

Creating a space where young people with HIV can be free

For 5 days each year, around a hundred 11–17-year-olds living with HIV in the UK leave their families for a summer camp called Freedom 2 Be. For many of them, this is one of the only times outside of hospital appointments where they speak openly about HIV. Although most of the adolescents have been told that HIV treatments are effective, they may have picked up other messages from their families: you must keep this a secret, do not tell your friends, people are not going to accept you.

Sun, now aged 26 years, first attended the summer camp when he was 16 years old. "I had known about my HIV for 4 years before that, but I hadn't knowingly met anyone who was HIV positive", he told *The Lancet HIV*. Surrounded for the first time by other adolescents who had been living with HIV since birth, "I remember feeling like this shiver and excitement", he said. Some of the other young people he has met there have become lifelong friends. "I was brought out of my shell through the friendships", he said. "You know, I did have friends in school, but I wouldn't share any of this stuff with them."

"One of the most challenging things for young people growing up with HIV is feeling that they're different, feeling that they can't connect with their peers in the same way, because they are holding something back", said Amanda Ely, Chief Executive Officer of Chiva, the UK charity which runs the camp.

Chiva was founded in 2002 as the Children's HIV Association and was initially a medical society for health-care professionals. It now focuses on direct work with those living with perinatal HIV, providing services up to the age of 25 years. Chiva has been running the camp each year since 2010, with three aims: to enhance HIV knowledge and understanding; to reduce social isolation and develop peer networks; and to enhance the participants' confidence, self-esteem, and future aspirations. A mix of workshops, outdoor activities, and social events are offered at a residential centre in the English countryside.

Some of the workshops use the arts and creativity to encourage self-expression. This may be less confronting than the more direct discussions of HIV that happen during other activities. "It's giving them space to express themselves in different ways and maybe recognise that they quite like that, or they're good at it", Ely said. "HIV is sort of kept in the space, and they will be encouraged to think about expressing their feelings or thoughts relating to HIV."

This year, participants were asked to make T-shirts that reflected how they might like to present themselves online. "I just put 'HIV is not that deep', which means, it's not a big part of my life, I kind of have it, and then that's sort of it", a 15-year-old girl named Wood told *The Lancet HIV*. "I'm a normal person: I think that was really important."

Outdoor activities, such as abseiling and rock climbing, are popular. "They're amazing and fun, but it's also about building that sense of connection and teamwork with different people in a challenging environment", camp manager Tom Burke said. "We know that that helps create the seeds of relationships that will continue far beyond a week-long residential."

Plenty of support is offered, with a ratio of three participants to each adult volunteer or member of staff. Many of the volunteers are young adults living with perinatal HIV who attended as participants when they were younger.

TJ, who is aged 17 years, said that the camp has helped him to be less shy and reserved. "It brings out that side of you to be courageous and try new things", he said. "It's caused me to develop a more outspoken personality, which I enjoy."

Caroline Foster, Consultant Physician in Adolescent HIV at Imperial College Healthcare NHS Trust in London, UK, said that the Chiva camp was often a "life-changing" and "transformative" experience for those who go. "They are completely free to be who they are without worrying about their status", she said. "I mean, some of them have just leapt into my clinic afterwards, just having had a fabulous time." But not all her patients can engage with this kind of support. "We do have a cohort in clinic for whom HIV is not spoken about at home; it is an absolute secret", she said. "Their parents would never allow them to go to camp as that risk of disclosure is just untenable."

To try to address this challenge, Chiva is now doing more work with families, including a residential weekend for families. The whole family is invited, with some activities aiming to foster more open communication about HIV within the family. As with the young people's camp, meeting other families with similar experiences is central.

Evaluations of the camp show benefits in terms of knowledge, confidence, and social connections, Burke said. "A residential can never mitigate the challenges they're facing 52 weeks a year, but they are creating the structures that allow them to navigate the rest of the year much better and into adulthood."

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