

# In Our Own Time



## Talking about HIV and sharing our status with others is a huge challenge for young people living with HIV.

Stigma and negative attitudes of others make it hard to be open and talk about our lives, whether we were born with HIV or acquired it through other ways at a later stage. There has been so much progress in the treatment of HIV that helps us to live longer and healthier lives, but little progress in addressing the stigma and discrimination that creates the isolation and rejection we experience. There is still so much to do in supporting us to learn about our HIV status, to be able to talk to others, and to share our HIV status with friends and partners. There is also so much to do to end the stigma that surrounds HIV.

READY+ has been exploring why support to young people for HIV disclosure continues to be such a neglected area and organised workshops with adolescents, peer supporters, health professionals, parents and caregivers in Zimbabwe and eSwatini to inform this brief.

As young people, it is our right to know about our HIV status. We should have clear and honest information about our health in order to make decisions. Whether we were born with it or acquired it at a later stage during adolescence or early adulthood, it is also our right to decide when and with whom we share our HIV status.



Article 17 of the United Nations Convention on the Rights of the Child states that every child should have “access to information and material from a diversity of national and international sources, especially those aimed at the promotion of his or her social, spiritual, moral, physical well-being and mental health”.

# What we want

## **Respect our rights:**

We want you to recognise how important it is for us to know that we are living with HIV. Knowing can help us adhere well to ARVs, stay happy, healthy, engage better in our care, feel confident and resilient! Keeping secrets does not help us or protect us, it only breaks our trust.

## **Knowing our rights:**

We are facing unique challenges as a result of living with HIV. Our experiences and the implications of sharing our diagnosis will differ. We need clear promotion of rights and responsibility around HIV disclosure to help us feel empowered and make our own informed decisions about whom we want to share our status with, rather than being told who should know.

## **Advocacy:**

We need to increase advocacy efforts to improve understanding of our rights and the importance for our generation to know their diagnosis in order to achieve better HIV and psychosocial outcomes and to protect our mental health and well-being. We need investment in resources that support youth-led advocacy.

## **Knowledge about HIV:**

We need clear youth-friendly messages about HIV care and support from our health providers and up to date messages about the advances in prevention and treatment, such as U=U, and new prevention technologies as well as messages that reflect differences around gender and sexuality. Better information means we are better equipped to manage and tackle stigma and discrimination and to share our status with others.

## **Build capacity and confidence:**

We need healthcare providers, parents and caregivers to feel more confident in talking to children, adolescents and young people about their HIV status, and to learn about ways to disclose and communicate with young people about their HIV status. We need training programmes and group discussions, readily available tools and materials that support our parents and caregivers in initiating discussions about HIV in an age appropriate and structured way. These interventions and tools must acknowledge the diverse lives of young people and recognise the additional challenges that groups such as LGBT young people face around talking about living with HIV.

### **Invest in peer support:**

We want peer support programmes that help young people living with HIV manage their own health and improve their well-being based on the sharing of experiences around living with HIV, including learning about, and sharing with others, their HIV status.

### **Safe spaces:**

We need safe spaces, adequate tools and support for us to explore and practice ways of effective communication around HIV and develop strategies for sharing with others without the risk of physical or psychological harm.

### **Laws and policies:**

We demand robust laws that guarantee our privacy and protect us from any types of discrimination. We demand strong policies that treat us with dignity and respect, protect our confidentiality and support the naming and sharing of our HIV status without prejudice. Decriminalisation of HIV transmission is critical; we are living with a treatable infection, we are not criminals. Governments must introduce laws and policies that recognise and protect our right to choose when and with whom to share our HIV status.



WHAT WE WANT



## Challenges faced by young people born with HIV

- **Knowing our status:** delays in disclosure from parents and caregivers.
- **Parental fear** of disclosing to children and adolescents
- **Accidental disclosure:** creating confusion, fear, anger, trust issues towards family, parents, caregivers
- **Unstable family structures:** orphanhood, frequent change of caregivers, becoming a burden to the caregivers
- **Poor treatment literacy** which will lead to poor adherence
- **Frequent absence from school** due to illness or caring for ill relatives.



## Challenges faced by young people who acquire HIV

- **Self-stigma, feelings of guilt, shame** (I did this to myself! I deserve it!)
- Fear of bad parental reaction leading to **being asked to leave home**
- Fear of disclosing to parents and **losing financial support**
- Dealing with the burden of **keeping a secret**, hiding treatment and going to a clinic alone.
- **Stigma and discrimination** at health-care settings, judgments around transmission linked to sex, drug use, sexual orientation that are not socially accepted



## Common challenges faced by young people living with HIV

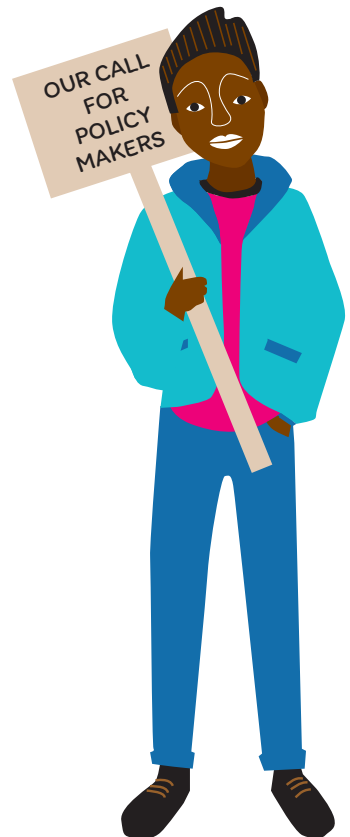
- Limited investment in support groups and safe spaces for young people.
- Poverty which leads to poor nutrition and missed clinic appointments because of travel costs
- Barriers to services due to age of consent policies
- Stigma and discrimination from families and society, limiting the opportunities of having friends and relationships
- Criminalisation of HIV transmission leaving young people isolated, emotionally unstable and in fear of having sexual relationships.
- The negative influence of faith-based healing practitioners in some cultures, leading young people to abandon medication
- Lack of knowledge about HIV and lack of youth friendly materials about treatment, prevention and new technologies
- Rejection and denial through late diagnosis leading to adherence issues and co-infections
- Dreams and hopes shattered through dropping out of school and isolation from others.

## Call to Action:

If we want to end AIDS by 2030, we need to address the challenges which are being faced by young people in managing their treatment and being able to talk about HIV without fear of prejudice - this is very critical!

We call for policy makers to:

- Engage with young people living with HIV and come up with a clear plan on positive youth leadership in the HIV response, empowering young people who are ready to lead in ending AIDS by 2030.
- Reform and adapt the laws and policies that criminalise HIV transmission to reduce societal stigma and discrimination and help us engage in relationships without fear and prejudice.
- Reform and adapt policies that protect the right of privacy and confidentiality of people living with HIV, providing healthcare providers with much needed communication skills, clear guidelines and code of conduct.
- Promote the integration of HIV clinics with other general clinics so that young people feel more comfortable attending without fear of being seen going into an HIV specific clinic.
- Support comprehensive updated sex education programmes at school with a focus on HIV. This will not only raise awareness at school and prevent HIV transmission but also reduce the level of stigma and discrimination among the youth population, especially when provided with updated information such as U=U.
- Remove barriers to services



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/>