



Freedom to Be Evaluation Report August 2017



People think that living with HIV means we can barely survive, but living with HIV we can thrive.

Young Person, Camp 2017

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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 the Elton John AIDS Foundation, ViiV Healthcare UK, BBC Children in Need, The MAD Trust, Happy Days Charity, MAC AIDS fund, and donations from members of the public.

In order to gauge the impact of this funding, CHIVA aims have been analysed against funding measures, as detailed in this report.

F2B 2017

F2B ran from Monday 14th to Friday 18th August at the Hollowford Centre in Derbyshire. Each F2B camp has a theme and this year's was 'Acceptance', which was reflected in the various workshop activities.

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 91 campers attending F2B 2017, 51 of whom were female and 40 male.

The geographical spread of campers is provided in Figure I.

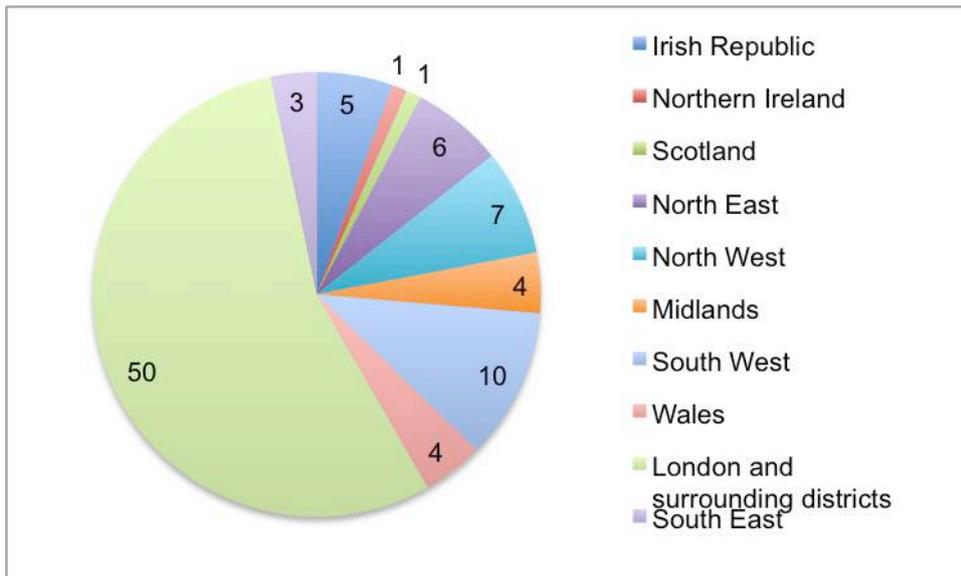


Figure 1 – regional distribution of camp attendees

Workshops and activities

In order to supplement participants’ knowledge and understanding of how to live with HIV, two workshops explored living with HIV. The ‘HIV knowledge and understanding’ workshop sought to establish campers’ sound knowledge around basic HIV facts involving CD4 and viral loads, how HIV medicine works, legal rights and protection from discrimination, and reproduction information. ‘HIV knowledge and understanding’ also addressed adherence, exploring what adherence to medication means. More specifically, the workshop addressed the small but important role that medication plays in campers’ lives, what makes taking medication and adherence difficult, and what helps.

The ‘Skills and strengths’ workshop explored talking to other people and acceptance. The aim of the workshop was for campers to consider their experiences and wishes regarding telling other people about HIV, and to develop the skills and confidence needed to do this. This was supported by the ‘Tree of life’ exercise that focused on acceptance by exploring campers’ skills and strengths, hopes and dreams, and the people who are important to them.

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 aims of these workshops were to alleviate fears, concerns and misunderstandings about HIV, and to allow discussions about sex to take place in a safe, non-judgmental space.

As well as the two main HIV workshops, four creative workshops explored this year’s theme of acceptance. Through performance poetry, art, drama, and music,

campers developed various methods of self-expression, exploring their feelings related to HIV whilst also increasing their self-confidence through the growth and recognition of various skills and strengths.

Outdoor activities provided for campers included abseiling, canoeing, and football, and on-site team-building activities included bush craft. Other activities included yoga, dance, and a party and film on the final evening. The theme for this year's party was 'Light and Hope'. A games room was also available, as well as a pamper area and nail bar that were open nearly every evening.

At the closing ceremony on the final day of camp, participants and volunteers wrote postcards that were either a message to their future self or what they had learned during camp. Some of these messages are included in the conclusion.



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 four CHIVA staff, 17 key workers (volunteers) and eleven camp leaders (volunteers aged 18–24).

All camp leaders were living with HIV and except for one, had previously attended camp as a participant. Out of the 17 key workers, 13 live with HIV, seven of whom grew up with HIV and had previously been camp leaders, and six of whom had previously attended F2B as participants. The remaining four key workers not living

with HIV were professionals from various fields: children and young people's mental health, social work, social science, and the voluntary sector.

Nine of the 11 camp leaders all undertook a four-day training course, 'The Essentials of Youth Work', two months prior to the camp. The remaining two were returning camp leaders and had completed the course in 2016. 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.

Key workers undertook a training weekend that provided a background to CHIVA's work and approach, child protection, medication information, HIV information, camp information (including timetabling and roles), and role plays and small group discussions to explore challenging behaviour scenarios.

For the second year running, the 11 camp leaders were supported by a camp leader supervisor employed by CHIVA, who was previously a participant in CHIVA activities.

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; out of 91 attendees, 89 campers completed this form.

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

Measure 1: Many children growing up with HIV experience significant isolation due to its low prevalence but also the secrecy that still surrounds the virus. F2B combats this by bringing together a critical mass of HIV positive children and creating an environment that encourages open conversations and challenges negative perceptions.

The majority of F2B 2017 campers (92%; n=82) noted that being around other young people with HIV was either 'very important' or 'sort of important', while a slightly lower figure (83%; n=74) thought the same about being around adults who also have HIV. Further demonstrating that F2B provides an environment that encourages campers to have open conversations about HIV, is the fact that a large number of campers (26%) noted people and relationships as the thing they liked most about F2B. This included meeting new people and making new friends, as well as reuniting with old friends and 'community', which supports the F2B aim to decrease campers' isolation and increase their peer networks. This was further demonstrated by 3.5% (n=9) of campers who noted that 'meeting others with HIV', and 'talking to people who have HIV' was the thing they liked most about F2B, and 6.5% (n=16) of campers noting that they most liked the fun and supportive environment, which offered a family atmosphere that encouraged respect and acceptance.

As with previous years, through being around other young people (and adults) with HIV, and undertaking educational and creative workshops, campers learned 'That you are not alone, people are there and going through the same thing' (Young person, F2B 2017).

Measure 2: At least 40% of those attending this intervention will be coming for the first time.

This year, 46% (n=41) of campers were attending F2B for the first time.

Measure 3: The evaluation at the end of each intervention will ask questions on the friendships made and how the young people will keep in touch. At least 80% of those who attend F2B will state that they intend to keep in contact with people they have met over the week.

The majority of campers at F2B 2017 (86.5%; n=77) stated that they plan to keep in touch with people they met at this year's camp.

Measure 4: Those young people who live in the most isolated regions of the UK in areas of lower HIV prevalence are able to attend camp: 40% of campers live in regions of the UK outside of London.

As demonstrated in Figure 1, 55% (n=50) of campers were from London and the surrounding districts, with the remaining 45% (n=41) from regions of the UK outside of London.

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

The approach to this goal was foregrounded in this year's F2B theme of acceptance. Through the acceptance of HIV, or even the beginnings of acceptance,

a foundation is created for these young people to confidently build their knowledge and understanding of living well with HIV. [This aim was also supported by the 'Tree of life' exercise that focused on acceptance by exploring campers' skills and strengths, hopes and dreams, and the people who are important to them.¹]

Measure 1: Knowledge and understanding of HIV is improved following attendance at camp: 70–80% of campers report improved/increased knowledge and understanding of HIV.

77.5% of campers (n=69) who completed the final F2B evaluation noted having learned something new about HIV. The HIV-related areas learned about included the law, HIV facts, medication and adherence, talking about HIV, and self-acceptance/confidence. As noted below, in relation to the workshops, an even higher figure of increased HIV knowledge was reported.

Measure 2: Detailed knowledge of living well with HIV is critical to the self-management of HIV and to challenge self-stigma. Specially designed youth-friendly workshops ensure knowledge and understanding and explore the impacts of HIV on well-being, self-esteem and share experiences of growing up with HIV.

F2B workshops provided factual knowledge of HIV – especially 'Knowledge and understanding' – while other workshops such as 'Skills and strengths' and the creative workshops worked on ways to increase campers' self-esteem and overcome self-stigma.

Out of the 89 'Knowledge and understanding' workshop evaluations completed by campers, 80% (n=71) noted having learned something about living with HIV (e.g. the importance of self-esteem, talking about HIV, and seeking support when necessary) or HIV facts (e.g. relating to medication, the HIV virus, and the law):

You can have HIV negative babies.

About HIV and how ARVs work.

The effects of not taking meds.

More about UK laws.

CD4 counts.

How to transmit HIV.

¹ For this exercise, campers created a symbolic tree, with the roots representing their past, the ground their present, the trunk their skills and abilities, the branches their hopes and dreams, and the leaves representing the special people in their lives.

The 'Skills and strengths' workshop further explored the impact of HIV on well-being and self-esteem, or rather, how confidence, HIV knowledge, and an awareness of available support can help campers to live well with HIV. This was demonstrated through campers' responses when asked to state one thing learned. Out of the 88 evaluations received for this workshop, 37.5% (n=33) noted forms of self-acceptance and self-confidence, while a further 26% (n=23) stated talking about HIV (who to talk to and how to talk about HIV). It is worth noting that campers' acknowledgement of the importance of talking about HIV was not solely in relation to disclosure: some campers made a connection between talking about HIV, the importance of having a support network, and well-being:

That you are not alone, people are there and going through the same thing.

The creative workshops (art, drama, poetry and music) were designed to enable the discussion and exploration of feelings and experiences of growing up with HIV, with facilitators supporting campers to process their discussion through creative practices.

For the art workshop, an arts facilitator worked with small groups to reflect the camp theme of acceptance. Campers made boxes through which they were able to tell a story that, while relating to many different aspects of participants' lives, also encouraged them to think about HIV and acceptance. In this workshop, campers also designed and made lanterns, which were linked to this year's party theme of 'hope and light'.

The drama workshop facilitator was given the camp theme in advance to help shape and direct the session; however, this activity was led by what the young people brought to the session, whilst being guided to explore their experiences of HIV. Through a combination of drama games and activities to encourage the expression of feelings and sharing stories with peers, drama sketches were devised that developed the theme of acceptance.

The poetry and music sessions enabled an exploration of narratives about acceptance, expressed through music, singing/rapping and poetry. For the poetry workshop, the facilitator introduced rap, spoken word and performance poetry to make this session relevant and accessible to campers, before sharing his own poetry, which inspired the group. This created an open and safe environment for young people to write and perform their own poems about personal experiences of living with HIV, which resulted in impressive and moving performances.

One camper who took part in the music workshop noted that the session was about 'coming together through music', highlighting that these workshops were not just about learning creative skills but also about building supportive networks through shared experiences of HIV.



This is reflected in the number of campers who learned something about self-expression and self-esteem during the creative workshops: 40% (n=8) of music workshop attendees learned something about music as self-expression, how it could increase their confidence, and made them feel hopeful; 22% (n=4) of art workshop attendees noted having learned something about hope and confidence; 55.5% (n=5) of poetry workshop attendees noted self-expression and confidence as one thing learned; and 16.5% (n=2) of drama workshop attendees learned about self-expression, while a further 16.5% noted 'acceptance through drama' as the workshop topic.

Aim 3 – enhance participants' confidence, self-esteem, and hope and aspirations for the future

Measure 1: Young people attending camp experience enhanced self-esteem and confidence about living well with HIV: Over 70% of campers report improvements in their mental wellbeing in relation to living with HIV and describe an increased acceptance about a life with HIV. (This could be through outward-bound and team activities, developing friendships, through creative expression, performances, or during the workshops.)

In response to this year's new question, which asked campers whether they think F2B has helped them feel better about living with HIV, the overwhelming response was that yes, camp had made them feel better about their status. 76 out of the 89 responses to this question (85.5%) selected 'yes', while 14.5% (n=13) of responses

selected 'maybe' and no campers selected the 'no' option. A few campers even wrote a few words to emphasise how much F2B had made them feel better:

A lot.

Hell yes.

Definitely.

From the responses to this seemingly simple question, it is clear that F2B has had a positive impact on campers' self-esteem and their acceptance of HIV.

F2B also enhances participants' confidence and self-esteem through its outward-bound activities and creative workshops, which provide campers with new skills or bring to light their existing skills and positive attributes, thus increasing these young people's level of self-esteem. To measure this, question 7 of the camp evaluation asked campers to comment on what they learned about themselves during F2B 2017.

Nineteen out of the 89 respondents left this question blank, stated 'nothing', or that they did not know what they had learned about themselves. Out of the remaining 70 responses to this question, the majority (58.5%; n=41) noted elements of acceptance and self-confidence:

How instead of being afraid of having HIV, I can be confident and empowered.

That I can get on with or without HIV.

That the sky is the limit for me.

About my HIV and how to live with it.

That I found the real me and I have changed so much.

I'm more than my HIV.

I can do things that I didn't think I could do.

I'm not alone, I'm not different.

A further 20% (n=14) of campers noted skills and positive traits that they learned about themselves, or emotions that they have acknowledged, which also demonstrate an increase in self-confidence:

I'm not too bad at dancing.

That I am funny.

That I'm a good friend.

I need to be calm.

I learned to have fun.

That I display a lot of musical talent.

The possibility of talking to others about HIV and feelings in general, and how to do

this, was mentioned by 13% (n=9) of campers as something they learned about themselves:

How to connect with others.

Socialising with different people with the same status.

I've learned to open myself and make more friends.

Have been more open about my HIV.

It's not bad to express emotions.

These responses demonstrate that campers learned that they are capable of expressing their feelings, and ways in which to do this, potentially reducing the isolation experienced by this group of young people.

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

The measures reported for Aim 1 already demonstrate that the majority of F2B campers thought that it was very important to be around other young people and adults with HIV and that they plan to keep in touch with people they met at this year's camp. Out of those campers who had attended F2B before (48), 85.5% (n=41) reported having kept in touch with previous year's attendees.

Furthermore, when asked to name their favourite thing about F2B 2017, as with previous camps, numerous campers (45.5%) stated people, relationships, making new friends and reuniting with old ones, being around others who have HIV, and the supportive and family like atmosphere provided by other campers and the staff. In addition, general comments relating to the creative workshops demonstrate that campers found them to be 'inspiring'.

Conclusion

Workshop and camp evaluations have demonstrated that F2B 2017 largely achieved its four goals, and that F2B remains a significant step in helping campers to live well with HIV.

The first goal of F2B is to facilitate the development of peer friendships and networks in order to address the high level of isolation experienced by this group. The old and new relationships formed and maintained between campers is vital to F2B, and 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 (85.5%), and the number of campers who plan to keep in touch with those people they met at F2B 2017 (86.5%). This is even higher than last year's figure of 77%. As noted by

one camper, 'The best thing about being here is meeting new friends that have HIV and I can speak to them about it instead of keeping it all a secret.'

The second aim of F2B is to supplement participants' knowledge and understanding of how to live well with HIV. Living well with HIV involves an acceptance of HIV, hence this year's theme. The theme of acceptance encouraged campers to work on ways in which they could explore whether and how they were able to accept their HIV, with the aim that this would form a foundation for these young people to increase their self-esteem and willingness and openness to learn about HIV. It is evident from questionnaire responses that campers learned a great deal about how to live with HIV, with regards to an increase in knowledge of HIV facts, through the 'Knowledge and understanding' workshop. Furthermore, in response to all of the workshops, campers noted things learned about themselves that demonstrated a greater acceptance of HIV and thus a higher probability of living well with HIV. As one camper implies, there is a correlation between an increase in HIV facts and self-esteem: 'I have learnt how to be more confident of myself living with HIV. I learnt more things about HIV, so now I don't have a lack of knowledge from it.'

A further goal of F2B is to enhance participants' confidence, self-esteem, and hope and aspirations for the future through creative and arts-based activities, sports and outward-bound activities, and emotional support. Increased self-esteem and confidence were noted in multiple ways across all workshops, both implicitly and explicitly.

The creative workshops provided campers with a safe space in which to explore their HIV status and how they felt about it. The exploration and sharing of narratives was key in the creative workshops, as campers learned that there were others who had similar experiences with HIV, which lessened feelings of isolation and allowed campers to voice their previously silent feelings: 'I've learnt to accept myself and sit humbly and socialise with different people. I have learnt to review my status, to feel open and to feel comfortable about myself.' Evaluation responses have demonstrated that the creative workshops resulted in campers not only acknowledging an increase in self-esteem but also in a more hopeful reconsideration of aspirations. Some campers specified particular career paths they now wanted to follow, while others noted that the workshops and F2B in general made it clear that HIV was not as large an obstacle to future aspirations as they had previously thought.

It is clear that the final goal of F2B – to facilitate participants' access to a broader community of people living with HIV so as to provide them with knowledge, support, guidance and inspiration – was achieved. An overwhelming 92% 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 83% of campers thought the same about meeting adults at F2B who also have HIV.

The combination of community, support, factual knowledge about HIV, and creative and therapeutic opportunities has helped this year's campers to develop their skills and strengths and come to terms with accepting their HIV, all of which has provided a foundation for a healthy, aspirational future. In the words of one camper:

For me being here made me feel free. I used to be worried about my future but now I feel much better. I used to think I am the only one with HIV but I was wrong and thanks for proving me wrong I really appreciate it.

This piece was written by young person who attended camp for the first time. Dani lives with HIV and also has additional physical needs and uses a wheelchair.

Hi my name is Dani I'm 13 and I live in the south coast. I was born with HIV (but I like to call it Bob!). This year was my first time at camp and I absolutely loved it. The camp leaders and managers planned things in advance so I didn't have to worry about a thing. The activities I took part in were, surviving in the forest (it was a little bit creepy but I suppose it will help me for the future), canoeing(I got my shoes wet but it was so fun). I picked drama as the creative subject and it taught me how to express my feelings. The place that the camp was at was really accessible and that help me so much because I am in a wheelchair. I would definitely go back next year.

