we do advocacy?

"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."



"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)

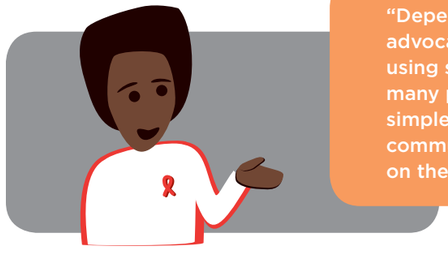
How can we measure the impact of our advocacy?



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."

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_Young_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
(http://itpcglobal.org/wp-content/uploads/2015/02/ACT-Toolkit-2.0.pdf)

Community Toolbox. *Developing a Plan for Advocacy*
(http://ctb.ku.edu/en/table-of-contents/advocacy/advocacy-principles/advocacy-plan/main)

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.

"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 still 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."


ARASA
AIDS & Rights
Alliance
for Southern Africa
ITPC
INTERNATIONAL TREATMENT
PREPAREDNESS COALITION