

Health Care Professionals & Parents/Carers Evaluation

The impact of the CHIVA summer camp reported by the health care providers and parents/carers

December 2010

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The Children's HIV association received funding from the Elton John AIDS Foundations and Pfizer to run a pilot summer camp for HIV positive young people. The camp ran from 15th-19th August 2010. Additionally to the evaluation of the young people's experiences being undertaken by Sigma Research, a small evaluation was undertaken to gauge any impacts and/or changes viewed by health professionals offering health care to these young people and their parents/carers. This report sets out the findings from this.

Section One: Health Care Professionals

1. Methodology

Two months after the CHIVA Summer Camp "Freedom To Be" (F2B) the doctor and/or nurse of each young persons attending were asked to complete an online survey. This survey had been specifically designed for them to identify any changes they had seen in their patients since F2B. The survey questions addressed the following topics: (1) Changes in the way young people engages with healthcare professionals; (2) Changes in confidence of the young people; and (3) Changes in their well-being (specifically addressing knowledge of and approach to HIV as well as the development of peer relationships).

A total of 10 responses were received, many of who work with more than one of the young people and the responses therefore represent reports on 47 out of the 79 attendees¹ (59%). We need to acknowledge that most young people only have appointments every three months, some of the health care professionals would not have had the opportunity to see these young people in this two month period.

2. Results

2.1 Changes in the way young people engages with healthcare professionals

'They seem more at ease with their diagnosis' (Healthcare Professional)

¹ This is due to the paediatric HIV being a specialism, therefore young people travel far to these specialist clinics or the HCP travel to them.

- **50%** of the respondents indicated that their patients now demonstrate more confidence in their mutual interactions.
- **50%** of the respondents describe their patients' eye contact/body language as now being more direct.

The responses from the healthcare professionals suggest that F2B has facilitated a more positive relationship between them and many of their patients. The qualitative responses suggest that these changes are closely correlated with an increased acceptance by the young people of their condition and therefore a more positive approach to HIV and their healthcare (see also paragraph 2.3 below).

2.2 Changes in confidence

- **80 %** of the respondents report a higher level of self-esteem in their patients.

One of the main aims of F2B was to foster a higher level of self-esteem amongst the attending young people. The results of the survey suggest that healthcare providers saw a correlation in young people attending F2B and an increased levels of confidence and self-esteem.

2.3. Changes in their well-being

'Feedback from voluntary sector organisations working with patients report more knowledgeable and inquisitive in lots of areas' (Healthcare Professional)

2.3. Knowledge of HIV

CHIVA saw being in receipt of adequate information is a significant contributing factor to the well-being and confidence in young people diagnosed with HIV. Providing this information was therefore one of the key objectives of F2B. Respondents to the survey were asked whether their patients appear to be more knowledgeable in regards to a range of topics that were covered in various workshops during F2B. The feedback obtained suggests that F2B has indeed increased the knowledge base of the young people attending, as demonstrated in the table below:

Area	% of respondents stating
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	young people appears more knowledgeable
Adherence	60%
Having children	30%
Healthy living	20%
Medication	50%
Sex	40%
Support services	10%
Talking to others	70%
The clinic	20%
The science of HIV	40%
Their rights	30%

Whilst for every topic there exists at least some young people who appear to have increased their knowledge in this area, improvement is most noticeable in: *Talking to Others* (70%), *Adherence* (60%) and *Medication* (50%), followed by *The Science of HIV* (40%), and *Sex* (40%). On an individual scale this will be largely dependent on age, optional sessions attended and prior knowledge, as well as the topics of conversation which occurred in the clinic. Whilst a couple of respondents noted that prior to F2B the baseline knowledge of some of the young people was *'already quite good'*, for others F2B proved to be a significant and unique source of information, as noted by one respondent;

'Perfect timing for patient recently disclosed to for education not previously able to have before disclosure' (Healthcare Professional)

It must be noted that the indicated changes represent the increase in knowledge as demonstrated to health professionals. A more accurate assessment will be produced by approaching the young people directly on improvements in their knowledge of HIV, which will form part of research commissioned by SIGMA (results to be released in January 2011).

2.4 The young people's approach to HIV

'They are more engaged in clinic and more eager to learn' (Healthcare Professional)

- **50%** of the respondents stated that the young people in their care appear to demonstrate a higher level of interest in regards to health care issues.
- **90%** of the respondents stated that the young people in their care are more inquisitive in regards to their health care.

Besides the information factor, young people need the motivation and capabilities to better interact with their current and future environments. The responses received indicate greater interest and willingness of the young people to be informed and involved in their healthcare. The quantitative data received as shown above is supported by qualitative responses which indicate that the young people show greater interest in discussing HIV, are more willing and eager to ask questions, and are generally taking a more active role in managing their healthcare since the camp.

'They engage more in conversation about their illness now rather than their parents doing all the talking' (Healthcare Professional)

The qualitative responses from the responses indicate that these changes could in part be a result of a decreased sense of social isolation and stigma on behalf of the young people as illustrated in the quote below.

'More open in their discussions and they feel less stigmatised and less alone' (Healthcare Professional)

2.5. Developing peer relationships

'They both expressed how great it was and the fact that they were able to meet so many young people who may experience the same problems with regards to medicines and disclosure. They were also able to exchange tips and strategies to deal with such issues (Healthcare Professional)

Responses from healthcare professionals suggest that F2B was highly successful in meeting one of its key objectives: promoting the development of peer relationships amongst the young people thereby addressing their high levels of social isolation. 8 of the 10 respondents commented that many of the young people now talk about the

friends they made at F2B and actively keep in touch by means of a range of media (telephone, e-mail, facebook, etc). As illustrated in the quote featured above, these relationships can act as a vital source of practical information and support. Additionally, F2B appears to have increased contact between young people living in close proximity of each other, as noted by one healthcare professional:

'Some of our young people who went to camp together are now talking to one another in the waiting room (this has never happened before)' (Healthcare Professional)

2.6. Other

The respondents to the survey were additionally invited to comment on their patients' experiences at F2B and any further changes they may have noticed. These responses were all of a very positive nature and emphasised the young people speaking very highly of F2B and expressing a keen interest to attend future events.

'Both patients thoroughly enjoyed the camp and spoke very highly of it. The father of one of them emailed me to say how much his daughter had enjoyed the camp. They were both keen to attend again. It is an excellent idea and well worth continuing' (Healthcare Professional)

Section Two: Parents and Carers

1. Methodology

Two months after F2B, 9 parents/carers were approached to give feedback. 4 responses were received, after which telephone interviews were conducted with 3 parents/carers (1 could no longer be reached at the agreed time or number). The parents/carers were asked to indicate their particular reasons for sending their child to F2B, their child's reactions to F2B upon his/her return; and any changes they might have noticed in their child since F2B.

2. Results

The 3 parent/carers interviewed represented 4 HIV positive children who attended camp, 2 male and 2 female. Of the parent/carers interviewed, 2 were female and 1 male. They were from Ireland, the South/South West and London.

2.1 Why they sent their child to F2B

'To share experiences and make friends and basically to see how others were getting on' (Parent, interview 1)

All 3 parents stated that they sent their child in order for him/her to meet other people and make new friends and that they particularly wanted them to meet and make friends with other HIV-positive young people. Additionally, the parents expressed how they hoped that the F2B would be both an educational as well as an enjoyable experience.

2.2 Reactions from the young people when they returned home from the F2B

'She told me about the wonderful experience she had had, the kids, the good activities ... these children were free, they were excited, they were playing about. This reflects about how for once they were free'. (Parent, interview 2).

'She was absolutely praising the key workers to heaven. Team leaders were excellent, she thought the things they did was cool, that was a good thing and very unusual coming from a teenager'. (Parent, interview 3).

'They got a lot of information, more than they would get in the hospital' (Parent, interview 1)

The above quotes illustrate the very positive feedback the parents received from their children. They mentioned several times that their children were very enthusiastic about F2B as a whole and had found it to be a very enjoyable and rewarding experience, meeting new people and making new friends. As indicated in particular by the first quote above, the parent of this particular young people felt F2B was a significant life experience, where for once they could really be themselves in an environment void of stigma and secrecy. The parents also saw F2B as a significant learning experience, enabling the young people to receive education and guidance not available in their every-day environment.

2.3 Have you noticed any changes since your child attended F2B?

'It was a great experience, you could see it a difference in them, they are starting to grasp it and to accept it ... they have seemed to accept it more because they know there are more people out there ...if they are mixing with other children with the same problems, then they can realise that its not the end of the world' (Parent, Interview 1).

'Now when I tell her to do something, there's that element of her trying to do what she has been asked to do' (Parent, Interview 2).

'... Seems more knowledgeable, she learnt a lot through the teaching' (Parent, Interview 3).

The parent of interview 1 emphasised the readily apparent benefits of their child interacting with other HIV-positive young people. This respondent emphasised how, due to socialising with other HIV-positive young people, their child seemed much happier and was more accepting of his/her health status. The other 2 respondents also indicated that it was beneficial for their children to socialise with other HIV-positive young people, as well as other positive volunteers.

The discussions with the parents also revealed that F2B has succeeded in increasing the knowledge base amongst the attending young people. Additionally, the parents noted that their children appeared to have made many friends, many of which they kept in contact with since F2B. This information correlates with the feedback from the Health Professionals and the Sigma Research evaluation, suggesting that F2B has been successful in addressing in facilitating peer relationships among the young people attending.

Section Three: Conclusion

Responses from both Health Professionals and parents indicate that F2B was an extremely enjoyable and beneficial experience for the young people who attended. One of the elements most strongly emphasised was the opportunity F2B provided for these young people to make friends and build social networks - a vital element in addressing the social isolation experienced by this group.

Additionally, this feedback has shown that F2B acted as a key source of information, and has significantly increased the knowledge base of many of the young people attending. Through addressing some of the particular issues that many HIV positive young people face (social isolation, stigma, lack of information), it is likely that the camp will play a key role in facilitating the conditions that lead to better adherence and better mental and/or physical health outcomes. This is readily apparent through the more positive relationship many of the camp attendees now seem share with their healthcare professionals, as well as a more positive approach they now have in regards to managing their healthcare.