



Commentary

Leadership and Innovation—Listening to and Learning From Young People in Burundi



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 A B S T R A C T

This commentary describes young people's leadership from the perspective of a youth-led organization in the Link Up project in Burundi, Réseau National des Jeunes vivant avec le VIH. It describes processes that enable young people to guide, influence, deliver, and improve health service provision; the challenges faced by Réseau National des Jeunes vivant avec le VIH and how they are addressing these challenges.

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In addition to being a human right, the meaningful participation of young people has long been recognized by key actors in the field as central to the provision of effective and inclusive sexual and reproductive health and rights (SRHR) health services [1]. Comprehensive youth-friendly SRHR and HIV education, together with tailored programming designed for and by young people, can increase uptake and access of services, leading to lower rates of early pregnancy, HIV incidence, and other negative health outcomes [2]. However, there is limited documentation on exactly what successful youth participation and leadership in

the design and delivery of SRHR health services looks like in practice.

This commentary showcases youth leadership in the Link Up project in Burundi from 2013 to 2016, including what was required to meaningfully support youth-led organizations, common challenges, and how listening to and learning from young people benefitted partners in delivering integrated SRHR and HIV programming and advocacy work. In particular, the report shares the experience of the Burundian implementing organization, Réseau National de Jeunes Vivant avec le VIH (RNJ+) (National Network of Young People Living with HIV), the national network of young people living with HIV in Burundi.

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Réseau National de Jeunes Vivant avec le VIH's Story: Key Elements to Enabling Youth Leadership

Although formed as a peer support group for young people living with HIV in 2004, RNJ+'s evolution to a youth-led advocacy network began to accelerate with two sets of consultations

in 2012 and 2013. Led by and for young people living with HIV, the consultations documented participants' experiences and needs—first around treatment and care and then around accessing SRHR. The first consultation, initiated and led by RNJ+ volunteers without funding from partners or donors, revealed that young people living with HIV were experiencing difficulty discussing their HIV status with caretakers and with taking their antiretroviral medication and were facing intense stigma around openly living with HIV [3]. The consultation involved meetings at five public health facilities with three health care workers at each site, as well as three focus group discussions with a total of 18 adolescents and young people living with HIV who access services at the five health facilities.

The second consultation, supported by ATHENA Network and the Global Youth Coalition on HIV/AIDS (global partners in the Link Up project) [4], gave young people living with and affected by HIV a space to share their experiences accessing SRHR information and services [5]. While the consultation involved more than 1,200 young people through an online survey and was global in scope, RNJ+ led in-depth face-to-face consultations in Burundi with 20 young people who self-identified as young people sell sex, young people living with HIV, and/or young people who use drugs. The young people who took part in the face-to-face consultations were identified by RNJ+ staff through the community outreach they do. The consultations, which were facilitated by staff from RNJ+, helped identify some of the primary barriers to SRHR access and the lived realities of young people from the community. Young people living with and affected by HIV not only participated in the dialogues, but also led the information-gathering process and helped design the tools for dialogs with young people. The community dialogues they led began to build an evidence base for their advocacy work and for Link Up's priorities as a whole.

The Alliance Burundaise contre le Sida et pour la Promotion de la Sante (ABS) (Burundian Alliance Against AIDS and for the Promotion of Health), the umbrella organization of HIV service organizations that leads the Link Up consortium in Burundi, recognized the importance of working collaboratively with RNJ+ from the start of the project. ABS provided significant resources to young people, both financially and technically. The partners did not expect young people to volunteer their time; six young people from RNJ+ are paid as staff (ages 25- to 29-year-olds). As paid staff, they took part in program design and implementation. ABS sponsored RNJ+ to become a member of its network and an equal partner in the project, alongside the 15 other adult-led implementing partners in the Link Up Burundi consortium. Based on the results of its consultations, RNJ+ decided to open a youth center in Bujumbura to provide a safe space for young people to access information, peer counseling, HIV testing, and referrals for other SRHR and HIV services. ABS subgranted the significant start-up costs required (40,000 USD in 2014), providing RNJ+ with clear responsibility and accountability, and showing its support for the abilities of RNJ+ staff. Today RNJ+ has a membership of 420 young people living with HIV, supported by a board of governance consisting of seven young people living with HIV. The board of governance is elected every 3 years during a general assembly of members of RNJ+. RNJ+ operates in 14 out of 18 provinces, with a budget of approximately 70,000 USD in 2016.

RNJ+'s partnership with, and support from, local health service providers has also been instrumental in its success. Two providers—Rama and the Association Burundaise pour la Prise en charge des Malades Vulnérables du SIDA (Burundian

Association for the Care of Vulnerable AIDS Patients) (ABCMAV)—provided HIV test kits and condoms, ensured quality monitoring of services, and facilitated referrals to public health facilities for young people at the RNJ+ center to access a broad range of services. Rama provided training for three young people at RNJ+ on HIV counseling and testing so they could deliver those services themselves and arranged for a youth-friendly clinician to visit the center once a week to support RNJ+ staff and provide mentorship. This relationship has been critical in building the skills and capacity of the center's staff and has ensured quality service provision for and by young people. Peer-to-peer models of service delivery have supported RNJ+'s success in reaching young people from a variety of backgrounds and have empowered young service providers to take ownership of their service delivery.

Mentoring from ABS staff and global partners in the project has played a central role in building RNJ+ members' capacity to engage in national and global-level advocacy. As the project has evolved, more experienced RNJ+ members have provided mentoring to young people who are new to advocacy work or want to become more involved in RNJ+'s programmatic activities. For example, when participating in meetings, a more experienced youth advocate will attend and support a less experienced youth advocate to prepare for and speak up at a meeting.

Positive Impact: What Can Happen When Youth Leadership in Programming Is Supported?

RNJ+'s role in the Link Up project, and in the youth and HIV movements more broadly, has grown steadily since the inception of Link Up. RNJ+ members began by sharing information at the youth center and have ultimately taken on significant advocacy work based on their research. For example, three staff members received training organized by the International HIV/AIDS Alliance on how to document and respond to human rights violations through the REAct program (a community-based human rights monitoring and response system) [6]. National support for RNJ+ has grown so significantly that when one of its members sought a seat on the Global Fund to Fight AIDS, Tuberculosis, and Malaria's Burundi Country Coordinating Mechanism (CCM), representing people living with HIV, she received the full endorsement of partners in the Link Up consortium and is now a CCM member. Each country that receives funding from The Global Fund has a Core Coordinating Mechanism, a multistakeholder partnership with responsibility for the development, submission, and oversight of proposals to the Global Fund. The CCM is central to Global Fund funding and work, and it is rare for a young person to be granted a seat on it. RNJ+ members have represented young people living with HIV at International AIDS Conferences, in post-2015 and United Nations consultations, and at UNAIDS Programme Coordinating Board meetings.

Through the provision of integrated SRHR and HIV services, peer education, treatment adherence support, and advocacy capacity strengthening, RNJ+ is contributing to Link Up's overall aim to improve the SRHRs of young people most affected by HIV. The entire RNJ+ youth center is led and run by youth and young adults (15- to 29-year-olds), in partnership with public providers. Through a team of 12 peer educators, RNJ+ has reached more than 4,800 young people in 2 years who might not otherwise have had access to information, counseling, or services.

The youth center provides a free and safe space for young people living with HIV, which is critical to supporting their adherence to treatment, retention in care, and overall health [7]. In addition, RNJ+ has trained young people who sell sex and young people of diverse sexual orientations and gender identities as peer counselors, recognizing that a diverse group of young people are at risk of HIV exposure and need access to SRHR services, education, and information from peers they feel comfortable with.

RNJ+'s board, staff, and members have also gained knowledge and skills that will support their ongoing work in the youth and HIV movements. Specific examples of skill building include the Executive Director's selection as the first Fellow in a new collaboration between the Global Network of People Living with HIV and the International HIV/AIDS Alliance; a peer counselor's mentorship through the conceptualization and implementation of a female condom uptake project; and regular support to participate in regional and international advocacy forums.

Overcoming Challenges and Ways Partners Can Help Youth-Led Organizations Look to the Future

Ongoing capacity building and training for existing and new leaders

While RNJ+ is run by an impressive group of young leaders, most roles are concentrated in the hands of a small group of individuals, who have received training, mentorship, and exposure to new ideas and skills during the course of the Link Up project. As current staff members mobilize to identify new leaders, they are also continuing to train and mentor new leaders who can take up administrative and coordination roles.

Preserving institutional memory and creating a mentorship role for people ages 30 years and over

As young RNJ+ leaders grow in their roles, they also face the challenge of "ageing out." RNJ+'s membership consists of 15- to 29-year-olds. Although recognized for their expertise, these leaders are expected to move on when they turn 30 years and be replaced by younger advocates. This can leave leaders who have turned 30 years feeling unwanted and often has a negative impact on institutional memory. Many youth-led organizations struggle to grow with staff turning over every few years. RNJ+ is exploring ways of preserving institutional learning by reaching out to former members over the age of 30 years for support in leading workshops or participating in advocacy meetings, when RNJ+ has limited staff capacity and also by creating mentorship roles for members who age out to pass on their knowledge and experience to the younger, future leaders of the organizations.

Specific support for leadership of young women living with HIV

Specific challenges have arisen in RNJ+'s work with young women not openly living with HIV, who are often afraid to be open about their HIV status or associated with RNJ+. For young women in particular, this can lead to rejection and can further exacerbate gender inequities in relationships and at home. For those in leadership positions at RNJ+, the additional pressure of being open about their HIV status to promote the visible

leadership of people living with HIV can be overwhelming. RNJ+ encourages young women within the network to take up spaces when opportunities arise and to seek advice on HIV disclosure and how to manage this when in positions of leadership from older women living with HIV who are part of adult networks of people living with HIV.

Funding to address holistic well-being of young people living with HIV

RNJ+ has also faced the challenge of trying to meet growing demand for peer outreach and psychosocial support (services that are weak in Burundi and are offered by very few other organizations). Home visits and ongoing peer support can be costly and time-consuming, straining organizational capacity to deliver them. RNJ+ often works with young people who have unmet needs which are very basic, such as food, shelter, and education, or who are facing domestic violence at home. They make referrals to other service providers where they exist, but staff and peer counselors often feel unable to assist all of those who need it as these needs are beyond the scope of the center. With more staff, resources, and capacity, RNJ+ would be able to meet these needs—and they are working to secure these resources.

RNJ+'s experience—through capacity strengthening; mentoring; and meaningful and accountable partnerships—has made all the difference in its success. Its leadership is passionate and committed, but the recognition and resourcing of that leadership is imperative. Supporting youth-led organizations to build and implement their own ideas, valuing and respecting the perspectives and views of young people, establishing expectations and accountability on both sides, and formally giving young people decision-making power are just a few of the ways we can work together to build effective programming [8]. Youth-led organizations like RNJ+ face unique challenges, and moments for young people and their partner organizations to pause and reflect are critical to ensure that new leadership is continuously being built and that there is flexibility to improve and sustain service provision to meet the ever-changing needs of young people.

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