



Freedom to Be Evaluation Report Summary

December 2016

Living with HIV isn't bad and anything is possible

Young Person, Camp 2016

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Introduction to F2B

Freedom To Be (F2B) is a five-day residential summer camp for young people living with HIV in the UK and Ireland. The camp is comprised of workshops, outward-bound and recreational activities, and is intended to:

- i) Facilitate the development of peer friendships and networks in order to address the high level of social isolation experienced by this group;
- ii) Supplement participants' knowledge and understanding of how to live well with HIV;
- iii) Enhance participants' confidence and self-esteem through creative and arts-based activities, sports and outward-bound activities, and emotional support; and
- iv) Facilitate participants' access to a broader community of people living with HIV so as to provide them with knowledge, support, guidance and inspiration.

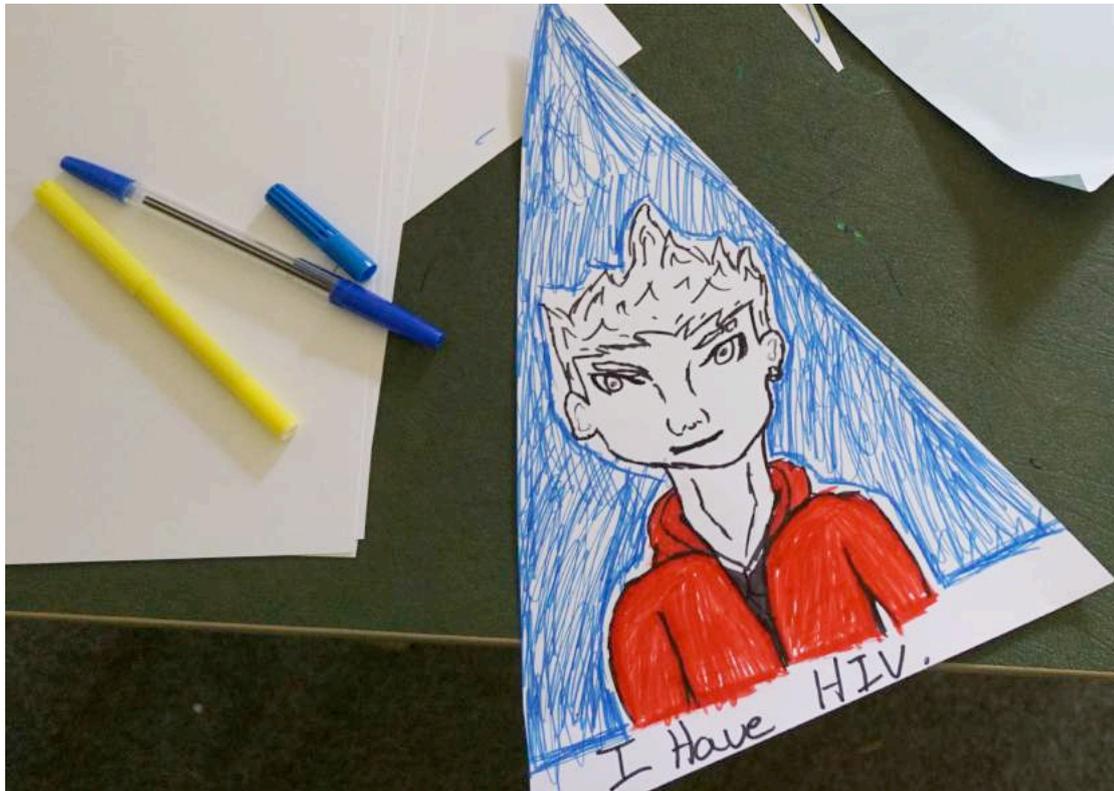
Funding

This year's camp was funded by MAC AIDS Fund, Elton John AIDS Foundation, ViiV Healthcare UK, BBC Children in Need, The MAD Trust, and a number of donations from members of the public.

F2B 2016

F2B ran from Monday 1st August at All Nations College in Hertfordshire. Each F2B camp has a theme and this year's was 'Living well with HIV'. The CHIVA Youth Committee held discussions on how they cope with the difficulties of growing up with HIV and what it means to live well with HIV, a theme connected to the idea that good health includes attending to wider social and emotional well being. Thus, this year's camp theme sought to include these broader impacts of HIV on emotional and social well-being.

Since the first camp in 2010, the age range was 13–17. This was lowered in 2015 to 12–16 and 2016 saw the first 11-year-olds attending camp, in response to the work CHIVA has undertaken in recent years to encourage the naming of HIV to children at a younger age. There were 81 campers attending F2B 2016, 44 of whom were female and 37 male.



The geographical spread of campers is provided in Figure 1.

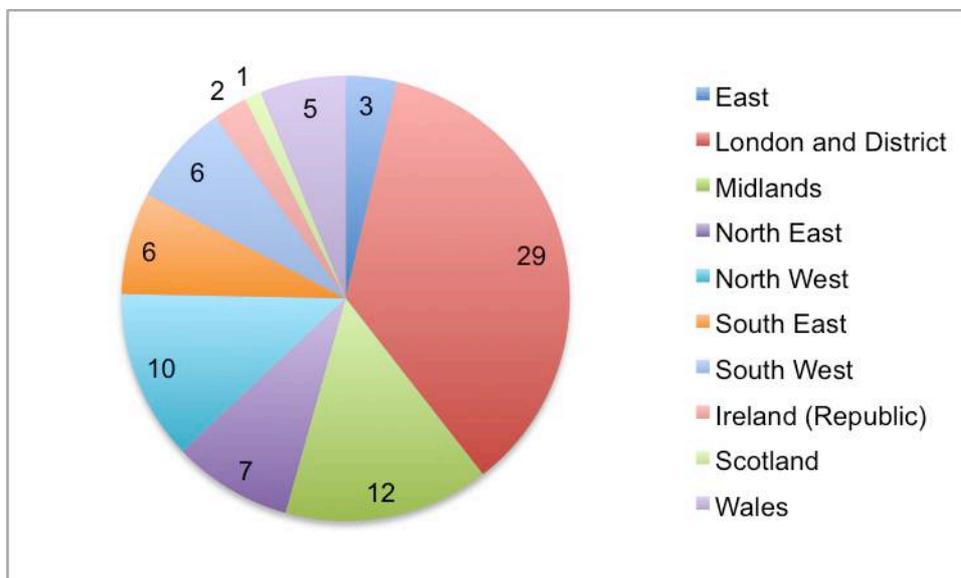


Figure 1 – regional distribution of camp attendees

Workshops and activities

In order to supplement participants' knowledge and understanding of how to live with HIV, two workshops explored living with HIV. 'Knowledge is power' sought to ensure campers' understanding of HIV, with clear information on transmission, CD4 and viral loads, how HIV medicine works, and legal rights

and protection from discrimination. The 'Live well, love life' workshop explored experiences of growing up with HIV through addressing how campers think and feel about their HIV, how this affects their behaviour, how to obtain support, and how to support one another.

More informal sexual health workshops were held in small groups of similar age and the same gender, where campers were able to anonymously ask questions by writing them down and putting them in a question box, and where they could partake in safe, supported discussions around sex and relationships, and HIV. The aim of these workshops was to alleviate fears, concerns and misunderstandings about HIV. The questions raised by girls included: what other STDs are transmitted through sex; what happens when you have unprotected sex with someone and you haven't told them you have HIV; what happens if you have sex with another HIV positive person (in relation to condom use); and is there HIV in period blood? Boys asked lots of penis-related questions; what to do if a condom comes off or breaks; and about the transmission of HIV through oral sex.

A programme of four TED-style talks was organised for the Thursday night of F2B 2016. These talks were designed to enable the participants to hear stories from their older peers. The four contributors, all with HIV, spoke about different aspects of living with HIV. Three speakers were young adults who had grown up with HIV, and they talked about: sharing your HIV status with partners; how to create your own meaning of HIV and why you need to deal with the internal stigma; and having a baby. The fourth speaker, a woman who acquired HIV in early adulthood, talked about stigma and language, becoming a mother, and being publicly open about her HIV status and engaging with activism.

Outdoor activities provided for campers included climbing, raft building, archery, high ropes, Bumble (confidence-building river activities) and football. Other activities included yoga, performance poetry, art, drama, and a performance evening and party on the final evening. The theme for this year's party was 'Return of the Super Hero'. A games room was also available, as well as pampering and a nail bar.

Staff

An experienced and varied team runs the summer camp. In line with the ethos of F2B that promotes young people's ownership of the camp, previous camp attendees are encouraged to take up the roles of camp leaders and key workers. This year's team consisted of six CHIVA staff, 16 key workers (volunteers) and nine camp leaders (volunteers aged 18–24). All camp leaders were living with HIV and had previously attended camp as a participant (except for this year's camp leader supervisor). Out of the 16 key workers, 11 (69%) live with HIV (five of whom grew up with HIV). Four had previously been camp leaders and four had also previously been a participant at camp. The remaining key workers were professionals from various fields:

teaching, nursing, social work, sexual health, event management, the HIV sector, life coaching, social science, and dental hygiene. Not all of the key workers with HIV were previous camp attendees or camp leaders. This was in order to achieve one of F2B's goals to provide participants with access to a broader community of people living with HIV, in order to offer them knowledge, support, guidance and inspiration.

The nine camp leaders all undertook a four-day training course, 'The Essentials of Youth Work', two months prior to the camp. This course provided a qualification in working with young people, accredited by the Open College Network, and it gave camp leaders a basic understanding of safe practices when working with young people; for example, managing boundaries. This course also helped camp leaders to gain a further understanding of the change in their role at camp, from participant to volunteer. This year, the nine camp leaders included a camp leader supervisor employed by CHIVA, who was previously a participant in CHIVA activities. This camp leader progressed to the camp leader role, followed by several years as a key worker, and has now joined the CHIVA staff team as camp leader supervisor.



Aims

In order to assess whether the aims of F2B were achieved, and what impact camp has on participants, evaluations were completed on the workshops, overall camp, and the experiences of the camp leaders and key workers.

At the end of each workshop, attendees completed a paper evaluation. A paper evaluation was also provided to campers at the end of camp, to gauge their overall experience of F2B. In the weeks following the end of camp, camp leaders and volunteers completed an online survey about F2B and the

support that was provided to them in their respective roles. All evaluations made it clear that they were anonymous.

Aim 1 – facilitate the development of peer friendships and networks in order to address the high level of social isolation experienced by this group

The achievement of this goal is evidenced through the number of returning campers who have kept in touch with people they met at previous camps (85%), and the number of campers who plan to keep in touch with those people they met at F2B 2016 (77%).

The old and new relationships formed and maintained between campers is vital to F2B, as the impact of these relationships is to help alleviate the isolation felt by campers.

This is supported by the numerous campers who noted that one of the things they liked most about camp was:

the old friends I see and the new friends I made.

Furthermore, an overarching theme to emerge from the questionnaire results was people and relationships. Campers stated that they most liked: the people in general (4%; n=9); meeting new people (8%; n=18); making new friends (4.5%; n=10); seeing old friends (4.5%; n=10); socialising (1.5%; n=3); and meeting other people with HIV (1.5%; n=3). One camper significantly noted:

...the trust we have in each other.

Alongside the interaction with others at camp, 2.5% (n=5) stated that talking about HIV, or having people to talk to about HIV (i.e. 'going into depth with personal experiences' and 'counselling'), was what they liked most about F2B, reiterating the importance of having peers who are also living with HIV, so that they can discuss HIV and how it affects their lives, in a safe environment.

Aim 2 – supplement participants' knowledge and understanding of how to live well with HIV

The centrality of this goal was foregrounded in this year's F2B theme of living well with HIV, along with the workshop 'Live well, love life' that sought to explore the experiences of growing up with HIV and the ways in which campers could gain support from each other and elsewhere.

To gauge whether participants' knowledge and understanding of HIV had been supplemented through F2B, the overall camp evaluation asked campers to note new things they had learned about HIV. Campers noted a total of 93 things (some campers provided multiple answers), 50% of which were HIV facts involving, for example, how the HIV virus works, transmission, and

medication. This increase in knowledge is supported by the campers who detailed a wide range of knowledge learned from F2B workshops this year. For example, facts about transmission (19%; n=14), employment (14%; n=10), the HIV virus (14%; n=10), rights, 16% (n=12) and confidentiality (9.5%; n=7) were noted by numerous campers as one thing that they learned about in the 'Knowledge is power' workshop. Those who learned something about transmission noted facts such as 'you can't pass it on by kissing'. In relation to employment, most campers stated that they had learned about being able to do certain jobs in relation to their HIV status, for example:

That you aren't restricted from doing as many jobs as I thought.

That you can't have a job in the army.

Increased knowledge of the HIV virus is evidenced by campers who noted having learned about how 'white blood cells have gates/doors' and 'the way HIV runs through my system'. With regards to rights, evaluation responses noted specific facts learned, such as 'that HIV is classed as a disability' and 'the equality act'. Knowledge gained in relation to confidentiality usually came up in relation to employment:

You have to tell your employer about your status if you want to be a dentist or surgeon.

I learnt that you don't have to tell your workplace or your college about your status.

While 50% of things learned by campers at F2B 2016 related to HIV facts, a further 35% (n=33) related to living well with HIV. These areas of learning included: sex education; positive life lessons; confidentiality, disclosure and trust; and the realisation that campers are not alone (and thus have a support network available to them).

Significantly, as a result of the workshops and increased HIV knowledge, campers reassessed their life goals in relation to HIV, learning that having HIV does not stop them from following certain career paths and having families of their own:

You can be anyone when you have HIV.

I have learnt that you should achieve whatever you want and don't let HIV get in your way.

In short, campers learned that:

I'm not too different to anyone else,

a noteworthy observation that demonstrates how the acquisition of HIV knowledge is fundamental to young people's self-perception and self-confidence, which in turn reduces their isolation.

Aim 3 – enhance participants’ confidence and self-esteem through creative and arts-based activities, sports and outward-bound activities, and emotional support

Increased self-esteem and confidence were noted in various ways across all workshops and through outward-bound activities, where campers noted having learned the importance of a positive self-image with regards to living with HIV:

That you should love yourself no matter what.

Always be yourself.

To gauge how F2B enhanced participants’ self-esteem and confidence, the overall camp evaluation asked campers to comment on what they had learned about themselves during camp, and 79 responses were gathered (some campers provided multiple answers). From these responses, we can gauge that 68% (n=54) of campers demonstrated some way in which their self-esteem and confidence were enhanced through the F2B experience.

Although this question asked campers to think about themselves, the responses demonstrate that many campers do this by taking into consideration their relationships with other people, and their relationship with HIV. 12.5% (n=10) of campers stated that the thing they learned about themselves was that they are not alone, reinforcing the importance of establishing peer networks for young people living with HIV, while the 16.5% (n=13) of responses that referred to having learned that campers were confident were often framed in relation to HIV:

That I'm able to do anything. I shouldn't let HIV stop me.

This is supported by the further 10% (n=8) of campers who alluded to an acceptance of their HIV status, saying that they had learned, for example,

To be myself, and to accept the fact I have HIV.

That even with HIV I can still love myself.

This acceptance is extended to this year’s camp theme of living well with HIV, with one camper specifically noting that they had learned ‘that I need to look after myself’.

Some camper responses suggested that they had learned something about themselves in relation to tackling isolation. 5% (n=4) of campers noted that they are not that different to other people, including those who are not living with HIV:

I'm no different from negative people.

The same number of campers said that they had learned they are able to talk about their status and share their feelings, while 2.5% (n=2) of campers recognised that they are currently unable or reluctant to share their feelings:

That I'm holding in a lot of anger towards people but I need to forgive

so I can feel better.

I'm not one to speak about his problems.

An increase in self-esteem was also demonstrated through the positive traits noted by 7.5% (n=6) of campers, such as 'I learnt that I am a nice person and caring' and 'I'm funny', and through the skills learned (11.5%; n=9):

I didn't know I could do canoeing.

I'm not afraid of heights.

That I can socialise.

I am more creative than I thought.

The creative workshops were evidenced as providing campers with a safe space in which to explore their HIV status and how they felt about it, which is a significant step for many campers who stated that they learned it was not only OK to share their feelings (perhaps being used to keeping their HIV a secret) but helpful:

...felt a good way to express how you feel.

It was also the case with outward-bound activities that campers learned they were more capable than they thought, able to approach and overcome scary situations. Just as one camper learned that 'I'm not afraid of heights', another camper learned through the creative workshops that

I was never able to talk about my status but I can a bit.



Aim 4 – facilitate participants’ access to a broader community of people living with HIV so as to provide them with knowledge, support, guidance and inspiration

It is clear that the final goal of F2B was achieved in a number of ways. Figure II demonstrates that 84.5% of campers thought that it was either ‘very important’ or ‘sort of important’ to be around young people at F2B who also have HIV, while 70% of campers thought the same about meeting adults at F2B who also have HIV, potentially further reducing the isolation felt by these young people.

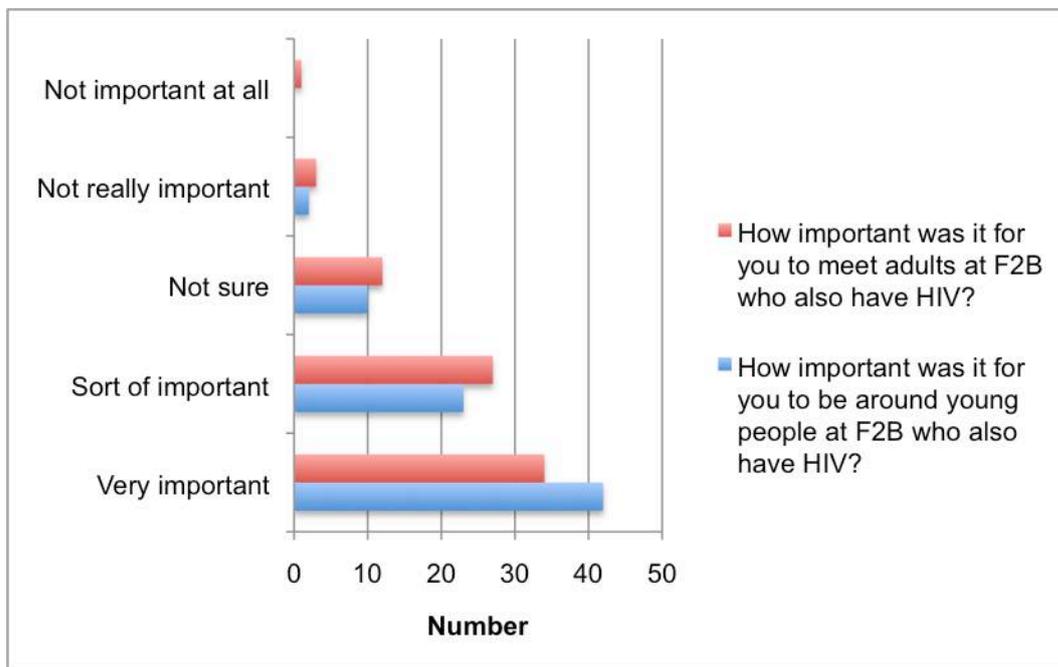


Figure III – the importance to campers of being around young people and adults living with HIV

The importance of being around other people living with HIV is reflected in the high number of campers who stated that their favourite thing about F2B 2016 involved people and relationships, be it making new friends, seeing old friends, socialising, or meeting other people with HIV.

The fourth goal of F2B was also supported this year through the TED-style talks, alleviating the feeling of isolation and providing campers with inspiring stories from other young adults who have grown up with HIV, as described by one camper who stated that ‘I wasn’t the only one who has been through tough experiences’. This reiterates a critical recurring theme from each year’s camp, which is that F2B often results in campers explicitly realising that they are not alone, ‘meeting new people in the same situation as me’, and that there is support available to them. Equally, while HIV is the focus of F2B, the workshops and activities also allowed campers to think beyond HIV, acknowledging that ‘it doesn’t define who I am’.



Conclusion

The achievement of this year's F2B aims demonstrates the importance of continued funding for the CHIVA summer camp, which continues to provide a safe space for young people living with HIV to: learn facts about HIV; learn how to live well with HIV; develop friendships with their peers; and access emotional support.

Out of this year's 81 attendees, 53 were not attending a support service, highlighting F2B's role in alleviating the isolation experienced by those campers residing in more remote areas, and in bringing together young people from across the UK regions (as demonstrated in Figure I). The long-lasting support networks that are fostered by these young people at F2B are unique to the summer camp residential experience, which provides the time and space needed to build up these young people's trust in each other, enabling them to continue these relationships once camp has ended (as evidenced by the achievement of Aim 1, with a high percentage of campers keeping in touch with people they met at previous camps). The intense intervention of a five-day camp, with young people surrounded by other young people and adults who are also living with HIV, guides participants towards a normalisation of HIV, as demonstrated by the above camper who noted having learned that they are no different from negative people.

F2B is a unique space that offers young people the opportunity to explore their relationship to their HIV, whilst providing activities and workshops that boost their self-confidence, helping to alleviate the isolation, fear and stigma that are often associated with HIV.