

# CHALLENGING STIGMA AND WORKING WITH HIV POSITIVE INDIVIDUALS IN BURUNDI

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## INTRODUCTION: THE BEGINNINGS OF THE NETWORK

This case study describes the journey of the National Network of Young People Living with HIV/AIDS (RNJ+) in Burundi. It explores the circumstances of its creation, the obstacles encountered, the opportunity that it has had to forge partnerships, and the great success it has achieved, despite the ongoing challenges of discrimination, access to financing and the capacities of young people.

The creation of RNJ+ in 2004 came in response to the precarious situation of young people living with HIV. At that time, a group of young people living with HIV committed to raising awareness through national television and radio, schools, military camps and the workplace. The group decided to create a network of young people living with HIV.

The work of this group of young people was appreciated by many, creating a large demand for their work. Many organisations thought more of working with young people living with HIV and wanted to see the project succeed. Although the idea was welcomed by some partners, such as the government minister responsible for the fight against HIV/AIDS and the National AIDS Council, it was not welcomed by some others, including the Burundian Network of People Living with HIV, which at the time was two years old.

At creation, RNJ+ faced several challenges. Discrimination against people living with HIV was more intense at that time. Most HIV positive young people who tried to raise awareness were exposed to discrimination in schools, families and communities. A typical example concerned one of the youngest founder members of RNJ+, Juste St Rachel Izerimana, who died in hospital after spending a month on the street, chased by his family. This tragedy occurred after Juste St Rachel Izerimana testified on national television about his experience of discrimination by his family. RNJ+ at that time was barely credible, composed mainly of very young people, most of whom were students without any experience of managing resources, in an environment of competition for the acquisition of funding, and in a context where many people were afraid of associating with young people living with HIV. It was almost impossible to access funding for our work.

In 2006, two years after its creation and after a long process of advocacy, RNJ+ was legally recognised. Until then, there was no possibility of accessing funding, but it was still possible to perform some activities, either by working with partners, or by undertaking activities that required only voluntary commitment. For example, each year, outreach sessions based on the testimony of young people living with HIV were held in public schools.

## THE LEADERSHIP OF PEOPLE LIVING WITH HIV QUESTIONED

Faced with the growing demands of people living with HIV, other groups and organisations of people living with HIV have been created. In 2012, there was a total of five networks of people living with HIV in Burundi. The existence of multiple networks creates complexity. It makes it hard to present a common voice of people living with HIV, and partners are sometimes confused as to which network should be regarded as the legitimate interlocutor and representative of people living with HIV.

2010 was marked by internal conflicts between some organisations of people living with HIV. This created a crisis of leadership, and caused the response to HIV to become paralysed. The conflict revolved around the community component of the funding of the Global Fund to Fight AIDS, Tuberculosis and Malaria, and commanded much of the attention that should have been given to intervention and community response. Such work was almost suspended, including socio-economic assistance, the prevention of HIV in the community, legal assistance for people living with HIV, and support for orphans and other children made vulnerable as a result of HIV.

This crisis could not leave anyone indifferent, and RNJ+ was affected. Organisations of people living with HIV came to be seen as profiteers, and impacts included HIV orphans being forced to suspend their studies.

The crisis passed after two years, but it took time to improve the image of HIV networks and focus again on serving the interests of people living with HIV. The two long years of crisis much tarnished relations between different organisations, and particularly organisations of people living with HIV. It was essential to rebuild relations in order to once again serve people living with HIV. Thus a consortium of organisations of people living with HIV was created, named ITEKA consortium, an acronym that means 'honour'. The five networks of people living with HIV have come together to create a framework for exchanging, and sometimes for working together.

The carrying out of an index study of stigmatisation of and discrimination against people living with HIV in Burundi offered an opportunity to demonstrate the importance of the consortium. The five networks of people living with HIV played a critical role in facilitating the realisation of the study, including in the chairing of the steering committee by the consortium, the recruitment and training of interviewers and supervisors, data collection and the supervision of collection.

A second opportunity that has proven the importance of the consortium came with the representation of people living with HIV in the Country Coordinating Mechanism (CCM) for the Global Fund. All networks of people living with HIV came together

and chose RNJ+ to represent them in the CCM. The choice of RNJ+ not only proved the importance and maturity of the consortium, but also demonstrated the esteem that other networks have for its work and leadership.

## YOUTH LEADERSHIP BEARS FRUIT!

After eight years of work serving the community, RNJ+ has proved its capabilities. Its leaders have grown and gained experience, which enabled them to develop a plan of action, mobilise resources and implement the plan. Since 2006, RNJ+ has reached over 20,000 young people across Burundi through awareness sessions based on the testimony of young people living with HIV. By offering testimonies, young people living with HIV have raised awareness among others, and encouraged them to participate in HIV screening, and adopt better behaviours towards HIV positive people. When testimony is made in front of an audience, it demands greater commitment from the community, and exposes attitudes of discrimination and rejection.

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In another proof of its success, RNJ+ was chosen as an equal partner with 15 other implementing organisations of the Link Up project in Burundi.<sup>1</sup> Link Up is a multi-country project that has the aim of improving sexual and reproductive health and rights (SRHR) services for young people living with and affected by HIV. This choice again proved the confidence that RNJ+ has developed.

The opening of a friendly and attractive youth centre by RNJ+, as part of the Link Up project, further demonstrated the value of youth leadership. The centre, unique in Burundi, offers services for sexual and reproductive health to young people, with a focus on key youth populations. In a context where homosexuality and sex work is criminalised, RNJ+ has taken the lead in ensuring access to services for marginalised youth groups. In addition, RNJ+ forged partnerships with private and public clinics to ensure that young people who attend the centre have access to all relevant SRHR services that meet their needs. Through a team of 12 peer educators and a staff of 5 young people, RNJ+ has reached 4,882 young people who would otherwise not be served with information, counselling and SRHR services.

## IMPACT OF THE BURUNDI CRISIS

However, when Burundi's political crisis started in May 2015, we had to close our youth centre for two weeks. The centre was just 50 metres from an area where tensions and violence were occurring. While the centre was closed, young people had no access to the information, training, HIV counselling and testing, contraception advice, and male and female condoms that we provide.

Our centre has since reopened, but has had to change its opening hours to provide services from 11.00 am to 4.00 pm daily. In addition, peer educators are still able to distribute condoms, but only in their area of residence, where they are known by other

<sup>1</sup> The Link Up programme - [www.link-up.org](http://www.link-up.org) - funded by the Dutch Ministry of Foreign Affairs, aims to improve the sexual and reproductive health of young people most affected by HIV and promote the realisation of young people's sexual and reproductive rights in five countries, including Burundi. It is being implemented by a consortium of civil society organisations, led by the International HIV/AIDS Alliance.

local residents. Being perceived as a foreigner is also a security risk. For their safety, peer educators have been encouraged to avoid organising any kind of group gatherings in their communities, other than at the centre.

## **CONCLUSION**

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It continues to be the case that discrimination against and stigmatisation of young people living with HIV offers a major challenge to HIV response, but the leadership of organisations of people living with HIV remains the cornerstone of response. It is important to consider youth organisations as equal partners that can make an important contribution to HIV response. The case of RNJ+ is one example; there are doubtless other youth organisations that are also doing great work. The example of RNJ+ also shows how a political crisis can affect civil society's work, and how it is important to set up strategies that allow the continued provision of SRHR services, particularly to young people that are the most affected.