Giving young people the services they need

Welcome to the third edition of the READY newsletter! We are talking about service delivery: how to provide quality health services that we want and need as adolescents and young people living with and affected by HIV. Adolescents and young people are diverse, so new approaches are required to meet our different needs and expectations.

What makes a good healthcare provider?

But what makes a good healthcare provider? I think it’s someone who loves their work and focuses on the young person’s needs. They must provide respectful care, and be supportive and responsible. Strong communication skills are essential: service providers should be able to express themselves clearly. A good provider can see the challenges a young person faces and listen to them without judgment.

What young people want: enhancing quality and accountability

As young people living with HIV, we know what it’s like to go to a clinic for the first time, afraid of what the doctor might say. We know what it’s like to go for a routine appointment every month to collect our antiretroviral therapy and talk to a counsellor, nurse or doctor. This experience can be great, especially if we have a good relationship with our healthcare provider – we might feel welcome, the service might be quick, and the provider might ask, “How’s life?”

But it can also go badly, if we’re feeling uncomfortable, guilty or ashamed or have to wait for hours in a dirty health facility. For girls and young women living with HIV who are pregnant, the experience can be mixed. Their doctors might congratulate them, smile and tell them everything is going to be okay. Or they might point their finger and say, “Why have you been having sex?”, “Why are you in this situation?”

Making differentiated service delivery work for adolescents

Adolescents lead full, active lives that aren’t geared towards accessing health services. This is also true for adolescents living with HIV. HIV doesn’t define them, but it does bring added complexities.

Meeting adolescents where they are – in all their diversity – means breaking down barriers to their engagement in care and taking services to them. It means giving them choices and the chance to make decisions about their healthcare.

Differentiated service delivery (DSD) can ensure that all adolescents living with HIV get support, including psycho-social support, and services that take their needs into account. But for DSD to work for adolescents, community and peer interventions need investment and stronger connections must be forged between the health facility and the community. Matteo Cassolato, Senior Advisor: HIV Technical (Treatment), International HIV/AIDS Alliance, said, “By simplifying procedures to obtain antiretroviral therapy, DSD can greatly improve the life of adolescents and young people. However, because needs for support and care change rapidly during adolescence, DSD models must be flexible and linked to support systems that allow for regular monitoring of adolescents’ and young people’s engagement.”

Confidentially speaking

Dr Catarina Mboa is a clinical and counselling psychologist. She’s currently supporting READY+ providers in Mozambique. We asked her about a key issue: confidentiality.

How do you ensure confidentiality when working with adolescents? First of all, I try to set a good example. As providers, when we discuss cases, I never mention clients’ names or describe them in a way that could identify them. We deal with confidentiality every day. We insist on it because our clients are so young, and they count on us.

What are the consequences of a provider accidentally disclosing an adolescent’s HIV status? An adolescent may not know their own status, and if they find out by accident, they could react very badly. Stigma and discrimination are still a huge problem in society. Adolescents need to be able to trust peer supporters and providers. Accidental disclosure is a breach of that trust.

What tools are available for healthcare providers to support confidentiality? In Mozambique, we have a psychosocial policy that covers confidentiality. We’ve also been working with the Ministry of Health on a tool around disclosure.

Useful resources and tools for service providers

- A video by the Adolescent HIV Treatment Coalition, in which Jane from South Africa shares some of the challenges she faces as an adolescent living with HIV, and explains how DSD helps her. See https://bit.ly/2vVIUJF
- “Ending AIDS by 2030: the importance of an interlinked approach and meaningful youth leadership.” See https://bit.ly/2E23EK0
Ideal service package for young people

Dr Fileaku Ngakongwa, PATA Technical Assistant, provides technical support to healthcare providers in the READY+ programme in Tanzania

What does service improvement entail? It involves working with healthcare providers, and improving infrastructure and accessibility. The provider must know how to deliver quality services; and sufficient resources, medication, equipment, space and staff must be available. The service should be accessible and advertised in the community.

In READY+, we want to see more one-stop-shops. So, as an adolescent, when I go to a health facility, I should receive all the services I need. I shouldn’t have to go from place to place. That’s how you lose clients, especially if they’ve travelled far.

As a provider, what kind of feedback do you value? I like hearing directly from young people how they feel about the service. I want to see how they improve clinically. If they look healthy, that means I’ve treated them well, and if they keep coming back, that means they’re happy with the service.

Do you think young people find it easy to talk to you? Yes, I think I’m a friendly clinician. I’m proud to say I can help people to open up. Sometimes I can see that new clients feel uncomfortable, but then we build a rapport.

What’s an ideal service package for adolescents and young people living with and most affected by HIV? An ideal package consists of sexual and reproductive health services, and HIV prevention, treatment and care. (See the READY Good Practice Guide: Adolescent HIV Programming [https://bit.ly/292qD9])

Providing psychological care to adolescents and young people living with HIV is vital. If mental health problems aren’t spotted early on, adolescents might not take their medication, resulting in a high viral load and poor health.

What should a very basic package include? HIV testing and counselling, contraception, HIV care and treatment, and psychosocial support.

Access to services for young people from key populations

BY JULIAN KEREGGOSIAN, CHAIR, BOARD, Y+.

Young people from key populations need to be free of stigma and discrimination to access HIV testing services. For young people who acquired HIV during adolescence, the stigma is even worse because people blame you. In my early 20s, when I went to hospital for my CD4 count and viral load tests, the nurse said, “You’re positive at this age?” He was comparing me to his children.

We need to use campaigns to reach out to young people from key populations: inform them about the services and go to them. In Lebanon, if a sex worker goes to a health facility and it’s clear that this person is or identifies as a sex worker or a young person who uses drugs, they will face stigma and discrimination. The NGOs which provide services for young people and key populations in Lebanon aren’t flexible or youth-friendly. Services need to adapt to young people’s needs, not vice versa.

In many countries, viral load tests are expensive and aren’t covered by insurance. In Lebanon, you have to pay about 300 dollars to take a CD4 and viral load test every six months. If you don’t do these tests, you aren’t given the treatment. Some NGOs are helping, but they can’t provide tests for everyone. This is a big issue as a lot of young positive people can’t access these services.

For technical guidance on HIV and young people, see [https://bit.ly/292qD9].

Tech watch: mobile apps

BY LOCA ANDREWS, ADVISOR, PROGRAMMENs AND COMMUNICATIONS, INTERNATIONAL HIV/AIDS ALLIANCE, AND JOE MILLER, SENIOR ACCOUNT MANAGER, MCC SAATCHI

Technology is everywhere. From remote villages to built-up cities, young people are using their phones to access information at the click of a button or swipe of a screen. The widespread use of low-data usage mobile applications, such as WhatsApp, is transforming the way young people find and use information. Social networks can provide one-to-one health information and referrals to services in a safe and confidential forum, which is vital when working with people from key populations.

The READY movement is seizing this opportunity to empower young people living with and affected by HIV by pioneering youth-friendly, technology-based health solutions. Two exciting initiatives will be launched soon: a READY+ mobile app for CATS and iREADY – an innovative programme in Burundi and Mozambique – in partnership with SPIDER.

The READY+ app, developed with young people living with HIV in Swaziland and Mozambique, aims to help young people in those countries adhere to their medication. It’s designed to spark conversations between CATS and the young people they mentor.

This is how the app works: young people create their own character who plays games that prompt young people to talk about their medication – how easy or hard it’s been to take that week, and any barriers they’ve encountered. M&C Saatchi led workshops to make sure the app was driven by what young people wanted: “nothing for us, without us.” We will launch the app in May 2018, and train CATS, implementing partners and healthcare providers how to use it. Watch this space!

Support the READY movement by following these events and posting to Facebook and Twitter #WeAreREADY. Visit www.aidsalliance.org/ready and follow us at fb.me/READYMovement.

9 May, new Guttmacher-Lancet Commission report on sexual and reproductive health and rights
20 May, International AIDS Candlelight Memorial
21~26 May, 71st World Health Assembly
11 July, World Population Day
30 July, International Day of Friendship
12 August, International Youth Day
11 October, International Day of the Girl

Dhilipola – a CATS in Switzerland visits a client at home.

Thank you! Y+ and the International HIV/AIDS Alliance would like to thank our current READY partners: Africaid, AIDS Legal Network (ALN), AddAdon, Alliance Burundaise contre le SIDA (ABAR), Community Health Alliance Uganda (CHA), Community Organisation of Youth against HIV Uganda (COYHA), Coordinating Assembly of Non-governmental Organisations (CANGO), Global Network of People Living with HIV (GNP+), Marie Stopes International, Macedonia Aid Network, McC Saatchi World Services, Network of Young People living with HIV/AIDS in Tanzania (NYP+), Nakaesita Initiative for Adult Education and Development (NIAD), Organisation for Social Services, Health and Development (OSSHD), PATA, Peer to Peer Uganda (PEERU), Regional Psychosocial Support Initiative (REPSI), REJUSIDA Mozambique, Réseau des Jeunes vivant avec le VIH au Burundi (RNJ+), Stop AIDS Alliance, Swaziland Network of Young Positives (SNYP+), Tanzania Council for Social Development (TACOSODE), Ugandan Network of Young People Living with HIV (UNYAPA), Zimbabwe Young Positives (ZY+).

We would like to thank the Dutch Ministry of Foreign Affairs and the Swedish International Development Cooperation Agency for their support for READY.

The Sustainable Development Goals (SDGs) reflect a broad, inclusive agenda. Could a shift to this wider approach benefit adolescent HIV care and improve the survival of adolescents living with HIV? And what’s the role of young people in shaping their own health services, and tracking the SDGs? Two new studies are worth a look:

1. A study by researchers from Oxford University, University of Cape Town and the International HIV/AIDS Alliance found that the broader vision of the SDGs – such as eliminating household poverty, protection from violence, social protection and employment – may help end AIDS and reduce AIDS-related deaths and illness. The study shows that HIV care for adolescents cannot be achieved through bio-medical health services alone. See [https://onlinelibrary.wiley.com/doi/pdf/10.1002/jia2.25056]

2. In an innovative study, marginalised adolescents living with HIV in South Africa designed and drew an ideal health facility: their ‘dream clinic’. Findings showed that participants viewed healthcare as broader than access to medicines or clinical care. The study indicates ways to boost the involvement of adolescents living with HIV in policy and programming, and implementing and monitoring the SDGs. See [https://onlinelibrary.wiley.com/doi/pdf/10.1002/jia2.25057]

Follow the movement! Dates for the diary

© Sydelle Willow Smith for the Alliance

© Peter Caton for READY

© Peter Caton for READY

© Peter Caton for READY