

# A qualitative review of psychosocial support interventions for young people living with HIV



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# Acronyms and abbreviations

AIDS	acquired immunodeficiency syndrome
GYCA	Global Youth Coalition on HIV/AIDS
HAART	highly active antiretroviral treatment
HIV	human immunodeficiency virus
NGO	nongovernmental organization
OVC	orphans and vulnerable children
UNICEF	United Nations Children's Fund
WHO	World Health Organization
YPLHIV	young people living with HIV

# Executive summary

*Adolescence being the difficult age that it is, the teenagers [living with HIV] encounter difficulties of a more personal nature such as self-awareness, defining their identity, building their peer group, making plans for the future, dealing with their sexuality. Generally, taking the step from childhood to adulthood is hard in more ways than one and generates inner conflicts materialized in confusion, identity crisis, stress, etc. From this point of view, they are not different from any other normal teenager. (Survey response from Romania)*

The increasing effectiveness and availability of highly active antiretroviral treatment (HAART) during the past decade has resulted in the survival into adolescence of thousands of children born with human immunodeficiency virus (HIV) who would otherwise have died in childhood. At the same time, despite growing awareness about effective interventions to prevent HIV transmission among young people, they still make up 45% of new transmissions worldwide. Whether infected during the neonatal period or during adolescence, young people living with HIV (YPLHIV) have unique and pressing psychosocial needs on top of the daily challenges of being an adolescent. In the absence of empirical data, and confronted by a disease whose implications change constantly, this review explores the interventions that organizations are implementing around the world to provide psychosocial support for YPLHIV and synthesizes their recommendations for future interventions.

When comparing young people from different parts of the world, in different age groups and with different modes of acquisition, the results of the review indicate that there appears to be far more consistency than disparity in terms of their problems and needs. Adherence to medication, disclosure of HIV status, issues relating to sex and lack of support networks are problems faced by all YPLHIV. The majority of organizations use a multidisciplinary team of individuals to meet these needs, with particular emphasis on individual and group therapy, educational support, and skills-building programmes.

The review stresses the importance of youth-centred and youth-led approaches that engage young people in the planning, implementation and evaluation of programmes. Respondents underlined the need for increased funding, capacity building and trained staff. They suggest that policy-makers put more effort into understanding the distinctiveness of adolescence, particularly in the context of HIV, and challenge them to make longer-term commitments to funding and programme support. Lastly, respondents argue that in order for their organizations to provide better services, they need further evidence of effective solutions, programme guidance and support tools, and increased collaboration and communication with one another and with policy-makers and funders.

# Background

*Treat young people as young adults, not big children.* (Survey response from the United Kingdom)

Young people aged 10–24 years make up one of the most vulnerable, yet overlooked, populations affected by the human immunodeficiency virus (HIV) pandemic. Forty-five per cent of new transmissions take place among this group (1), and there are currently an estimated 5.4 million young people living with HIV worldwide.<sup>1</sup> The continued spread of new infections, coupled with the increased accessibility to highly active antiretroviral treatment (HAART) and the subsequent longer survival of children infected during pregnancy, birth and the first year of life, means that the number of young people living with HIV is likely to significantly rise over the next 10 years. It is clear that health-care providers and policy-makers must be able to respond to the specific needs of this group of people living with HIV, needs that differ in a number of ways from those of small children or adults.

The Global Consultation on Strengthening the Health Sector Response to Care, Support, Treatment and Prevention for Young People Living with HIV, sponsored by the World Health Organization (WHO) and the United Nations Children’s Fund (UNICEF) in Malawi in November 2006 acknowledged that “lack of psychosocial support” is one of the eight priority challenges for young people living with HIV (YPLHIV) to which the health sector should respond (1). The report from the consultation states: “The development of guidance to address the psychosocial needs of young people living with HIV is long overdue. Once this is developed, it can be adapted at the country-level as a training manual, in order to create or strengthen staff capacity to provide psychosocial support for young people through HIV care facilities” (1). This qualitative review is intended to highlight and synthesize some of the expertise and experiences of the people and organizations working with YPLHIV.

## Literature review

Since the early 1990s, a number of studies have been published on the psychosocial implications of HIV in children and adolescents. Far fewer have analyzed the interventions designed to provide psychosocial support for YPLHIV in order to help them improve treatment adherence, strengthen their capacity to deal with disclosure and stigma, and prevent high-risk behaviours. A recent review of the literature concluded that little of the existing published research on interventions for psychosocial support focuses specifically on young people aged 10–24. Most cited interventions focus on children under the age of 10, family units, or the HIV-negative children of HIV-positive

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<sup>1</sup> There are currently no good estimates or projections of the number of adolescents aged 10–14 years living with HIV.

parents. Of the seven journal articles found in the search of both published and gray literature,<sup>2</sup> only one commented specifically on youth, rather than young children.

In their studies of clinical opportunities for YPLHIV, Wright and Draimin (2) write that individual counselling is just one forum where young people can gain support. Youth-centred programmes offering a non-threatening atmosphere and opportunities for participation are crucial. They argue that when children feel more connected to an organization, they are more likely to seek peer and professional support. Increased confidence can then lead young people to become involved in a range of activities provided by the organization, including peer mentoring, community service and community outreach programmes. In addition, collaboration with other agencies can help relieve the isolation experienced by young people. The authors conclude that programmes must address a balance between the challenges adolescents face and the strengths they possess to increase resilience and live healthy lives.

The lack of robust, evaluated data reflects the complexity and sensitivity of working with adolescents and HIV, as well as the difficulty in conducting intervention research on this topic. Although very little has been published, it is clear from much anecdotal evidence that psychosocial support for YPLHIV *is* being provided by many organizations in many countries.

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