

Enabling disclosure

Young people's experiences of sharing their HIV status

It's time each of us knew the full facts. When everyone in society has accurate information we can have honest and open conversations about HIV.

We urgently need new initiatives to combat stigma. If the myths and false facts surrounding HIV were rejected we could talk about living with HIV, free from fear.

The safer young people feel about sharing their HIV status the easier they find it to stay on treatment. And we can move a significant step closer to a world free from AIDS.



READY to Talk

BRIEFING

About READY

READY is a movement of youth-led and youth-serving organisations implementing initiatives designed to build resilient and empowered adolescents and young people. We know this is vital because AIDS is the second largest cause of death of adolescents globally, and the first in Africa.

Young people all over the world are joining the READY movement to demand their right to a healthy life whatever their circumstances, sexual orientation, gender identity or expression. Young people helped create the READY movement and they remain at its core.

The READY movement is led by the Global Network of Young People Living with HIV (Y+), with support from Frontline AIDS and its partners.

READY + is a programme working with, and for, adolescents and young people living with HIV in four southern African countries. At the beginning of the programme, young leaders went into their communities and spoke to their peers to understand the experiences, perspectives and needs of adolescents and young people living with HIV, as well as the communities around them. The key findings from these conversations are shared through three briefing papers. They focus on treatment adherence, sexual and reproductive health and, in this brief, disclosure.

READY Movement

www.yplusnetwork.org/ready-movement/



fb.me/READYMovement



@READY_Movement



@readymovement

Front cover photos (from left to right):

Peer educators from Tanzania (© Peter Caton), Ethiopia (© Benjamin Chesterton\duckrabbit\Frontline AIDS) and Uganda (© Gemma Taylor for Frontline AIDS).

Photos are used for illustrative purposes. They do not imply the health status or behaviour of the people in the photo.

Acknowledgments

This brief is derived from a community documentation process conducted by READY+ partners during 2017 and 2018. We would like to thank all the young people who conducted the interviews and each focus group participant.

We would also like to thank Audrey Nosenga, Cedric Nininahazwe and Precious Shongwe, the READY+ youth leaders who shared their perspectives on the data from the focus groups.

Coordinated by Georgina Caswell, Chengetai Dziwa and Linda Whitby (Frontline AIDS)

Data analysis: Rebekah Webb

Author: Laura Davies

Technical assistance: Cecilia Kihara, Luisa Orza, Matteo Cassolato (Frontline AIDS) and Tinashe G Rufurwadzo, (Global Network of Young People Living with HIV [Y+ Network])

Edited by Hester Phillips

Information contained in this publication may be freely reproduced, published or otherwise used without permission from Frontline AIDS. However, Frontline AIDS requests that it be cited as the source of the information.

Design: Garry Robson

Published: September 2019

© Frontline AIDS 2019

About Frontline AIDS

Frontline AIDS wants a future free from AIDS for everyone, everywhere. Around the world, millions of people are denied HIV prevention, testing, treatment and care simply because of who they are and where they live. As a result, 1.7 million people were infected with HIV in 2018 and 770,000 died of AIDS-related illness. Together with partners on the frontline, we work to break down the social, political and legal barriers that marginalised people face, and innovate to create a future free from AIDS.

Frontline AIDS

91-101 Davigdor Road
Hove, East Sussex
BN3 1RE United Kingdom
Tel: +44 1273 718 900
Fax: +44 1273 718 901
Email: info@frontlineaids.org
Registered charity number 1038860
www.frontlineaids.org

Research methodology

The content of this issue brief derives from a community documentation process, conducted by READY+ partners during 2017 and 2018, and a post-analysis reflection on the core themes, conducted in July 2019 with READY+ youth focal points from Y+.

A total of 36 focus groups were held in nine predominantly urban locations in eSwatini, Mozambique and Zimbabwe. Half of the focus groups were conducted among young people in their diversity, including adolescents aged 10-14, young LGBT people, young sex workers aged 18-25, and community adherence treatment supporters (CATS). The remaining focus groups were conducted among healthcare workers, parents and caregivers. A total of 300 people, many of whom are living with HIV, took part.

Two capacity-building workshops were held in each country. These trained a total of 116 young people aged 18-25 (mainly young women) in research methods, focus group facilitation and data collection. Each focus group was organised and facilitated by young people trained during these workshops.



◀ To disclose – or not?
© Frontline AIDS.

Disclosure and young people

For young people living with HIV, talking to others about their HIV status is complicated. Unlike most other illness and health conditions, there is considerable shame and fear surrounding HIV. Misinformation around HIV is common and people living with HIV face high levels of stigma and discrimination when their HIV status is known. Despite this, laws, policies and practices often put pressure on people to disclose their HIV status.

At all times we must respect the rights and wishes of young people living with HIV, empowering them to take their own decisions about when and how to share their HIV status with others. Young people who disclose their HIV status find it can bring benefits. When they feel able to talk about their HIV status they can seek support, making it easier to take treatment, stay healthy and keep their viral load low. If we want a world free from AIDS we must create communities where people are well informed and everyone living with HIV feels safe to talk about their status.

“Disclosing to a few people that I know will not talk about it to anyone; it is better than disclosing to everyone. Because, if you do that to everyone, some might call you names and in that process you get hurt.”

Focus group participant



Community adolescent treatment supporters (CATS) are young people who work between the health facilities and homes of children, adolescents and young people living with HIV to improve outcomes across the HIV care cascade. © Sydelle Willow-Smith.

Young people's experiences of talking about their HIV status

Choosing when to talk about HIV

The young people in our focus groups wanted the freedom to choose who to talk to about their HIV status and how and when to talk to them. Yet their choices were limited by their fear of people's reactions and the stigma they may face.

They were more likely to talk to an adult than one of their peers: "It is easy to tell this to elder people because they understand." Many of them had shared their status with their parents: "I won't tell the entire family because some of the family members are gossipers; I will tell my parents, those are the only people." Some young people had spoken to other close family members: "It's a nice opportunity when I am debating with my grandma that I can disclose my HIV, telling her that I am HIV positive."

Most of the focus group participants wanted to talk to their close friends about their HIV status but were worried that their friends did not fully understand the facts about HIV so would start to treat them differently or abandon them: "Disclosing to a few people that I know will not talk about it to anyone; it is better than disclosing to everyone. Because, if you do that to everyone, some might call you names and in that process you get hurt."

Many of the young people in the focus groups had spoken to their teacher about their HIV status: "It's normal to talk to a teacher about HIV so you are supported more, and to not feel alone in school." It was important to them that the teacher respected their confidentiality and did not share their HIV status with other pupils. Many had been the subject of gossip, been laughed at or avoided altogether. One child said: "Because of HIV, they won't play with me."

Almost all the young people in the focus groups were keen to make sure their HIV status was not known in the wider community. They felt that people in their communities still misunderstood the basic facts about HIV and transmission: "People are not yet educated about HIV disease, so they don't really know what it is to be HIV positive." One parent explained why they were nervous about their child telling other people in the neighbourhood their HIV status: "The risk is that neighbours will not accept this disclosure and start discriminating against this child and even some friends will not be friends anymore."

“People are not yet educated about HIV disease, so they don't really know what it is to be HIV positive.”

Focus group participant

“The risk is that neighbours will not accept this disclosure and start discriminating against this child and even some friends will not be friends anymore.”

Focus group participant

Sources of support

Throughout the focus groups, young people, parents, carers and healthcare workers all spoke about the practical and emotional support available to young people who shared their HIV status. Many people described how much easier it was for a young person to look after their health and take their medication if they had support from people close to them. One healthworker explained: "When someone who is HIV positive comes here and hasn't disclosed to the parents, not the mother or father or anyone, it becomes difficult to give ARVS [antiretrovirals] or treatment because they end up hiding the ARVS." If a parent or other caregiver knows the young person's HIV status they can remind them to continue their treatment: "When the parents know about it, they actually help them to take the medication. Also they help whenever ... to help monitor the food."

One healthcare worker said: "Young people find it difficult to come here because they think when they go to hospital they will come across their parents or neighbours." Many young people chose to visit health clinics further away from their homes to avoid being seen; involving longer, more difficult journeys, often organised secretly. Those young people who were able to tell certain people their HIV status could get support to attend their healthcare appointments. When young people's parents knew about their HIV status they were able to remind them about their appointments and help arrange for them to attend. Some young people said it was easier to attend appointments when their teacher knew their HIV status, so they knew why they needed time off school. One parent echoed this: "[The teacher] will know what to tell others, 'in my classroom I have a child who is not feeling well so every month she has to go to the clinic for check-ups'"

Some young people described how they liked being able to confide in someone: "Once I disclosed to my negative friend and she accepted me for who I am, gave me advice and told me not to worry about this; it is not the end of the world, you can still build yourself to something else. So I was quite inspired." Another young person described how she had talked to a friend at school, who then revealed her own HIV positive status: "we comfort each other".

As well as gaining emotional support, some young people saw telling their friends about their HIV status as an opportunity to educate them: "I would feel free to disclose it to peers because this would be a great time to explain to them that HIV isn't only spread through sexual intercourse but it is also possible to be infected in other manners, like you can be born with it." Another young person described how their family had gradually learned more about HIV: "When we were eating I was given my own cup and my own plate ... but when they went to the clinic they were told that you cannot get HIV from sharing or eating with the same plate. So now it is good that they are understanding."

I would feel free to disclose it to peers because this would be a great time to explain to them that HIV isn't only spread through sexual intercourse but it is also possible to be infected in other manners, like you can be born with it.

Focus group participant



Making it easier to talk about HIV

Stigma lies at the heart of all the problems young people face when sharing their HIV status. If stigma was eliminated young people would be free to talk openly about HIV. The young people in the focus groups said they would find it easier to talk about their HIV status if their families, friends and communities had a better understanding of HIV. They described the myths and misconceptions around HIV that are so common in their communities and the stigma and discrimination that exist as a result. For example, over and over again young people spoke about people refusing to eat with them or share cutlery because they wrongly thought this could put them at risk of contracting HIV. “When you reveal or disclose your status people tend to distance themselves because they know you are HIV positive.”

The fear of HIV-related stigma made young people very cautious about who they chose to talk to about HIV. They only wanted to share their HIV status with people who they thought would respect their desire for confidentiality: “For my trusted friends I know I could tell them and they would keep it a secret.” Young people often chose one or two family members to talk to, who they felt able to trust: “She only talks to her parents, the father and mom, but the aunt she is more into gossiping, so she will tell the world.” This need for confidentiality impacts on young people’s healthcare decisions. They described being cautious about being seen anywhere where they might be identified as living with HIV, including health facilities and support groups. The more that young people feel able to trust those around them, the more likely they are to talk about their HIV status and access treatment and care.

The focus group discussions also revealed that young people know they can live long, healthy lives if they take HIV treatment: “I could disclose it; [if people] discriminate [against] me or not, I know that I will keep on alive. I know that I can even live longer than someone saying they are not HIV positive.” However, the benefits of treatment were much less widely known among their families and communities.



We need love and family support because, if outside home we are not supported, and in the family we are not supported, this brings us many problems in our mind, and [it is] the reason why we suicide ourselves and quit medication, and sometimes we run away from home.

Focus group participant



Young peer supporters are on the frontline of keeping other young people healthy. © Peter Caton.



If families have all the information they need to fully understand HIV they are better able to support a young family member who is living with the virus. In the focus groups, some young people explained that their families thought they should not waste limited resources on them as their life would be short. This meant they were denied opportunities; some were taken out of school or refused work and others were refused food. "We need love and family support because, if outside home we are not supported, and in the family we are not supported, this brings us many problems in our mind, and [it is] the reason why we suicide ourselves and quit medication, and sometimes we run away from home."

Talking about HIV in relationships

Repeatedly, young people spoke about the problems they faced talking about their HIV status to their sexual partners: "After disclosing to my partner my relationship broke down." In most cases, young people felt their relationship would not survive if they told their partner so they felt obliged to hide their HIV status. Many said their only option was to have relationships with other people who were also living with HIV: "We can no longer make choices in terms of lovers or boyfriends. Because of our situation we just have to choose the person that accepts you, you are not able to make a choice." But there were exceptions: "Personally, I think I can [disclose] ... if someone loves me, he knows I am HIV positive, he loves me for me, so I can do that." Another young person explained: "What I would do with my boyfriend is to see if he loves me or not. And then the second step is that I would invite him to the clinic to see our status and make an HIV test. Either he is HIV positive or not, but then I would disclose my status to him."



▲
Ntsiki and Sipho are peer supporters in Swaziland.
© Jenny Berg for Frontline AIDS.

Telling children and young people their status

The advice and the reality

The standard advice for parents and caregivers is to tell children of school age their HIV status, in stages dependent on their age and mental capacity.¹ At a practical and emotional level, some parents do not have the information and support they need to know how to begin the process of telling their child about their HIV status. If children are not told but discover their status later, they can struggle emotionally as they come to terms with the fact that someone they trusted had kept their status from them. One parent explained: "I think it is important that you tell so the child can know and accept. If you don't tell,

1. World Health Organization (2011) 'Guidelines on HIV disclosure counselling for children up to 12 years of age'. Available at www.who.int/hiv/pub/hiv_disclosure/en/

and when they find out when they are 16, they might be angry and not take the medication and not trust the parent because the parent did not tell the truth.”

Some parents and carers said they were worried about frightening or upsetting their children if they told them their HIV status: “Some might withdraw from engaging in social activities, blocking themselves in their house, not wanting to associate with others”. The parents’ and caregivers’ choices were also limited by the attitudes around them. Some spoke about their fear of talking to their child about their HIV status in case others in the community found out and their child was then stigmatised or discriminated against.

Wanting to tell children they are HIV positive

Many of the carers and parents in the focus groups said they found it difficult telling their child they were HIV positive but still believed it was best for them to know so they could get the support they needed. One grandparent explained how her grandson visited the health facility each month for a support group “so, he can understand what he has, and he is only 13 years old and still comes to support group, but now he knows what he has. This is what helps me, because for me to tell my grandson that he has HIV is very difficult.”

Children living with HIV can only make informed decisions about their lives if they are aware of their HIV status. As they get older and have more control over their own healthcare, they are unlikely to prioritise their treatment if they do not know why they are taking medication. One parent described why they wanted to talk to their child about their HIV status: “I feel like it is important to disclose to the child ... so that they are fully aware why they are taking the meds, firstly, and secondly, by telling them earlier we are ensuring acceptance of their status. And then they know that ‘this is who I am and these tablets are helping me to survive’ ... I would have told the child that this medication is for life and no one should tell you to stop these meds except the doctor... no church, no traditional healer, no friend should tell you to stop taking the meds.”



I feel like it is important to disclose to the child ... so that they are fully aware why they are taking the meds, firstly, and secondly, by telling them earlier we are ensuring acceptance of their status.



Focus group participant



Parents sharing their own positive status with their children

Parents' concerns

Many of the parents who are themselves living with HIV explained they were reluctant to tell their children about their status. They did not want their children to be worried about them or afraid of them dying: "The hard thing is that they think their parents are going to die. That's the hardest part." They were also concerned that their children would no longer respect them. In families where both the child and the parent were living with HIV, parents said they were afraid their child would blame them for passing on the virus: "We want to tell them but it is difficult."

Potential benefits

Young people need support and information to help guide them through the process of discovering that their parent is living with HIV, and parents need guidance to help them share their status. Many parents wanted to tell their children in the hope they might learn from their experiences: "Maybe they will not make the same mistake as I did." One parent saw talking about their HIV status as an opportunity for dialogue around HIV: "It is a chance for you to explain to them what it is, how you get it, and it does not mean death."

Parents hoped that, by talking about their own HIV status, their child would feel less isolated and realise they are not the only people living with HIV: "The kids should know mom is also taking medication and it's better to know that. The kids should know this disease can happen to anyone and anyone can be infected." One parent said: "We might also treat each other as treatment buddies, whereby even if I forget they can remind me to take my medication, and if they forget I can also remind them to take their meds."

Many parents thought their child would be able to support them once they knew about their HIV status: "I think it is proper to tell them my status ... people have knowledge about HIV, so it is likely that they will accept it and they will also assist me." Many parents also felt their children could give them practical support: "If I disclose to my kids it means that the day I don't feel powerful enough to [go to] hospital I can send my child with no fear."

“If I disclose to my kids it means that the day I don't feel powerful enough to [go to] hospital I can send my child with no fear.”

Focus group participant



Young people's recommendations

“ We want to provide information and support so we can all make our own choices, without fear of being judged, of being physically abused or of being excluded from society. It is this very fear and exclusion that is in the way of our efforts to end AIDS. *Annah Sango, READY leader.* ”



Governments

- 1. Support bold new initiatives to eliminate stigma and discrimination.** It is time for a fresh start – no more images of people looking ill – we need to focus on positive messages about the benefits of treatment and ensure that new campaigns reach all members of society, including caregivers, teachers, church leaders and healthcare workers.
- 2. Remove all policies and laws that criminalise people for not disclosing their status.** Disclosure has to be the choice of the individual.



Implementers / health facilities

- 3. Focus on education.** Young people need everyone in their lives to have a full and accurate understanding of HIV, transmission and treatment. Make sure complete, up-to-date information reaches everyone, young and old, and encourage open and well-formed dialogues in communities.
- 4. Design youth-friendly services.** Peer-run services are particularly helpful, such as the CATS (community adolescent treatment supporters). More peer services are needed, including sexual health services. Young people should be meaningfully involved in the design of these services.



Communities

- 5. Create safe spaces.** Support groups are a valuable way of allowing young people to share their experiences in confidence with others who are living with HIV. We also need safe spaces that are open to everyone. Young people want to, and need to be able to, formulate friendships and relationships with others, whatever their status.
- 6. Encourage positive role models.** Healthy young people who are openly living with HIV are a real inspiration to others; they can act as coaches or mentors for their peers. In addition, identify champions among community leaders who are prepared to speak out and lead positive dialogues.

“ We want to provide information and support so we can all make our own choices, without fear of being judged, of being physically abused or of being excluded from society. It is this very fear and exclusion that is in the way of our efforts to end AIDS. *Annah Sango, READY leader.* ”



READY+ aims to advance sexual and reproductive health and rights (SRHR), psychological wellbeing, care and treatment with, by and for 30,000 adolescents and young people living with HIV in Mozambique, eSwatini, Tanzania and Zimbabwe. The programme is being implemented by an innovative and multi-disciplinary consortium of youth, SRHR, HIV and communication partners.

READY+ is one of a portfolio of projects being implemented under the READY programme. For more information, visit <https://frontlineaids.org/our-work-includes/ready/>



Funded by the Embassy of the Kingdom of the Netherlands, Mozambique