Policy Briefing

NATIONAL AIDS TRUST
Securing rights
Stopping HIV

Supporting the Next Generation:

improving the quality of life of young adults living with HIV

Introduction

Young adulthood is a formative stage in everyone's life - a time of transitions, self-discovery, and independence. For people aged 18-27 living with HIV in the UK, these years are also shaped by a unique intersection of experiences: the shift from paediatric to adult healthcare, the challenge of managing a stigmatised condition in social and professional settings, and the ongoing need for support and community.

This is the first generation who will enter adulthood with the knowledge that undetectable means untransmittable ('U=U'), life expectancy that can be as long as anyone else's and where they should expect and deserve legal protection under the Equality Act.

Young people living with HIV in the UK are achieving incredible things - pursuing education, building careers, starting families, and shaping their communities. With the right support, connections, and access to accurate information, they are thriving. These successes among young adults living with HIV (whether they acquired HIV vertically or later in life) show what is possible when young people are given opportunities to shape the services and policies that affect them.

As of December 2025, the UK Government has recommitted to another HIV Action Plan to get England to zero new transmission and improve quality of life for all people living with HIV. This goal requires the experiences and needs of young adults living with HIV to be brought to the forefront. While the UK has made significant progress in the care of people living with HIV, young people living with HIV report poorer life satisfaction, higher unmet mental health needs, and more barriers to care compared to older age groups. According to Positive Voices data[1] (using the available 18–34 age category), their self-rated life satisfaction is notably lower than the average for all people living with HIV. These disparities are mirrored in findings from UK and global research which highlight persistent gaps in youth-specific services, limited peer-support networks, and persistent stigma in healthcare, further education and the workplace.

This briefing was informed by discussions with young people living with HIV, who are part of National AIDS Trust's advisory group for a project on the rights of young people. Our project team then consulted stakeholders supporting young adults living with HIV including HIV consultants and voluntary sector organisations.

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1. https://www.gov.uk/government/publications/hiv-positive-voices-survey/positive-voices-2022-survey-report

Our Vision

With our advisory group of young people, we explored what change they wanted to see and how it would look. Their vision for young people is that they all receive comprehensive, holistic support throughout all life stages of life before, during and after the transition to early adulthood. Young people living with HIV should be able to easily access community, and support tailored towards their age group (and other intersecting identities) that will help them navigate new responsibilities, opportunities and relationships. Young people living with HIV deserve to be understood in their entirety and have their psychological, emotional and socioeconomic needs met.

To achieve this vision, our advisory group outlined four priorities:

1. Sustainable funding for and expansion of youth friendly clinics and support services that focus on mental and physical wellbeing

2. Increase knowledge of HIV, HIV stigma and what it means to be a young adult living with HIV across the NHS, voluntary sector organisations, workplace and education settings to address HIV discrimination

3. Government strategy around meeting the economic needs of young people by investing in programmes to support young people into housing, employment, education and financial stability

4. Working with young people to co-develop research, performance indicators, policy solutions and support services

Living well with HIV

Life satisfaction is shaped by a mix of good physical and mental health, social connection, financial stability, and a sense of belonging. For young people living with HIV, these elements can be harder to secure - not necessarily because of living with HIV by itself, but because of the environments they live in.

This is reflected in Positive Voices, which shows that young people living with HIV report significantly lower life satisfaction scores than older peers. We heard that this gap is likely to be particularly pronounced for those living outside major cities, where specialist services and peer networks are less accessible. For example, one young adult described growing up in a small town where they felt like the only person living with HIV, with no spaces to relate to others, and not discovering support available from a voluntary sector organisation, Chiva, until the age of 16.

These experiences mirror previous research which found that stigma remains a major barrier to engagement in school, work, and community life for young people living with HIV. Improving life satisfaction requires investment in community spaces - both physical and digital - where young people living with HIV can connect.

Beyond individual health needs, life satisfaction is also shaped by the broader social determinants of health - such as income, housing, education, employment opportunities, and access to safe community spaces. For some young people living with HIV, poverty, insecure housing, and limited access to education or stable employment can compound health challenges.

These pressures can make it harder to prioritise healthcare, maintain treatment adherence, or thrive in further education or in the workplace, especially when basic needs are not met. Addressing these social determinants is essential to improving health outcomes and ensuring that young people can not only live well but thrive across all aspects of their lives.

Youth unemployment has increased over the past few years, reflecting levels of unemployment at the start of the COVID-19 pandemic as of September 2025. Young people are competing for limited opportunities to enter the workforce, and some entry level roles offer less than living wages or salary that cannot match the increasing cost-of-living. Positive Voices data show that people aged 18–34 are more likely to be unemployed than older adults, and younger adults are less likely to be up to date with bills, indicating greater difficulty meeting basic living costs (e.g. rent, utilities and food). Financial insecurity is made harder by having additional health-related costs such as travel to appointments and support services.

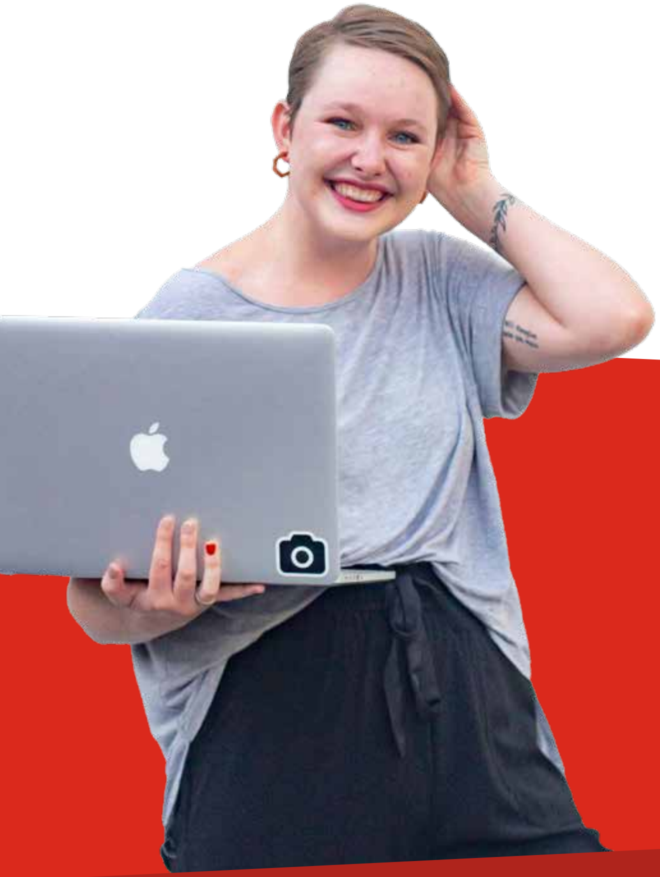
Transitions to independent living can create challenges for young people to managetheir health. This may be due to new responsibilities, environments and expectations that comes with working and paying bills. Young people living with HIV can face barriers to accessing support from local authorities and charities. Financial insecurity can undermine health outcomes and engagement in HIV care.

Meeting these needs means pairing targeted financial assistance (e.g., travel bursaries, hardship funds) with welfare-rights and benefits advice embedded in youth HIV services. To support young people living with HIV to achieve socioeconomic independence, clinics and voluntary sector organisations have to establish pathways or deliver programmes where they connect young people with employment and financial planning support.

Some young people living with HIV have had to undertake care responsibilities from a young age, this may be the case where their parents are also living with HIV. Young carers can find it hard to balance managing their healthcare while also supporting a parent, guardian or family member. Often young carers are a forgotten population by schools, universities, healthcare and workplaces: numerous reports identify that young carers face barriers to attainment in education and careers. HIV clinics and local authorities should connect young adult carers with resources and advocacy support focused on the rights of young carers where relevant.

Recommendations:

- UK governments, local authorities and health boards should fund and expand youth-specific peer networks and support groups, including in rural and semi-rural areas.
- Ensure HIV education in schools which actively challenges stigma and discrimination.
- University staff should undertake HIV literacy training and regularly review their reasonable adjustment and disability policies with panels of students with lived experience.
- NHS and commissioners should co-locate welfare-rights and housing advisers in clinic, building on the model already developed by youth clinics.
- Clinics should remove practical barriers for attending appointments with travel/data bursaries and rapid hardship funds.
- The government should introduce a Carer's Strategy which would be developed with people who are or previously were young carers, including young people living with long term conditions such as HIV.
- NHS and local authorities should create formal referral agreements between youth HIV services and youth employment and welfare support services.



Navigating healthcare through change

For those who acquired HIV before adulthood, the transition from paediatric to adult HIV care is a pivotal moment - and a known point of vulnerability for retention in care. Positive Voices also shows that young people rate their satisfaction with HIV care lower than any other age group, with fewer reporting that they feel involved in decisions.

Person centred care seemed to be important to all the young people consulted on this briefing. Person centred care meant they felt like they had active partnership with clinicians and nurses and the support they received for their health reflected their needs and lifestyle – both health-related and otherwise.

One young adult living with HIV highlighted the importance of rapport: “it depends on how comfortable you are with your healthcare professional... Rapport is important to build comfort and not all HCP try to build relationships and some just check bloods”. For some people who transition to adult clinics they feel they are very clinical in comparison to paediatric services where you might have stronger relationships. Others spoke about the difficulty of giving feedback: “Sometimes you don’t know how to complain and what to do with that complaint/feedback.”

The Chiva Standards of Care emphasise that transition should be a planned, phased process, beginning well before transfer to adult services and centred on the young person’s readiness, needs, and preferences.[2] Implementing this will help achieve person centred care that is shaped around the future and current experiences of the young people this impacts. Chiva explains that each young person should have a named transition lead, a written plan, and opportunities to meet adult clinic staff in advance. As entering young adulthood can be a time of constant and abrupt change, it is both beneficial and necessary to have that consistency within HIV care.

Youth-specific HIV clinics have proven effective in supporting both health and psychosocial needs. For example, the ‘900 youth clinic’ provides care for young people over 16 years old who are newly diagnosed or transitioning from children’s services to adult services. The transitional care consultant leads a multidisciplinary team providing medical, psychological, dietetic, contraceptive, sexual health and peer support for young adults living with HIV and their partners. Chiva specialist support officers attend clinics and provide psychosocial support, which can include emotional support and helping with wider life challenges e.g. housing / financial issues which can affect health and wellbeing.

However, such models remain limited and patchy across the UK, with some areas offering no dedicated youth pathway at all. Without sustained funding, access to these approaches will remain unequal across the UK and health inequalities will grow.

Recommendations:

- The NHS and Department for Health should protect and expand youth-friendly clinics that integrate clinical care with peer support and flexible access.
- The NHS should ensure all staff receive training in HIV literacy, confidentiality, and cultural competence.
- NHS trusts and hospitals should involve young people in designing Patient Reported Experience Measures (PREMs) and create opportunities to collect feedback and communicate changes as a result.
- All clinics should provide clear, accessible information about the rights of patients and complaint processes.

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[2] https://www.chiva.org.uk/professionals/clinical-guidelines/

Primary care and sharing HIV status

Healthcare experiences are also shaped by the wider system. Several young people living with HIV described poor HIV literacy among non-specialist staff, leading to unnecessary questioning or mishandling of information. This erodes trust and can deter young people from seeking care outside their specialist clinic.

The British HIV Association (BHIVA) recommends that people living with HIV share their HIV status with their GP, so they can get optimal care by enabling GPs to manage potential drug-drug interactions and to provide holistic care that addresses both HIV-related and non-HIV related health conditions. However Positive Voices data shows that those aged 18–34 are significantly less likely than other age groups to have told their GP about their HIV status.

Sharing your HIV status is a personal decision. People living with HIV have the right to choose when, how, and with whom they share this information. For many young people, however, the stakes can feel particularly high. Stigma, past breaches of confidentiality, and negative experiences in healthcare can make confidence and trust fragile, particularly in primary care.

Young adults living with HIV described why:

“[Young people living with HIV] are expected to educate their GP and they shouldn’t have to and [GPs] ask potentially intrusive questions.”

“There is a fine line between curiosity and ignorance.”

“A friend had their HIV status shared across the room by the nurse.”

Some young people are not aware that they have control over which healthcare professionals have access to their health information. Without this information, they are not aware that sharing their HIV status is their role, not done for them. For example, one young adult living with HIV told us “I would’ve assumed that my GP knew about my HIV until I was told recently they aren’t automatically given that information.”

Building young people’s confidence to share their status requires more than simply outlining the benefits. It depends on people knowing their right to confidentiality, visible accountability when it is breached, training in primary care, and support for young people to be able to assert their rights in medical settings.

Recommendations:

- HIV clinicians should take a person-centred approach when supporting young people to understand the benefits of sharing their HIV status with primary care.
- Primary care networks and NHS Trusts should implement existing programmes that educate healthcare staff on HIV and HIV stigma such as the HIV Confident charter mark.
- NHS bodies and regulators should apply clear sanctions and accountability measures for breaches of confidentiality.

Mental health and wellbeing

"Cultural barriers to accessing mental health... shapes your understanding and choices as a young person."

Mental health conditions disproportionately affect young people living with HIV, with 44% aged 18 to 34 having a diagnosed mental health condition. Yet services are often not designed with the needs of young people living with HIV in mind. Highlighting the value of support when available, one young person living with HIV told us: "Until people access mental health services, they don't realise how useful it can be".

Chiva's 2025 Standards set clear expectations for youth-appropriate psychological care. Psychological support should be integrated within HIV care with clear referral pathways, not treated as an add-on. But young people living with HIV who need support most often face the steepest barriers. Months-long waits for NHS talking therapies; private counselling that's priced out of reach; and generic services without HIV literacy or cultural competence - too often leading to poor experiences and worse outcomes.

In conversation with HIV consultants, there was concern about how experiencing adverse childhood events (ACEs) as a young person with HIV can impact on engagement with HIV care. Young people living with HIV should be able to access psychological support where the healthcare professional has competency in emerging adults and navigating ACEs. Both community organisations and adult HIV clinics should be funded to provide this support.

Services should actively encourage peer support (including Chiva's youth and family programmes) and create an atmosphere that recognises the diverse experiences of young adults accessing these services. A member of the advisory group pointed out that community organisations need to be more mindful that not everyone acquires HIV through sexual transmission or during adulthood.

For many young people, their parents may also have lived with HIV and this may have shaped their attitudes towards mental health support and other aspects of care. Older family members may act as the 'gatekeepers': in some cases, they might decide against their children accessing HIV support services or other forms of support. A person's relationship to HIV stigma can be complicated by their experiences within their wider family unit, especially if other members are living with HIV. For this reason, support programmes and resources for parents living with HIV and families affected by HIV need to be funded and expanded.

Recommendations:

- UK governments and health boards should ensure all HIV services have the necessary resources, staffing and pathways to implement the BHIVA Standards on psychological support for adults living with HIV.
- UK governments, health boards and local authorities should ensure that young adults living with HIV can access peer support services including those tailored to the needs of young people.

The difference peers can make

Peer support can play a pivotal role in supporting people to live well with HIV. Peer support can take various forms but at its heart is the ability for someone living with HIV to talk to, hear from, and discuss their life and needs with someone also living with HIV. The National Standards for Peer Support in HIV highlight that peer support empowers people living with HIV by improving physical and emotional wellbeing, enhancing self-management, reducing social isolation, and delivering measurable benefits for individuals, communities, and the wider health system.

But Positive Voices data and the focus group we he;d show that some young people living with HIV never access it - sometimes because they don't know it exists. For example, one person living with HIV told us: "lots of young people who don't know Chiva exists or don't ever find out."

Young adults living with HIV highlighted the value of youth-led and specific spaces, such as those provided by Chiva including their Blueprint programme. However, across the UK there are barriers to youth specific services. For example, one person living with HIV told us: "I'm the youngest at [my peer support group]... there are people who don't know you can grow up as a child with HIV."

Funding realities compound the gap. With HIV voluntary-sector organisations' budgets shrinking, organisations are less able to sustain or scale youth-specific peer support offers. For example, Positively UK previously ran a peer programme for young people that closed due to funding cuts.

Recommendations:

- UK governments, health boards and local authorities should expand investment in peer support services. This should include making make peer support more accessible by offering it in-community, in clinic and online.
- Funders and commissioners should ensure continued investment in support services tailored to meet the needs of young adults living with HIV including Chiva's Blueprint programme.
- HIV voluntary-sector organisations and NHS providers should ensure youth peer support services are visible, accessible, and co-designed with young people.

Conclusion

Young people living with HIV in the UK face a distinct, interconnected set of challenges that demand targeted policy and service responses. Lower life satisfaction, heightened mental health needs and barriers to care are not inevitable consequences of HIV; they stem from gaps in provision, economic hardship, and the persistence of stigma and discrimination.

Our focus group participants described experiences that were personal yet widely echoed: isolation in towns without peer connections; being expected to educate their own healthcare providers; and navigating cultural barriers to care. Positive Voices findings show these are not one-off stories, but patterns seen across the country.

There is clear evidence of what works. When services are co-designed with young people and meet health, mental health, social and economic needs together, outcomes improve. Youth-specific clinics (e.g., the 900 youth clinic) and voluntary-sector programmes (e.g., Chiva's Blueprint) demonstrate the impact of peer connection, multidisciplinary support and practical help with issues like housing and finances.

UK governments have committed to ending new HIV transmissions by 2030. Delivering on that ambition requires supporting people living with HIV, including young adults, to live well with HIV. This means investing in and expanding youth-friendly services, tackling stigma and discrimination and meeting young people's holistic health, mental health and social needs.

Acknowledgment

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