



Report from the residential weekend run in July 2007

'It was fantastic to be able to meet people who could understand where I'm coming from. Thanx to this I have been able to speak about my problems openly and this has given me confidence.'

Magda Conway
January 2008

Thanks

I would like to thank NM Rothschild without whose financial support this residential could not have taken place. I would also like to thank all those who referred young people and who took the time to work with us to make, at times, complex travel arrangements, or who travelled down to London to ensure these young people had the chance to come.

Special thanks go to Amanda Ely, Imaad James, Linda Toocaram, Tom Burke and Trish Allen who worked so tirelessly over the weekend. Their enthusiasm, flexibility and commitment meant that the weekend ran smoothly.

Finally, I would like to thank the 25 young people who arrived at London Bridge shy, scared and excited, who threw themselves into every aspect of the weekend, and who gave so much to us and to each other.

The Children and Young People HIV Network is core funded by the Department of Health and part of the National Children's Bureau. The aim of the Network is to ensure children and young people both infected with and affected by HIV who live in the UK have a voice in policy and practice development.

Introduction

The Children and Young People HIV Network ran a residential consultation weekend in July 2007 for HIV infected young people between the ages of 13-18. The aims of the weekend were:

- To consult with a group of HIV infected young people on their information needs post-disclosure and on the journey to adulthood.
- To offer a group of HIV infected young people the opportunity to meet others living with the virus and build informal peer networks.

The findings from the consultation will direct the content of the CHIVA website information pages for young people and will be presented in other publications and work being developed with this group.

This report presents the process of setting up such an event, the format and activities of the workshops, sets out some of the information gathered, and how feasible it would be to run such an event in the future.

1. THE PROCESS

This section offers an overview of the process and planning undertaken when organising the residential.

1.1 Referral process and allocation of places

Places were initially allocated under a specific remit. Requests for referrals, a short explanation of what we were planning to do and why, and a referral form (see Appendix 1), were distributed through a number of health and social care email-based networks: African HIV Policy Network, Children's HIV Association, National Children's Bureau, National AIDS Trust and Terrence Higgins Trust.

Before referring, professionals were asked to confirm that the young person was definitely fully aware of their HIV diagnosis, was interested in being considered and that they were available for the dates. The form itself asked for:

Name
Age
Area of residency
Gender
Ethnicity
Any issues with immigration

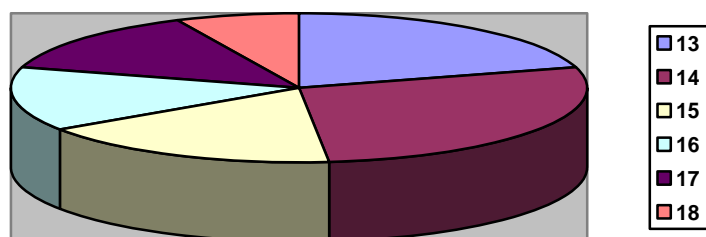
All in all, 65 referrals were received, although only 30 young people could be accommodated. Of the 65 referrals, only 15 were from young men and 50 were from young women. It was hoped that by using this information, places could be allocated to reflect the national demographic of children and young people living with HIV, with a broadly representative ethnic and gender balance. An attempt was made to include an even spread of ages and to ensure the experiences of young people in the asylum and immigration system were included. As one of the aims was to reach isolated young people, it was felt that those outside of London should be allocated a higher proportion of places as they have less opportunity to access services. Therefore just over half of the young people who eventually came lived outside of London (Chart 1.2).

It is important to note at this point what we were actually asking the young people to undertake. Some potential referrers reported that going away for a weekend with a group of strangers to talk about a topic which for many is never spoken about outside of a clinical setting was too overwhelming a prospect for some young people. Some young people initially voiced an interest in coming, and then, when offered a place, felt they were not ready.

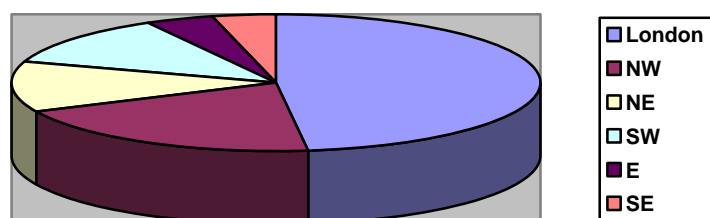
Initially 30 places were available, with a 1 to 5 worker-young people ratio that did not include the coordinator (a total of 7 staff). Due to a number of last minute cancellations, a few 'no-shows' (which was expected) and a staff member having a family emergency, 25 young people ultimately attended with 5 workers, plus the coordinator.

1.2 CHARTS

1.2.1 Age



1.2.2 Who came from where



1.3 Letters and paperwork

Those who were offered a place were written to through the person who referred them. They were sent information about the weekend, and asked to complete a number of forms, which included parental consent, behaviour agreement, emergency contacts and additional medical/health information (see Appendix 2) with a SAE for the forms to be returned. Once these were received, a second letter was sent to the young person's home with details of the meeting point, a clothing list and more details on what would be happening over the weekend.

A risk assessment of the entire weekend was produced and shared with management and the key workers for input and agreement.

As this was a group of young people who did not know each other, or know the workers, very clear behaviour guidelines were drawn up and these included what disciplinary action would be taken if these were broken.

1.4 Key workers

Most of the young people did not know anyone else and so it was important to establish key worker groups to assist integration and to give the young people a named member of staff they could go to. The key workers were there to

offer both practical and emotional support, which was essential in ensuring the well-being of the young people over the weekend.

The key worker team were all experienced workers, specialising in working with young people, HIV, participation and consultation. The team met prior to the weekend and all received individual briefings and a pack for the workshop activities. The team had a de-briefing each evening during the residential. The coordinator did not take on key worker duties, as during a weekend such as this, there are many practicalities that need to be negotiated with the centre, and the workshops need to be set up and dismantled each day.

Each young person was designated a key worker, and each key worker had responsibility for 5 young people. Their role was to support their designated young people both practically (such as the storage of and reminders to take medication) and emotionally. The key work groups met each day for 'check-ins'. The young people were delegated a key worker by age and gender, each key worker group had a gender mix and kept similar ages together. Young people who knew each other were purposely separated so that everyone was in a similar position of not knowing each other – this worked extremely well.

A few young people were specifically designated a key worker due to a particular situation or issue. For example, one key worker is one of the oldest known surviving children born with HIV. He was specifically paired with a young person who's physical inability to take his medication was a grave concern to both the parents and professionals involved. Throughout the weekend, the key worker took his medication at the same time as all the young people in his key worker group. This approach, where there was no real negotiation as everyone went into the same room at the same time and just took their medication, worked well. Only a weekend such as this can offer this kind of opportunity.

1.5 Travel

Transport was arranged to leave from central London. All the young people attending were asked to travel to London where they could meet everyone, have some lunch and then we all travelled together in a coach to Norfolk. All transportation costs were covered, and although some of the transport arrangements were far from orthodox, with young people meeting for the first time at railway stations, all young people arrived safely from across the country.

1.6 Accommodation

All young people were accommodated in dormitories that slept between 4-6. As with the key worker groups and the small groups in the workshops, these were designated prior to arrival. Each young person was rooming with at least one person from their key worker group (see 2.1) and one person from their workshop group. Obviously there were separate dormitories for the boys and for the girls.

1.7 The centre

The residential centre was chosen as it offered a good programme of outward bound activities led by qualified staff; had separate rooms available for running the workshops; was in a remote location; and had large grounds that included a football pitch. The location meant that there were no concerns around young people deciding to explore the local town and the grounds gave the young people the space to 'do their own thing' together.

As is generally the case with such centres, the facilities were being used by a number of school and youth parties. Therefore it was decided that we would not specifically inform the centre of the precise nature of our visit (not that it was officially required, but curious staff did ask). It was felt this was in the best interests of the group and demonstrated to them how importantly we considered their confidentiality.

2. FORMAT AND ACTIVITIES

The weekend was planned to allow for both intensive workshops, activities that focused on team building and some free time for the young people to get to know each other on their own terms.

This section sets out the workshop activities and their findings. The workshops aimed to encourage the young people attending to think about their experiences of HIV, primarily focusing on post-disclosure and what did, or would have, supported them in this journey. These findings will offer practitioners the opportunity to hear and learn from the young peoples' experiences, and through this to improve practice for the next generation of positive young people.

The activities run during the workshops on Saturday and Sunday morning were based around sharing and exploring personal experiences and feelings. The full breakdown of activities used for both days can be found in Appendix 3. The initial activities were focused on bringing the group together and supporting them in feeling comfortable in talking about HIV in the abstract, as opposed to offering their personal experiences. The findings set out in this section are from the activities that explored the young peoples' experiences and encouraged sharing and debate.

The majority of young people who attended gave their views and experiences with little prompting. The level of bonding and support the young people offered each other was extremely impressive. The acceptance of each other's experiences and the frank and open discussions that took place were at times humbling. From the first instance of the group meeting it was stated that we would be encouraging them to talk openly within the workshops about their experiences of HIV. This gave many of the young people the 'green light' they so very much wanted to eloquently and passionately express themselves and to describe their experiences.

2.1 Groups

Primarily the activities that were undertaken were small group work, with 6 young people in each, as the topic and issues would not be appropriate for discussion in the larger group. Effort was made to include large group sessions at the start and end of each morning. The young people were allocated small groups, and in each of these young people would be placed with one person whom they were also sharing a dorm room and one person from their key worker group. That way, there were people to talk with afterwards, but also the young people got the opportunity to mix.

2.2 Day 1: Meeting up

We had hoped to undertake a team building exercise at our meeting point in London, but due to complex travel arrangements this was not viable. The group met at the Children's Commissioner's Office for England at London Bridge. The young people were asked to say their first name and where they had travelled from. They were then given a very brief introduction to the purpose of the weekend, what was planned and what was expected from

them. They were then introduced to their key workers and went into key worker groups to get to know their group a little better, find out the role of their key worker and sort out practicalities such as support and storage of medication.

The journey took three hours, after which the young people were shown around the centre, and given their rooms. After dinner, centre staff ran an evening team building/problem solving activity in the grounds.

2.3 Day 2: Workshop 1

The initial two activities were designed to bring the group together and encourage them to talk openly about HIV in the abstract. There was an initial big group activity to establish ground rules and why they were so important in this context.

The young people were then asked to go into their key worker groups for a 'pub quiz'. The quiz consisted of 9 questions that aimed to ensure everyone had a good knowledge about HIV and encouraged group discussion and debate to agree on a group answer. Areas covered included routes of transmission, the law and data (see Appendix 4).

Then the young people were designated their workshop groups for the weekend. They worked in these on all activities with the exception of the sexual health session where single gender groups were used.

The initial activity in the workshop group was continuing to talk about HIV in the abstract. The groups were given letters such as those sent to a magazine Agony Aunt. Group members took it in turn to read out the letters and then the group discussed how the Agony Aunt should respond. All letters made reference to HIV (see Appendix 5).

2.4 Activity: Talking to you

This was the first activity where the young people were asked to recount their personal experiences. The aim was to look in some detail at how they found out they had HIV and at the questions they had at different times. The young people were asked to write responses to different questions on colour-coded paper, relating to the questions, in the shape of bricks and clouds. After each question, the group would look at all the answers and talk about their experiences. These bricks and clouds were then collated and presented as a display, thereby demonstrating all the shared experiences the group had.

2.4.1 Bricks

The young people were asked four questions about being told about their HIV diagnosis. What follows are the questions and then a summary of the answers given:

Question 1: At what age did someone tell you you had HIV?

Ages ranged between 'I've always known' to 16. 14 young people had been told between the ages of 11-13, 6 before this and 5 after. The general

consensus of this group of young people was that 12 was the optimum age, and definitely no later.

Question 2: Who told you?

This varied, but generally involved a health professional (Nurse or Doctor) and a parent/carer. When asked 'who do you think should have told you' there was a split between a medical person (Doctor/Nurse) and a parent/carer. Some young people wanted to be told by a Doctor or Nurse as they saw this as medical information. Others wanted to be told by a parent or carer as they saw it as something more personal.

Question 3: Where were you told?

This varied from in the home, in a support service or in the hospital. The discussion around this was very interesting, as some young people felt they wanted to be somewhere 'safe' and familiar, such as the home, whereas others said somewhere neutral or somewhere they never had to go back to.

Question 4: Who was there?

Generally this was a parent/carer and either a medical person or a support person. For planned disclosure, some young people reported quite a few people being present. Unplanned disclosure was also reported,

'I was on my way to bed and my Mum said 'you've got HIV'.

2.4.2 Conclusion

These questions produced very powerful discussions where the young people shared their experiences with each other, and were surprised with each other's reactions. Some of the young people had 'an idea' that they had HIV before they were told:

'I'd caught a glance at my notes once, but didn't want to say anything'. This produced feelings of fear and anger.

During these discussions, in one group a young person stated:

'It doesn't matter where you're told and who tells you – it doesn't change the information. You've still got HIV and you've still got to live with that.'

The group who heard this comment all agreed.

It is also important to note that within this group of young people, no one said they wish they had not been told. This probably reflects where this particular group are in coming to terms with their diagnosis, which is why they wanted to attend a residential. Even those who were obviously still struggling still wanted to know, and many wanted to know earlier than they had been told.

2.4.3 Clouds

The clouds represented the questions that were or were not asked at different points during and after the naming of HIV. The responses offer an insight into

what needs a young person has post-naming and where professionals can possibly assist in the future.

Cloud 1: Questions you asked

The young people were asked if they could remember the questions they asked at the time their HIV diagnosis was given to them. For some that was not possible, as they had been told at a young age or 'always knew'.

The answers fell into 6 categories and most young people asked a number of questions.

- Mortality: *'Am I going to die?'*
- Who knew: *'How long have you known?', 'Why didn't you tell me sooner?', 'Who else knows?'*
- Transmission and what having HIV actually means: *'What is HIV?', 'How did I get it?'*
- *'The first question was why me?'*
- Denial: *'When are we going to eat? Do we still get KFC?' or 'Can I play football now?'*
- Nothing: *'I didn't ask my mum any questions (even though I had questions to ask!)*

Cloud 2: Questions you wanted to ask

This question was asked to see whether once the young people was told that they had HIV or once they had been given the answer to their initial question, they felt they could ask all the follow-up questions they wanted to at that time. Again this differed, as some young people asked their questions, whereas others, for whatever reason, felt they could not.

There were some personal questions that relate to specific circumstances for individual young people, but on the whole the responses fell into 5 categories:

- Transmission: *'How did I get it?' 'Who gave it to me and how did they get it?'*
- Mortality: *'Will I die?'*
- *'Why did this happen to me?'*
- What this means for life now: *'Is it curable?' 'What does it do to me?' 'What's gonna happen from here?'*
- What does this mean for my future: *'Can I have children?' 'Will I ever find love from others?' 'Why can't I tell anyone?'*

What is clear from the responses to these two questions is that a degree of detail is important, even if the young person does not ask. An observation is that parents/carers and professional have the long build-up to naming/disclosing HIV to the infected child, yet for that child the journey only just begins at that point. Parent/carers and practitioners may feel relief that this task is now completed, but full recognition needs to be given to the long-term impact this information subsequently has on that young person. Their ongoing need to ask questions and to have information reiterated to them is key.

Also, equipping and supporting parent/carers to continue offering an open dialogue outside of a medical setting is hugely important. Many young people reported that HIV was never spoken about at home, and they felt unable to raise it. Reasons for this included that the young people did not want to make their mother feel guilty about transmitting HIV, and that it could remind the family about the bereavement of a parent through HIV.

Cloud 3: Questions you had after being told of your diagnosis

The young people were asked if they could remember having any questions in the weeks after they had been told their diagnosis. This was to help look at the needs for young people once they had recovered from what for many was a shock (some reported that they had guessed or had overheard conversations, so had an idea pre-naming).

The unanswerable question of 'why me?' was still there for many. As one young person wrote, '*Why me, why me Lord, why me Lord?!*'. Also still evident was a lack of understanding of what it meant, 'What does the word mean?' On the whole though, the responses fell into 3 categories:

- The future, whether it is about a cure: '*Will somebody find a cure soon? In my lifetime?*' or things they 'can' or 'can't' do, '*Can I still live in America?*' '*What can I do and can't do? Will this effect my future life?*'
- Sex and relationships was very important, whether it was about having sex, having children or getting married. '*Can I have sex? Can I have kids without HIV?*' There was a need for detail, so several wanted to know '*Can I have kids without giving it to my partner. Will my kids have HIV?*'
- Medication, whether it is about continuing it, starting it and how long they would need to take it: '*What medicine will I have to take and for how long?*'

For this question, they were lots of references to 'cans' and 'can'ts' and 'what I am allowed to do'. Perhaps this is due to the age of the young people, but this came out often during the weekend. During the quiz, the young people were obviously shocked when they found out there were actual laws that were

supposed to protect them from discrimination (the Disability Discrimination Act 2006 was cited). One young woman asked if she was 'allowed' to get married. Reinforcing the message that 'You can do what your peers do, you just may need to be a little more careful about certain things' is extremely important for this group.

Cloud 4: Questions you have now:

Finally we asked the young people what questions they had now. Of these questions, the responses mainly fell into 5 main categories:

- Confidentiality and employment, thinking about the future, about adult services as well as employment: *'How much confidentiality is there when you're older?' 'What do you do when applying for jobs? What do you say?'*
- Disclosing to peers: *'Will I be accepted in my 'group' if I told my friends?' 'When can I tell my friends? Are they trustworthy?'*
- There were many questions about sex and relationships, these were mainly about disclosure to sexual partners: *'How do I develop a relationship with my girlfriend? How do I tell her? Should I have one-night stands?' 'At what point in a relationship do I disclose my status?'* Also there were questions about having children and whether they will be HIV positive, *'Will I be able to have a baby that won't have HIV!!'*
- A cure: *'Is there ever going to be a cure?'*
- Many wanted to know about life expectancy: *'What's my life expectancy?' 'When do we get AIDS? And how old will we be?' 'Do we all have full lives?' 'Am I going to die?'*

2.4.4 Conclusion

This simple exercise offered an insight into the experiences of HIV infected young people. There are very prominent themes, which can be explored in practice, whether this is in a medical or social support setting. Many of their questions and fears are simply answered. Some are unanswerable, but then to be told that no one really knows why you were infected and your sister/brother was not is at least an answer of a kind.

What is clear is that this group need relationships built on open dialogue; they need to have at least one person they can trust and ask questions. This weekend offered them the chance to reflect and discuss, and so many questions came out. This opportunity for reflection and space to think is extremely important for them. They also need to be signposted to places where they can access more in-depth information.

2.5 Activity: Fishing for answers

This activity was set to explore issues relating to talking to others about HIV, including sexual health and sexual partners, and what specific information is

needed in this area. The young people were divided into single gender groups set by age. Facilitators were briefed to not presume everyone is sexually active, or that they were not sexually active.

Each group member used a fishing rod to 'catch' a fish. Each fish had a different question attached to it, and the young person could either answer the question or open it out to the group (questions in full can be found in Appendix 6). What follows are the key areas that came from these discussions.

2.5.1 Question One: Talking to friends and what would help you to do this?

Concerns were raised around friends' reactions and what was mainly highlighted here was that the friends do not necessarily have the correct factual information or knowledge about HIV.

'I don't know what their reactions will be. They might not have the knowledge that we do.'

'Even though you have good mates, you're just not sure you can trust them.'

The playground culture around HIV also added an additional barrier, as one young person stated about a friend of theirs:

'If someone's ill, she says 'they've got AIDS, AIDS!'

There was also concern as the education in school on HIV is generally perceived to be either poor or confined only to detached science classes that don't look at the social implications of the virus, and so their friends do not have access to the correct information,

'People don't know. We had a teacher who said you could get HIV from kissing.'

The general consensus was that if you were thinking about telling a friend, you would have to first ask lots of general questions to see how they reacted to HIV and what they actual knew, before considering disclosing.

2.5.2 Question Two: What are the issues around becoming a parent?

Most of the groups had thought about being a parent. The older groups had many questions about getting pregnant, such as 'Would a positive partner be better?', and wanted in-depth information about vertical transmission. All the older young women said they hoped to be mothers one day.

This located a need for some young people-friendly resources that explained in detail about becoming a parent.

2.5.2 Question Three: What are the issues around talking to a possible sexual partner, or a current sexual partner about HIV?

'It's tough enough starting a relationship without HIV. It's tough to get over that burden, feeling obliged to tell them.'

For this group of young people, only one had told a friend and only one had told a sexual partner, with pretty disastrous consequences. It was obvious they felt stuck. Some were in relationships and wanted to say something, but they were waiting. Additional concerns were about families, as the young people were aware that if they disclosed their status, they might be putting their family 'in danger'.

One young person said, *'Like the websites for how to make best man speeches, I wish there could be one for how to tell people about HIV.'*

This is a great suggestion and could follow the guidelines on disclosure to sexual partners offered in sexual health clinics, with alterations to the language so they are appropriate for this age group and cover more than just sexual partners. Offering them a similar point-by-point guide to consider would help them think through the process both with sexual partners but also with friends.

2.5.4 Question four: Who can you talk to about sex and sexual health?

This varied, as is the case with all young people. Some said their nurse or doctor, others their Mum. Some suggested web-based information. The older group of young women talked about sexual health services, and the consensus was that none of them would use them. This stemmed from a fear of the questions they would be asked, how people would react to their answers and how confidential their information would be kept. Many cited cases where they had had blood tests in non-HIV specialist services and the reactions they had had there. (Discrimination at the hands of healthcare workers was a key finding in research produced by City University London entitled *'HIV-related discrimination reported by people living with HIV in London, UK'* (December 2007), where over half of people who reported discrimination said it was by those working in health).

Young people on the residential also highlighted that a lot of sexual health information they receive focuses solely on sexual transmission of HIV. They felt this leads to greater stigma around the disease and that if other routes of transmission such as vertical transmission were stated too, there would be less stereotyping.

Young people spoke about their experiences of Sexual Health and HIV education in schools,

'In an RE lesson my teacher said if he found out he was HIV positive he would shoot himself. I've never been back to his lesson since.'

2.5.5 Question Five: Where do you want sexual health education from and how should it look?

The general consensus was it needs to be simple, *'In the style of a magazine'*, with easy to understand language and, *'It needs to have meaning'*. Contextualising the information to reflect young peoples' lives was extremely important.

The young people also spoke about educating their peers and that HIV education needs to mention that young people can be born with it and how life is for them.

2.5.6 Question Six: What do you feel you ought to tell a boyfriend/girlfriend and what do you actually want to tell them.

Trust was crucial here. Many young people's parents had told them they were not allowed to tell their siblings about being HIV positive. This meant that they found the concept of trusting and telling anyone very difficult. The fear of having their trust broken and how they would then trust anyone again was a real sticking point for some.

'I have a boyfriend but I haven't told him. I love him and I want to tell him, but I'm just too scared and I don't know how'.

2.6 Conclusion

This group of young people have predominantly been brought up in an environment of 'secrets'. The impact of being told your diagnosis and then being told not to tell anyone has meant for this group that they felt unable to even start to consider talking to others about this. It does present a difficult dilemma for practice. Confidentiality is important in a climate that discriminates against those with HIV, yet how does one balance confidentiality with ensuring that HIV positive young people are, when ready, able to talk to their peers and sexual partners about this. As one young person stated,

'I'm sick of all the secrets, sometimes I just want to tell everyone and get it out in the open.'

This presents an issue for disclosure work, and this could be explored and in many cases managed in a clinical setting. When a child is finally told their diagnosis, rather than being told to tell no one, they could be asked if there was anyone they would want to tell (once the need for confidentiality has been explained to them in full). This could then be negotiated by the parent/carer and health professional. One must not underestimate the impact of being told not to tell anyone. During these young peoples' lives they are going to need to tell people. Starting as a child from the premise that 'this is so terrible you must not tell a soul' can be extremely debilitating, especially when coupled with living in a house where HIV is never spoken of and siblings do not know.

This session highlighted the need for some resources specifically for this group that explore keeping themselves sexually healthy, negotiating safer sex, talking to sexual partners and on having children. It also highlighted the fact that friends are equally as important as sexual partners to this age group. Anything produced that looks at talking to sexual partners should also focus

on 'talking to people', as the process will be similar for friends and sexual partners.

2.7 Activity: Life Maps

This used an arts-based exercise for the young people to explore their lives so far and their hopes and dreams for the future. Each group had a table of art and craft materials and were asked to create a representation of their life-journey and told that they would then be asked to share that journey in their small group. They were reassured that they could include as much or as little detail as they wished; that they could start the journey at a place they felt comfortable, and that when sharing what they had created, they could again give as much detail as they were comfortable with. This was extremely important as a number of the young people had come from conflict and war and so this meant they could share as little or as much as they wished.

This was a personal exercise, and gave the young people space to reflect on their lives, but also an opportunity to look to the future. The workers were there to offer support during the exercise, but also, to give the young people space. This exercise worked on many different levels, but it did give the young people a chance to hear about the lives of others, and realise that so many of them shared similar experiences, such as the death of one or more parents.

Thinking about and talking about the future, their hopes and their dreams, was so important to this group. Some were very clear on where and who they wanted to be, whereas others, who were still struggling with their diagnosis, needed to be encouraged to think ahead. Once they had overcome this initial obstacle (for many this meant believing that they were actually going to live and not die), they started to plan and dream and there was a noticeable change in them even in that short amount of time.

2.8 Activity: Tree of life

This was one of two activities that were used to finish off the workshop. The young people were given paper in the shape of leaves and were asked to write down their hopes and dreams on these and then to stick them on the 'tree of life'. This offered the group a visual depiction of all the young peoples' hopes and aspirations, and reinforced all they shared in common as a group.

2.9 Activity: Group Statements

To conclude the workshops with a physical activity that allowed the young people to express the thoughts and feelings the weekend had provoked for them, the young people were asked to prepare 'group statements' to perform to the rest of the group.

Each group needed to decide:

- What statement about HIV they wanted to make
- Who they were making this statement to ('our group', their peers, parents/families, doctors, society, government, global community etc.)

- What form this statement would take (spoken word, song, dance, role play etc).

The young people were given two rules to work within when preparing. Firstly that the performance piece would start and end with a 'freeze', and if possible, this 'freeze' would convey a message. Secondly, that the performance would take no more than 3 minutes in total.

The groups decided on their messages and rehearsed their performances. Each group stood against a wall in the same room, and then performed their piece in a round. This was an exceptionally powerful activity, which the young people enjoyed.

In brief, the performances were as follows:

Dispelling the myths

The group started by dispelling myths about HIV transmission by a pair showing the action (sharing a drink, holding hands, kissing) and the group saying the myth. They then spoke about isolation and sung (accompanied on guitar by one of the young people) the chorus of, 'You are not alone' by Michael Jackson.

X-Factor Audition

Three acts audition for the X-Factor, two are appalling but one has talent. Before making their choice, the judges ask some health questions. The talented performer discloses his HIV status, at which point the judges physically recoiled and said he had not got through. When he complained, they called security to take him away. In their freeze, they chanted 'stop the stigma'.

Collecting for charity

This role play looked at how when collecting for a charity, the public were interested and wanting to help, until they found out it was an HIV charity, and then they did not want to know.

Stigma and bullying

This group looked at how children can be bullied, and how this is part of the stigma of living with HIV. They role played how a group of young people gang up on an individual and how name calling and isolation can and has affected them.

2.10 Final round:

In the final group round, the young people were asked to reflect on their experiences over the weekend and each tell the group either what they would take away with them, or if there was something that had been particularly important to them this weekend.

Primarily the young people felt privileged to be involved in the weekend:

'I never thought I'd say this, but I feel lucky to have HIV. If I didn't have it I wouldn't have had the opportunity to come here and meet you lot'.

They wanted the residential to be longer, and they wanted to do it again. Making new friends and not feeling alone were recurring statements.

'I thought I was the only person with this. Now I know I am not alone. This has changed my life, and I'm so happy!'

3. Conclusion and Recommendations

3.1 Conclusion

The impact of this weekend on the individuals involved cannot be underestimated. Since the weekend, the feedback from those who referred the young people has been extremely positive. Most refer to how changed these young people are, more confident and relaxed. The best conclusions come from the evaluation forms completed by the young people.

'I loved the weekend, loved the people that came, felt comfortable around them because we have the same problem so I really enjoyed it'

'I loved it! Thank you for giving me this opportunity and please do it again!'

'It has been a great weekend and has given me friendship and confidence, I hope there will be many more of them as it gave me an insight that I am not alone.'

'We could stay for like a week and talk about more things.'

One young person wrote:

'From this weekend I think I have gained more information about HIV than any leaflet could give me. The key workers and the workshops answered all the questions I had. I think that more residential weekends should take place to give more HIV children the experience I have had. This weekend has been different to the other weekends where it's children who are affected and infected. With this weekend with all infected people we all got to share similar experiences and realise we are not alone.'

3.2 Recommendations

3.2.1 Resources

The utter lack of resources and places to acquire information for this group is well known. These findings will direct the content of some web pages, but paper resources are needed too. Although this is a small group, they have very specific needs, and these need to be included when producing health promotion and information for HIV positive people.

3.2.2 Supporting parent/carers to talk about HIV

Parent/carers need to be supported not only through the disclosure process, but also in the complexities and need for open conversations that having an HIV infected child presents. This is an area that needs communication between health and the voluntary sector, and between these two, parents can be supported outside of a clinical setting to communicate with their children about HIV. This is not an easy task, as many parents may not feel ready or equipped to do this, but some steps should be made in this direction.

3.2.3 More residential weekends / national large group activities

As the number of HIV infected young people in the UK is relatively low, and isolation is a major experience for most of them, bringing large numbers together and the opportunity to see how much they have in common has a massive impact. Just the experience of looking around the room at your peers and knowing that you all have HIV cannot and should not be underestimated.

3.2.4 Listening to this group of young people

HIV is a relatively new disease, and we now have a large group of young people entering adulthood who were born with it. This offers for the first time a resource of information and experience that should not be overlooked. Only this group can really tell us what it is like to grow up with HIV and what they need to support them in this journey. This source must not be overlooked, and what they tell us should be central to developing good practice when working with this group. Prior to this, practitioners were second-guessing, but now we have the opportunity to ask and then act.

4. Learning

This section presents two areas where what was set in place prior to the residential was found to be not entirely effective. This will be of interest if the reader is planning to run a similar event.

4.1 Medication

Appendix 2 shows the paperwork we asked the young people and their parent/carers to complete. In hindsight we should have included a separate sheet for those taking medication (both HIV and others) to set out in advance what they took, when they needed to take it and whether there were any additional needs in this area. Medication requirements are always going to have the potential for adding complexity to a weekend away, so careful planning of this in advance is advised.

It is also worth considering that if a young person is in residential care, they may need their medication monitored or forms completed. If this is the case, it is important that this process does not stigmatise that young person and set them out as different from the rest of the group.

4.2 Arrangements

Many of the arrangements for moving the young people around the country were organised by their health professionals or voluntary sector organisations. Volunteers were used to escort young people. From our experience making contact with this person prior to the residential is important, as is the understanding that the young person attending, if under 18, is the responsibility of those organising the residential, and therefore arrangements made with that young person need to be relayed and confirmed with the organisers.

For example, we had one young woman who could not decide whether she wanted to stay. She called home and spoke to her Mother, as did her key worker. Her Mother said that she should stay, and the young woman was supported in agreeing. The next day she suddenly changed her mind and called the volunteer who had escorted her and asked her to come and collect her – all without the knowledge of the workers. After she left, she called young people on the residential and told them she wished she was still there. Had we been informed by the volunteer that this call had been made, we as a team were confident we could have supported this young person in her anxieties and in deciding to stay. There is little doubt that the weekend would have benefited her immensely.

4.3 Referrals

There will always be a number of 'no-shows' at events such as these. In hindsight, talking to referrers about the young people who are given places, and discussing whether that young person may need specific support in getting to the meeting point (they may need to be brought by a staff member) may lessen the number who do not show.

Appendix 1: Referral forms

REFERRAL FORM

Youth Involvement Residential (13th – 15th July 2007)

All information provided will only be used in the selection process for this residential. Prior to completing this form, please ensure each young person:

- Is between 13-19 years of age
- Is HIV infected and knows about their diagnosis
- Is available from 13th July - 15th July 2007
- Has parental consent if under 16
- Wants to be involved

Please return referrals by the 8th June.

ABOUT YOU: Organisation/individual making referral

Contact name:

Job Title:

Organisation:

Contact telephone number:

Address:

Email:

YOUNG PERSON

We need the following information about each young person you are referring. You may refer as many young people as you wish. At present, no places are guaranteed.

Name:

Age:

Gender:

Ethnicity:

Where they live (nearest city, county or region):

Is this or has this young person been in the asylum/immigration system:
Yes/No

Appendix 2: Forms sent to young people

Consent Form for the residential being held between 13th – 15th July by the National Children's Bureau

This form will be used as consent for the residential being held at the Overstrand Centre, run by Kingswood Activity Centres, in Norfolk from the 13th – 15th July 2007. It is the responsibility of the people who referred you, or you and your parent/carer, to arrange your transport to and from the meeting point in London. From that point, all transportation, accommodation and activities will be organised by the team from the HIV Network. The information in this form will be kept in a confidential file at NCB and will be shredded after the residential.

General Information

Name _____

What I like to be called _____

Date of Birth _____ Male/ Female _____

Address _____

Telephone number _____

Name of parent(s) / carer(s) _____

Name of hospital you attend _____

Name of your consultant _____

Are you taking HIV medications? YES/NO

Do you want support in taking this medication over the weekend? YES/NO

Do you have any medical needs / conditions that you feel we should be aware of (other than HIV)?

Do you have any special food requirements or allergies that you feel we should be aware of?

Do you have any access requirements that you feel we should be aware of?

Emergency Information

If there is an emergency we need the name and address of someone we can contact. If possible, two contacts would be helpful.

1. Emergency contact name _____

Address _____

Telephone number _____

2. Emergency contact name _____

Address _____

Telephone number _____

Name of Doctor (GP): _____

Doctor's address and telephone number: _____

Photography and video

Your confidentiality is extremely important to us. We will want to take pictures throughout the weekend that can then be sent to all the young people attending as keepsakes. We will also take pictures that do not show the young people's faces, but show them doing activities. These pictures will only be used at HIV related events and no young person will be recognisable. We are also considering giving the young people access to video cameras to film their time, this will only be for distribution amongst the young people, although we may use the sound for presentations at HIV related events. Before using any images in a public arena, we would first always seek your permission. Do you give permission for this? Yes / No

Signatures

Your signature

Signature _____ Date _____

Your parent/carer's signature

Please ask your parent/carer to read and sign this form if you are under the age of 18 (if you are 18 and living at home, it may be nice to show your parent/carer this form and they can sign it if they wish.)

Name _____

Signature _____ Date _____

Contact phone number: _____

Behaviour Agreement

Please sign one copy and send it back to us – you keep the other copy

To keep all of you safe, physically and emotionally, we are asking every young person to sign a behaviour agreement. Breaking this agreement could result in you being sent home.

- Alcohol at the residential is absolutely forbidden and any found will be confiscated and destroyed.
- Anti social behaviour, which includes bullying, racism, sexism and homophobia will not be tolerated. Teasing because people's accents are different, or because you come from different parts of the country or the world, is not acceptable.
- The use or possession of illegal drugs is completely unacceptable and will be dealt with accordingly; this may result in the involvement of the police.
- If you have to smoke, you must only smoke in the designated smoking area.
- The Overstrand Centre will have its own rules that will be about keeping you safe and making sure everyone's stay at the centre is a good one. We expect you to keep these rules.

We expect all our participants to:

1. Be kind and courteous to others.
2. Not shout at others or swear.
3. Treat equipment and other people's belongings with care.
4. Take part in the activities provided.
5. Not cause danger to anyone including to himself or herself.
6. Not hit/kick/bite/scratch anyone else.
7. Not leave the group without telling a member of staff.
8. Not resort to any form of bullying such as:
 - **Physical;** hitting, kicking, taking belongings
 - **Verbal;** name-calling, insults
 - **Indirect/emotional;** spreading nasty stories, excluding from groups.

Discipline Steps

We will always give you the chance to explain unacceptable behaviour and where we can, we will hope to sort this out without giving you a warning.

We will have a three step warning system:

First warning: this will be a verbal warning from a member of staff.

Second warning: this will be another verbal warning with a telephone call to your guardian/parent.

Third warning: if you receive a third warning that will mean that you get sent home.

Under severe circumstances you could be sent home immediately.

By signing this form I agree to the rules set out here.

Name:

Signature:

Date:

Appendix 3: Workshop plan

Session 1: 9:15 – 10:25 (Saturday 14th July)

Ground Rules

9:15 – 9:50 Activity One: Fact & Fiction (Magda/Amanda)

Big group (but working in key worker groups)

Aim: to establish a general awareness about HIV and get YP use to hearing it and talking about it in the abstract.

Outcome: to start thinking about HIV and undertake group activities relating to it.

First exercise: 9 Question Quiz (then answers).

9:50 – 10:25 Activity Two: Agony Aunt Letters

Small group

Aim: to get the YP to start talking about and thinking about HIV.

Outcome: to have talked in the abstract about issues relating to talking about HIV.

Small Groups

You will have a set of letters:

- One person read out one letter
- One person leads on answering it
- Opened to group for any other comments

Session 2: 10:40 – 11:50 (Saturday 14th July)

10:40 – 11:15 Activity Three: Talking to you

Small Group

Aim: to look at some details about how they found out they had HIV, and questions they had at different times. These needs to be put in some kind of time structure, and will be used to structure the information produced for the website and for the possible published material.

Outcome: to have colour coded bricks (for their answers) and clouds (for the questions they had/have) filled in.

Bricks

Red: At what age did someone tell you, you had HIV?

Blue: Who told you?

Yellow: Where were you told?

Orange: Who was there?

Clouds

Light blue: Questions you asked

White: Questions you wanted to ask

Light yellow: Questions you had after

Pink: Questions you have now

11:15 Activity Four: Fishing for answers

Single gender groups, sexual health focus session.

[NB Do not presume everyone is sexually active, or that they are not sexually active.]

Aim: to explore issues relating to sexual health, what would help this group of YP and what they need to know.

Outcome: to locate areas and issues that HIV infected YP need to have information on regarding their sexual health.

Have a rod and a lot of fish shaped questions with hooks on. Take it in turns to hook a question and then answer it. Everyone has the option to opt out; this question will then be open to the group to see if someone else wants to answer it. Facilitate discussion and debate. Record this session on dictaphones.

11:45: Final Big Group for the morning

Session 3: 9:15 – 10:25 (Sunday 15th July)

9:15 Introduction

Big group to introduce morning

9:25 Activity Five: Life Maps

Small Groups

Aim: using a creative exercise for the YP to look at their lives, what has happened, where they are now and what they want in the future.

Outcome: learn what information we need to produce for those children growing up now who have HIV, what this group needs now and what they think they will need in the future. In facilitated discussion, try to draw out what would have/could support them through the issues/experiences they raise.

Creative exercise to produce life maps/life river/life journey. What is important is it is something that is reflective, about now and about the future. Look at:

- Key events leading up to now.
- Where they are at now.
- Hopes for the future.

Ask YP to feed back to the small group (KW making notes so we can understand the maps and ask them if we can keep them or if they want to take them home, can we photograph them).

Come back together for game

Session 4: 10:40 – 11:50 (Sunday 15th July)

10:40 Activity Six: Tree of Life

Big Groups

Introduce 'Tree of Life' and give 5-10 minutes to fill in leaves etc.

10:50 Activity Seven: Group Statements

Small Groups

Each group needs to decide:

- What statement they want to make
- Who they are making this statement to (our group, their peers, parents/families, doctors, society, government, global community etc.)
- How they are going to make that statement (speak, song, dance, quick role play etc).

Rules:

1. They need to start and end in a 'freeze' (photo, still) and that needs to say something. It can be the same freeze, or something different (get them to all count [in their heads!] when they are in the freeze so they break out of it at the same time).
2. The statement must take no more than 3 minutes; it can be shorter, but not longer.

11:20 Presentation/Performance

Each group will stand in a different part of the room and then we will go around in a circle with (if possible) each statement flowing into the next. Hopefully this should look excellent.

11:40 Final Group Round

Appendix 4: Quiz questions

- Who travelled the farthest to be here today?
- What is HIV?
 - a) Bacteria
 - b) Syndrome
 - c) Virus
- Is there a cure for HIV/Aids?
- Name 3 places where HIV can be found in the body?
- Name three ways in which you can be infected with HIV?
- Approximately how many people are infected with HIV in the UK?
- How many under 19s are living with HIV in the UK
- Do people living with HIV have any legal protection
- Today in the UK, out of every 100 HIV+ women who have a baby, how many will be HIV positive?

Appendix 5: Agony aunt letters

Letter One

Dear Aunt Agonia

I went to this party a month or so ago and met this dead fit girl. I got her number and we've met up a couple of times. Last week my mate Leroy said he had a new girlfriend, and when he showed me her picture off his phone, it was her.

I texted her and she said she wasn't his girlfriend, just a friend. But then on Saturday night I bumped into them out together. Leroy was all over her, and she pretty much ignored me.

What should I do? Do I tell my mate, or should I just forget about it? Also, I really like her, she's pretty and smart.

Help!

E

Letter Two

Dear Aunt Agonia

I found out I've got HIV a year ago. It was a real shock and I didn't really know what that meant and what I should do. I've learnt now that lots of people live really well with HIV and as long as I take a bit of care of myself, I should be OK.

I met this boy three months ago. He's really kind and caring and I think he really loves me. We have sort of had sex, but I got freaked out. Should I tell him I have HIV. I feel like I should, but then I'm so scared that he might just split up with me, and worse than that, tell everyone.

What should I do? I've got so confused about it that I've stopped answering his calls.

J

Letter Three

Dear Aunt Agonia

My best mate has gone all weird and I don't know what's up with her. We used to share everything, but lately she's sort of shut me off. I have tried to ask her and said that she can tell me anything, but she's just got all crazy and started shouting stuff about me not understanding. We're both 14. Is it a hormone thing? What should I do? We've known each other for years and I just don't get it. How can I be a good friend, but not get shouted at?

A

Letter Four

Dear Aunt Agonia

I am 12 years old and for as long as I can remember I've been going to hospital and having to take these tablets. There was one time when I was ill and had to stay in hospital and the Doctor and my Dad told me I had bugs in my blood, but then I got better and no-one said anything more.

Last night I was watching Comic Relief and I saw these people in Africa talking about the tablets they were given, and those tablets had the same name as mine. They had something called Aids or something like that, and they showed people dying and now I'm really scared.

Do I have Aids? Am I going to die – is that why no one will tell me? My Mum died when I was very little, and I was told she had cancer, but maybe she didn't and maybe I've got what she's got. I don't know who to talk to.

Please help me.

T

Appendix 6: Fishing for answers (questions)

Question One

- ❖ What do you think is most difficult about talking to friends about being HIV positive?
- ❖ What do you think would help you decide how or if to talk to friends about being HIV positive?

Question Two

- ❖ Do you think about being a parent in the future?
- ❖ What do you need to know about this?

Facilitator prompts:

Do you need information on safe conception?
Would you know where to get this information?
Has anyone talked to you about this?

Question Three

- ❖ Have you had the experience of talking to a boyfriend or girlfriend about being HIV positive?
- ❖ YES - what helped you do this? What was difficult about doing this?
NO – what information would you need before feeling able to do this?

Question Four

- ❖ If you had questions concerning your sexual health and/or sexual relationships would you know who you could talk to about this?
- ❖ What do you want to know, or feel you need to know?

Question Five

- ❖ Where do you want to get sexual health and relationship information?
- ❖ How should it look?

Facilitator prompts:

If it's a person, is it nurse, teacher, parent.
Do they want it in one format e.g. leaflet, or do they want it on-line

Question Six

- ❖ What do you feel you ought to tell a boyfriend/girlfriend?
- ❖ What do you want/wish to tell them?