

UK Family Project Residential Report

Learning from families living with **HIV**.



UK Family Project

a Elton John AIDS Foundation

'Post-it' messages from the young people's workshop

Branch Out!

Encourage others!
=>

More organisations
in Island

They
Could
stick
posters

★
Educate
children
about =>
HIV ★

HIV Groups
Can help change
lives!

Make people
listen and
know that
people need

gather all young
people to pass
information

☺
More warnings
about
unprotected
sex! =>

★ you can still ★
have fun ★

sexually
transmitted
diseases

people want
to go
but they don't
know where to
go.

* people think if
you have HIV then
they are not apart
of us.



hand
out flyers

Support
with HIV
and help cope
with it.

people
probably know
that people in
Bangor have it
so why don't
they

we need to
encourage
each
other!

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PROJECT INFORMATION AND ACKNOWLEDGEMENTS

The UK Family Project is a collaborative initiative that aims to reduce the impact of secrecy and stigma on families living with HIV, facilitate more comprehensive and earlier testing for undiagnosed children, improve family communication on HIV, sex and relationships and ensure that families receive support using the best possible practice models and methods.

It is funded by a generous grant from the Elton John AIDS Foundation and is a partnership between Positive Parenting and Children, Waverley Care and Belfast Health and Social Care.

We will be achieve our aims through a number of UK wide activities and developments

- ▶ Run two family residentials (October 2009 and October 2011)
- ▶ Run a practice sharing and networking event for practitioners who support families living with HIV
- ▶ A network of support and social care professionals / practitioners
- ▶ Develop resources and guidelines on disclosure
- ▶ Develop a communication workshop and guidelines for parents and practitioners involved in family work
- ▶ A guide to models and methods of support for families living with HIV
- ▶ Planning and development that support the testing of children and young people at risk of HIV
- ▶ Service development in Northern Ireland

As a result of this work professionals will be more confident to support parents to disclose to their children, parents will understand the needs of children and young people and the effects of secrecy. More disclosure will take place and more children will be tested for HIV. Parents will also develop skills and be more confident to discuss sexual health. As a result teenagers will feel empowered with accurate information and support to manage their own sexual health. Many families throughout the UK will benefit from this work and the lasting legacy of the tools developed will benefit many thousands in years to come.

Positive Parenting and Children is an established provider of HIV support services for children, young people and families in South London since 1987.

Waverley Care is Scotland's largest charity providing care and support to people living with HIV and Hepatitis C, and to their partners, families and carers.

The Regional HIV Social Work Team based at the Royal Victoria Hospital, Belfast provides a service across Northern Ireland. For their young people and parent's support work they are in partnership with ACET Northern Ireland.

ACET (AIDS Care, Education and Training) is an interdenominational agency with a Christian ethos, responding to HIV and related issues of Sexual Health, Alcohol and other Drugs. They are sub contracted by Belfast Health and Social Care to develop the parent and young people peer support in Northern Ireland. The Elton John AIDS Foundation (EJAF) is an international nonprofit organisation funding programmes that help to alleviate the physical, emotional and financial hardship of those living with, affected by or at risk of HIV/AIDS. Sir Elton John established the Elton John AIDS Foundation in the UK in 1993 to support innovative HIV prevention programs, efforts to eliminate stigma and discrimination associated with HIV/

AIDS, and direct care and support services for people living with HIV/AIDS.

Since its inception, EJAF has disbursed over £14.9m to 479 projects in the UK, making it the largest HIV grant-making charity in the country. EJAF has also funded over 800 programmes across Africa, Asia, and Eastern Europe. For more information about The Elton John AIDS Foundation (Registered Charity No. 1017336) visit www.ejaf.com

We would like to acknowledge the participating families who, in many cases, travelled some distance and spoke openly about their personal situations, to Elaine Pearson, Jeremy Sandell and the staff of PPC, Waverley Care, Northern Ireland Regional HIV Team, ACET, Amanda Ely and Babs Evans, EJAF.

INTRODUCTION

In October 2009 Positive Parenting and Children (PPC) in partnership with Waverley Care, Scotland and Belfast Health and Social Care Trust regional HIV Social Work team, held a weekend residential for families living with HIV from across the UK. The weekend was funded by the Elton John AIDS Foundation as part of their two year funding of the UK Family Project, co-ordinated by PPC.

Eleven families were accompanied by professionals from all three organisations to St Barnabas Adventure Centre in Sevenoaks, Kent. Staff provided a relaxed and comfortable environment for the weekend.

The residential for families living with HIV was planned in order to make a connection for families across the UK, share experiences and bring further understanding to the knowledge base on disclosure, testing children and young people for HIV, and support needs, with the intention that relevant services become more responsive and families feel better informed and supported. The weekend ran workshops where these topics emerged, for young people and parents (2 joint and 2 separate sessions), and facilitated by trained peers based on an action research framework. The residential also provided families with a chance to experience a range of new activities in a safe and secure environment.

Information was collated from a range of sources including transcriptions of the workshops, diaries kept by participants, flip chart notes and evaluation forms. The themes discussed included:

- I. Disclosure
- II. Testing children
- III. Support and information
- IV. Other Matters

I. Disclosure

Background and explanation

Disclosure is the act of telling someone that you are HIV positive or that you are affected by HIV. Disclosure implies that this information by definition is a secret or is confidential. Disclosure is a long-standing complex issue not least because there is actual and anticipated experience of stigma and discrimination with a disclosed HIV diagnosis. Stigma in this context is described as being gossiped about, verbally or physically harassed or threatened, and verbally insulted or physically assaulted (The People Living with HIV Stigma Index 2009).

For an infected child there is a momentum towards disclosure from the day of diagnosis, so that they can know their own diagnosis and be at the centre of managing their condition. The CHIVA guideline on disclosing to a child or young person is available on their website (Conway, Donaghy and Melvin 2008).

Disclosure of a parent's status to their affected child does not have the same clear ethical grounds as disclosure to an infected child. Parents can be reluctant to communicate to their child that they have HIV because of stigma and discrimination.

Describing disclosure in these terms gives an impression of a decision made to do so, a planned event. However, disclosure can be abrupt, unplanned, and accidental. The need to avoid this more devastating method provides one of the main drivers to planning disclosure for those who are affected by HIV.

To improve support for people during the disclosing process, hearing the experiences of those who have been through the process is a key learning opportunity.

The workshop discussions were wide ranging when considering disclosure, reinforcing the notion that it has many aspects that affect family life. However, in the main, they centred on parent's experience of disclosing their HIV status to their children. Disclosure of HIV status to schools and friends was also briefly discussed.

► Stigma

There was a fear of stigma as a consequence of disclosure of HIV status to others. Attendees relayed experiences that included bullying, isolation and aggressiveness. Actual stigma and anticipated stigma constituted a barrier to disclosure to others, in particular schools and community members.

► The best time to disclose HIV to a child

Participants offered their personal accounts when discussing what would be the appropriate age to disclose to their children. They suggested that there is no "perfect time" and that it should be done in stages. Within this group a number of young people had been disclosed to before they were 12 years old and some parents recommended the age group 9-11. People understood the need to provide age appropriate information that

did not overwhelm. Parents did not want to burden their child and in some cases this prevented some parents from disclosing. In their parallel workshop the young people described the shock, sadness and worry that came with disclosure. Reassurance was repeatedly sought that the parent was taking their medication, as this was the tangible focal point that kept the fear of parental death at bay, and that life could go on. The fact that the young people could readily recall the negative feelings of being disclosed to or finding out creates an understanding of why parents see disclosure as a burdening on their children (see further quotes in Appendix 1).

Yes, because I have had a parent coming to me and telling me

'we know about you, we know you have got HIV, so keep your child away from our children, we don't want your child anywhere close to ours'.

It's not a joke, they come to your door - my neighbours have done dreadful things

- Parent

► Positives experiences from disclosing HIV to children

Attendees discussed experiences where disclosing had benefited the relationship between the parent and child, as well as having benefits to the parent's own emotional wellbeing.

► Reaction from others following disclosure of HIV status

Your child is the only person that can understand you and you will be surprised that even if the worst is against you, your child will be there, that friendship will be there and they will keep it as a secret

- Parent

Disclosing to family, partners, friends and others, including employers evoked a number of different reactions. Participants offered experiences of being supported but also some experiences of rejection. Participants also acknowledged that at times their own expectations of other people's behaviour had led them to misinterpret the actual reaction "I went to the dentist because of bleeding gums, I told him, and he said OK but when he put on his gloves I thought 'here we go he's doing this because of me', but that is what they do, so you do have to trust the people you talk to". Due to the range of reactions, participants concluded that selective disclosure should be practiced.

► Cultural matters

Cultural differences were seen to be an important factor in terms of participants' understanding of HIV. The cultural expectations and stereotypes, including that of sexual promiscuity, related to the virus were closely linked to the personal meaning people attached to being infected with HIV. Such cultural expectations heightened a sense of immense fear and the necessity to confront one's own or a loved one's imminent mortality particularly from those participants who came from Africa.

I think we should practice selective disclosure and disclose, we ought to tell people who you think will handle your privacy

- Parent

► Participants value of the support they received in terms of disclosure

Most group members valued the help they received from services in terms of disclosure. The support received was considered vital. Some reported that they felt unable to tell / disclose. However, a sense of ownership was acknowledged, and that the difficulty to disclose was frequently related to the parents' own needs and emotions.

Summary

Reports of the improved closeness and trust in a family or parent child relationship on the one hand, and the discrimination and stigma experienced as a result of disclosure on the other, illustrates the contrasting considerations that parents have to balance in their decision-making about disclosure. In addition, parents of African origin (approximately three quarters of the participants) have to consider what meaning the information will have for the recipient given the higher mortality rate in Africa for people who are HIV positive. Whilst the young people did not describe stigma, their devastation at the point of disclosure reflects their negative association with HIV. Individual circumstances will affect the impact of disclosure such as the attitude of family members, the support available, the parent's acceptance of diagnosis and strength to deal with the result. There is a need for management of HIV information so that unplanned and accidental disclosures are avoided. Planning onwards disclosure to selected friends and family members may reduce the family's experience of stigma. There is evidence from this group that the messages from the clinics and CHIVA in relation to explanation have been absorbed. A staged approach to disclosure using age appropriate information and conversation, building up knowledge and leading to the naming of HIV, is seen as best practice (Conway, Melvin and Donaghy p.5). When discussing disclosure parents didn't highlight whether their child is infected or affected; the need to disclose to their children is an issue regardless of their status.

II. Testing Children

Background and explanation

This workshop discussion reflects one of the main aims of the UK Family Project which is to address the issue of untested children at risk of HIV. It is a complex area not least because there are issues relating to consent and confidentiality. The protocols for testing infants, children and young people are available in the UK National Guidelines for HIV Testing 2008 (BHIVA et al 2008 p16-7).

'Antenatal HIV testing and diagnosis has been a great success and shows what can be achieved with a focused and well-targeted strategy. There appears to have been less attention given to identifying undiagnosed HIV-positive children' (British HIV Association 2009 p.5)

► Readiness

Testing at the right time and recognising the emotional state of the parents in order to have them on board was reported to be of significance when offering a test. One mother in particular felt that her needs were met when she was offered some time to come to terms with the news that she was HIV positive. Not being in the right frame of mind cannot be the main consideration when a child's need to be tested is more urgent, however forcing the issue of testing

When offered to test my children I thought that was not the right time, I was not well. I think if I had tested the child at that particular moment and found out that they were positive I would not have coped.

- Parent

I brought the children and they tested negative and I felt reassured that I am the only one that is sick and that they are all safe. But as you, every time they are ill or I see something on their skin I am always concerned, so I ask the doctor - he did say that once they are negative there is no need to retest them but I am always concerned. I know it is bad thinking but I sometimes want to test them again. I am always looking at them, looking at their skin, but I will take them again just to be reassured but I want to make sure they're ok.

- Parent

when a family is in crisis may not be in the child's interest either.

► Consent issues and uncertainty of tests administered to children abroad

Amongst our participants we found a range of responses to the testing of children. All but one participant whose children were in the UK reported having had their children tested for HIV. A few parents reported having their children HIV tested without their consent in their country of origin. Parents who reported having their children tested in Africa were not confident as to which test had actually been carried out. At first one mother questioned the relevance of the workshop as she had tested all her children, however in the course of the workshop it became apparent to the mother that in fact one of her children had not been tested. The mother stated an intention to get this child tested.

► Negative test results

The reasons for resisting the testing of your child have previously been recognised (BHIVA 2009) and remain a focus of this and other projects. What was unanticipated was that some participants described how they did not trust the HIV test and felt a need to get their children retested if there was a negative result. There was a real sense of anxiety for some in relation to a negative HIV test, preventing them from accepting what they know is likely to be accurate. It is not known whether the parents think that their children continue to be at risk of transmission. Internalised stigma may lead to the belief that your family is never fully safe from you infecting them.

Summary

The discussion with the parents highlighted why this is a difficult area to provide support in. There is clearly a spectrum of responses to testing children – those who feel they are not ready to deal with this, those who are straightforward and can reduce and simplify the issue and those who can never be reassured that their child is negative and want to re test at intervals. Careful handling is required.

III. Support and Information

Background and explanation

Across the UK resources and funding to provide services vary enormously which is felt keenly by many families. It may not be practical or appropriate to duplicate services that work in urban areas of high HIV prevalence areas, in low prevalence rural areas. Services, both statutory and voluntary provided in low prevalence areas have to adapt resources and innovate to meet complex need in families, scattered across their region, and different models may be needed. The needs arising from isolation can be very

pronounced for those families, some of whom are living away from their extended family and community due to immigration and the dispersal process. Most asylum seekers are dispersed away from London and the south east of England to other towns and cities across the UK (NAT and BHIVA 2006 p.3)

When talking about the services and the support that is provided to people infected or affected by HIV, subthemes emerged. Experience of services varied from individual to individual, however it was clear from participants' accounts that most felt more should be done in terms of supporting families and individuals.

► **More support for children (by going to groups and/or at school)**

This was a recurrent theme in both the parent and the young people workshops. In particular, the need for their children to have somewhere they can go and talk to other children in similar situations. Parents recognized that their children needed an outlet for their concerns and worries as a result of keeping the HIV private. Young people may not always be ready to talk and additional support to facilitate their involvement in peer support should be available. Participants wanted schools to be better informed about HIV so as to better support infected and affected children.

You feel safe because you meet other children with the same matter; they have sessions if you are HIV positive and give you medical facts so you can learn.

- Young Person

I don't want to go to groups and talk about it. Because it makes you feel emotional and I don't like to feel emotional. I used to be like that when my mum used to tell me to go to groups too, when my mum asked me, I was like ' I don't want to go to groups' but it was beneficial.

- Young Person

Regional differences became apparent with children from Scotland and Ireland appearing to be the most isolated and their carers the most unaware of the sources of support available. One participant felt that services provided predominantly for gay men, should adapt to accommodate children in Ireland.

► **Additional support at the point of diagnosis and advocacy needs**

Attendees discussed their feeling of being overwhelmed, vulnerable and without a voice. They further reported feeling ill supported when they received their diagnosis. This experience of isolation and helplessness was further heightened when participants had not receive post and pre-test counselling and when they had very little awareness of the sources of support available to them.

► **Empowering and strengthening**

Discussion next shifted focus from the support offered by services to what participants can do for themselves. Participants suggested ways to empower themselves and others. The workshops provided the opportunity for people to think about ways and strategies to continue to support one another after the residential. It was recognized that people may have varying levels of confidence in accessing mutual support.

Some people are not empowered enough or not able to access formal services for support so if you were to offer informal gathering galleries where they could simply come to meet and chat to similar like you or me they would.

▶ **The need for information and internet support**

Participants were also directly consulted on the CHIVA project and its development of a comprehensive website which will have be secure area for HIV positive young people, an area for parents and for affected children, a data base of information about support services across the country and resource library.

They seemed to agree that the idea of setting up a website was a good one. The website was considered to be an effective media in providing information and consequently providing support to children. It was felt that it could also help to facilitate disclosure.

Participants had clear suggestions about its content and the type of information that the parent section should contain. Different ways and methods of accessing information appeared to be an emerging theme for both children and adults. They explicitly described what information needs to be provided with the focus on it being easily understandable, age appropriate and should involve young people in its design.

In terms of purpose, participants suggested that some of the information should be geared towards empowering and building resilience, so that children, whether they are infected or not, be better prepared to resist societal pressures to have sex early and without protection. It was also suggested that another aim could be to encourage the building of links and micro-communities within isolated children groups.

▶ **Residential as support**

The provision of a residential for families living with HIV in the UK was a successful way of connecting parents and families to share stories and encourage one another. When asked what was the best part of the residential, the top three answers provided included meeting people, sharing experiences and the discussions.

Summary

Expanding the opportunities for parents to talk will enable them to understand more about disclosure, testing and living with HIV in the family. It will reduce isolation and serve as a forum to encourage each other. Support services and peer support events should run in order to strengthen and empower. Support need not be provided in a formal manner by service providers but with an informality that will encourage those who are disempowered or can't access services.

Our participants wanted to be kept up to date and to have a good understanding of HIV. Information for families, particularly in relation to website, should use simple, jargon free language and provide basic up to date information. Where relevant it should be child friendly, creative, but with care over using age appropriate information. There was a call for information about HIV and childhood illness and behavioural issues, and HIV role models.

IV. Other Matters

▶ **The need for personal relationships and intimacy**

Participants were quite vocal in stressing their need and wish for intimacy as a way to feel desired, supported and “normal”. However it was clear that from participants’ accounts these needs were not routinely addressed within services and care packages.

The women in particular, linked their need for intimate relationships with their femininity and self –esteem. They reported to have become self-conscious because their figure had changed due to their taking of HIV medication and because of changes in their libido as a result of their HIV treatment.

The continuing stigma associated with HIV/AIDS was also cited as a barrier to sexual relationships. Further, the practicalities of taking managing treatment while in intimate relationships, particularly when one has not disclosed to the sexual partner, was also reported to be problematic.

▶ **Side effects of medication**

Specific support for people who had side effects of HIV medication was requested. This was an issue for a number of parents. The form of support requested varied from nursing, emotional and peer, suggesting that support across health and social sectors could be more aware of this need in general provision of services.

▶ **African families**

Some families had a unique set of needs based on being separated from family members due to migration. Many of the African families that attended had children and adult children back in their country of origin. The separation made disclosure and testing for HIV additionally stressful and complex. They would not necessarily feel able to leave the UK for immigration reasons to be with their child and deal with these issues face to face. They had to depend on the relatives or partners there to do things for them. The physical distance between parent and child and the prevalence of HIV in Africa are additional concerns for African families.

▶ **Confidentiality**

A number of instances were described where participants’ personal information, their HIV diagnosis, was misused or confidentiality breached. This left people feeling angry and upset, reinforcing feelings of stigma and worthlessness. The situations described were more common in health settings such as GP surgeries or dentists rather than HIV specialist services. It was felt to be ignorance at the heart of it, and that greater HIV awareness should be standard.

SUMMARY OF RECOMMENDATIONS

Recommendations for HIV support organisations and social care providers

1. Parents need to be able to share experiences when making decisions about disclosure and other parenting concerns. Methods can include groups, workshops and courses, social events and outings, online networks, residentials and befriending and mentoring schemes.
2. Support and intervention needs to respond to the different personal circumstances and hold in mind the number of factors in play when deciding to disclose.
3. Don't Forget the Children (Bhiva et al 2009) is the key document to refer to for testing children. Practitioners should be familiar with the document and its recommendations. For example this checklist for talking to parents about testing their children (p.17).
4. Don't assume that all children are tested, talk through each of the children with the parent, noting when and where they were tested.
5. (Another test can be offered where there is uncertainty. When the child is abroad, it is recommended that when the parent and child are next reunited, in the UK or country of origin, there is a plan to test/retest, Bhiva et al 2009).
6. If the parent is not ready to test their child or their fear of disclosure makes them resistant, ensure they have the relevant multi-disciplinary/peer support necessary to prevent the situation developing into a safeguarding issue. Work hard to keep them on board and in control. (Also a key message in Don't Forget the Children).
7. Service provision should be empowering and strengthening, and available from the point of diagnosis.
8. Be aware of the side effects of HIV medication and consider these in your assessment of support requirements.

Recommendations for CHIVA/BHIVA

9. At the point of testing an infant, child or young person, regardless of the result, the parent should be provided with accurate information about transmission, explain what a negative result means and how the child can remain negative.
10. Those involved in testing including midwives and GPs, should offer specific follow up appointments after diagnosis in relation to dealing with the diagnosis and finding the right support service.
11. Further information and advice on the impact of medication and its side effects for parents where there is an impact on self-esteem, self-image and maintaining and forming relationships.

Recommendations for health professionals and commissioners

12. Make testing children more accessible i.e. by using swabs instead of needles, use of support workers, testing in community venues or the home.

Recommendations for the UK Family Project

13. Develop decision making tools to enable parents to consider the benefits and disadvantages of disclosure and be able to plan and prepare for unplanned disclosure and negative outcomes.

14. The concept of 'selective disclosure' needs to be developed and accepted – to enable individuals to choose trustworthy friends or family members to disclose to who will give support and strength.

15. Develop guidelines that advise parents on how to handle their own and/their child's personal information.

- how to prevent and respond to accidental and unplanned disclosure (including information and case studies so parents know what the likely scenarios are),
- how to teach your children to keep the information private,
- how to decide who is a safe person to disclose to outside the household.

16. Further investigation is needed in relation to parental fear that the negative child may be positive. Is this disbelief in the test result, or misunderstanding about risk of infection inside the family home, that leads to anxiety about the affected child's health.

17. What are the best methods of getting children at risk tested that can accommodate the complexities behind the resistance to test and prevent child protection measures.

18. Help parents be straightforward in how they explain the test and HIV, like this parent. Provide information on what words to use.

Recommendations for all

19. Ensure families, young people and children are involved in the in the production of relevant HIV information.

20. Work together as a Sector to address the root causes of stigma, enabling families to openly address the challenges of living with HIV without needing to keep their illness secret. Specifically in communities where stigma is acutely felt, use relevant cultural media to disseminate accurate information about HIV and its effects.

APPENDIX 1 : METHODOLOGY

We used an approach based on action research which is a collaborative method of engaging with people.

“Action research...aims to contribute both to the practical concerns of people in an immediate problematic situation and to further the goals of social science simultaneously. Thus, there is a dual commitment in action research to study a system and concurrently to collaborate with members of the system in changing it in what is together regarded as a desirable direction. Accomplishing this twin goal requires the active collaboration of researcher and client, and thus it stresses the importance of co-learning as a primary aspect of the research process.” (Gilmore et al 1986 p161)

It's main value is to increase people's involvement in the creation and application of knowledge about them and about their world thus to provide people concerned by a particular phenomenon (in this case, HIV) a forum to develop knowledge, learn about themselves and about others and thus arguably become better able to support one another. In that sense, action research shares much with community engagement research and peer-support methods of practice.

This form of research is particularly relevant to working with marginalised communities and/or communities that are disempowered. Action research aims to develop theory which is not simply abstract and descriptive but is a guide to inquiry and action in present time.

A central premise of our approach was to avoid presuming we as practitioners know what questions need asking but rather let the group inform us through their own dialogue what questions and issues are relevant.

The broad issues to be considered within the residential workshops had been gathered from professional experience that informed the initial EJAF funding application and consultations were carried out on these areas of interest which provided lines of enquiry around, disclosure, service experience etc. The directions of workshops purposely remained open.

Six people affected or infected by HIV/Aids were recruited to lead the workshops, they were all current or former users of PPC services and a few had previously been involved in befriending and volunteering for HIV services. Five were parents and one was a young person. Five facilitators were female and one was male.

Facilitators received training in the action research approach and its rationale, as well as in basic facilitation skills, by an independent trainer. During the training event, they came to their own decisions in terms of how best to facilitate the discussions including: whether to disclose their experience or not and whether to facilitate alone, in pairs or with staff support.

Facilitators decided that each workshop was to have two facilitators for mutual support as well as the residential lead professional. Facilitators were supported and supervised by the residential lead as well as by an independent evaluator/researcher to ensure they felt prepared and able to lead the discussions. At the end of each workshop and group discussion group the facilitators were brought together to give them an opportunity to air their views on processes, content and dynamics observed within each group discussion. Staff from the partner organizations provided additional support for the peer facilitators on a one to one basis throughout the weekend, between the workshops.

Each workshop consisted of group of between 6 and 15 attendees.

Each attendee received a verbal explanation of the method, received a copy of the programme and the taping of the workshops was negotiated. Prior to recording verbal consent was obtained. They were informed that their participation was voluntary, so attendees chose what workshop they were interested in attending.

Following the completion of the residential, parents and young people received feedback forms; not identical as they had been adjusted to incorporate the differences in experience by the two groups (parents and young people). For example, HIV was not mentioned in the young people's form regardless of the fact that some of them were aware of the objectives of the residential.

The participants

8 families (at least one parent with one or more children) and 3 parents without their children attended the residential. There were 29 individuals in total; 13 parents, 1 carer, and 15 children and young people. 72.4% of the total participants were Black African and 17.25% were White from different parts of the UK and Europe (see Table 1). 12 out of 13 parents who came to the residential participated in a brief post-residential questionnaire; 9 mothers and 3 fathers whose average age was 44 and 49.5 years old respectively. Each parent had an average of 2.5 children.

The families had travelled from a number of places from the UK (see Table 2).

Ethnicity	Percentage	Count
Black African	72.4%	21
White European	10.35%	3
Mixed race (White British/African)	6.9%	2
White (Northern Ireland)	3.45%	1
White Scottish	3.45%	1
Other Asian	3.45%	1
Total	100%	29

Area of living	Percentage	Count
London	58%	7
Out of London*	17%	2
Scotland	8%	1
Northern Ireland	17%	2
Total	100%	12
*Hertfordshire, Woodgreen		

A high percentage of the attendees had become aware of the fact that they were HIV positive relatively recently. One third did not provide an answer to this question.

58% of the parents disclosed their HIV status to their children. The age of disclosed children ranged from 7 years old to 32 years old.

All but one parent reported that they had their children tested for HIV. 6 out of 11 of those tested were HIV positive.

12 young people (10-18 year olds) attended the residential, 8 female and 3 male, average age of 12 and 14 years respectively. Only 2 young people stated they knew what the residential was about. Families who had not disclosed to their children were included in the residential leading to a close management of the residential's objectives. Young people preferred to use art form to express their feeling and experiences.

Recruitment of the attendees

The families were recruited from HIV organisations nationally. Interested individuals were invited to contact the project lead and the regional leads for further information. Places were allocated on a first come first served basis.

Each prospective attendee received a letter informing them of the aims of the residential as well as a full copy of the programme to ensure their understanding of the event. They further received a health questionnaire, the venue details and a confirmation letter, and a copy of the programme. The model was explained to each attendee, the taping of workshops was negotiated and prior recording verbal consent was obtained.

We wanted to stress that we regarded the involvement of families in this study as central to our aims, and the process of their involvement, access to peer support and strengthening of community relationships, were an important outcome.

Lastly, participants were informed that participation in the discussions was voluntary and that they could opt in and out as they please.

Disclosure

The impact of stigma

“My son is always getting attacked, last Wednesday he was attacked by 3 boys, a few weeks ago he was attacked by 5 boys and he went into a terrible state. The school has isolated him because of his HIV status so he can't go the playground like the other children; he has to go after the other children.

Yes because I have had a parent coming to me and telling me ‘we know about you, we know that you have got HIV, so keep your child away from your our children, we don't want your child anywhere close to ours’. It is not a joke, they come to your door... my neighbours have done dreadful things.

That is the reason why some people do not want to disclose because when you tell them they may use it as a weapon, to mistreat it, that is why some people won't come for support and that the disease is progressing, people won't come for test they don't want to know that they are HIV positive.”

Disclosing your HIV status to your children

“I can tell you from my experience there is no perfect time to tell, but you have to prepare the child and when he knows and the child is able to understand the transmission and the effect of the illness, so nine is quite early but perhaps around 11 you give information, bit by bit you don't give too much information.

I am scared to disclose because I think she would be worried she will think I am dying so I feel very bad that she does not know, and I have told her about being careful with boys and not to let them lure her, but as far as telling her about HIV I have not.

I was told when I was 11, I looked at her and thought she was going to die, I was so scared.” (young person)

“I thought too that she was going to die I was 10, I also thought she was going to die but she said she was taking medication from that moment on I kept asking her did you take your medication? Did you take your medication?” (young person)

“I told my daughter when she was 7 and she became worried about my medication and asking whether I take my medication so if you talk to your children you can make sure she has the correct information, in a friendly way, but if you don't they may learn it from someone else, who will not give them information that is accurate or say that your mum is going to die and scare the child.

It was like a nightmare the day my mum disclosed to me, never thought it would be me, I saw that thing on TV, broken hearted, and distraught I was so scared sad and alone.” (young person)

There is not one size fit all but you know your son but 9 may be a good time to start talking about sexual health, having out of the open it empowers you and then you can start enjoying life without worrying about disclosure doesn't this belong above with the best age.....

Positives experiences from disclosing HIV to children

There was suddenly a bridge that was built ...there was always that distance between us. So now it brought us closer; I do not agree with parents who do not want the child to know because you'd be surprised that the child knows or that it will make sense, he asks what it is about him.

I met a father in the parent group that I attend. He said that there was a time he wanted to commit suicide, the child did not want nothing to do with the father, he saw the father was not working and on benefit, he went to counselling and he was supported to disclose but all that time the boy knew and he completely closed from the father, but after he disclosed he became open to his father.

That was the same with my daughter. So if we can't talk to our children we can go to a social worker or psychologist. Your child is the only person that can understand you and you will be surprised that even if the world is against you, your child will be there; that friendship will be there and will keep it as a secret.

I know that my mum is on treatment and that she might survive. (young person).

Disclosure of HIV status to others

"People tend to be so protective of you when you disclose and relatives can be more ugly, I know that some who disclosed to her sister she went and got disposable plates, disposable cutlery, disposable cups so because of this I try to be extra careful and show them I am extra careful.

I had a friend dating someone with HIV yet when she disclosed to him he did not want anything to do with her as he was in public office.

Disclosing is an issue if you have a big family. I have a big family so when I disclosed people use to get to my room so I felt obliged to let them know but then people would gossip behind me ... I told my brother, my sister, then my aunt and then all those [in my family] here in UK, I'd rather they heard from me, and I thought that I was going to prove that just because you have HIV does not mean you are going to die.

When I first told them I used the think that everyone knows, but those were my perceptions so I went to the dentist because of bleeding gums, I told him, and he said Ok but when he put on his gloves I thought 'here we go he's doing this because of me', but that is what they do (laughter), so you do have to trust the people you talk to.

... I have been fortunate that all the people that I have told have been supportive, so when I told then an intimate partner because I kept thinking about him getting sick which did not help the intimacy, but again he was supportive although we are no longer together ...

My father does not know because my mother said he won't cope, so that is fair

enough, but I do have older aunts and grandparents I would not disclose to because of the mentality, and that I do not want to get into arguments about how I got it.

I think we should practice selective disclosure and disclose, we ought to tell people who you think will handle your privacy, who know your people, your children and the school who know your community.”

Cultural issues

“When I was disclosed to by my mother I felt a lot of things but happiness was not one of them I was sitting in the kitchen and it was a normal school day but then she started crying and said she had something to tell me, I said ‘what is it?’ Cause then she gave the cues that it was some big and bad. I thought someone was dead or going to die. She said I have HIV, I used to see it on TV even when I was in Africa in sitcoms so I was like ‘oh my god she’s dying, she is all I have’. I had never met my dad, I’ve always been with my mum and she’s always been strong, the woman of the family always there working really.” (young person)

“I was not aware of HIV back home, so when I came here I really became aware of HIV and that people are really sick, look skinny, but I did not get much info back home.

I was diagnosed when I came back (from Africa) in 2003, I did not have symptoms but kept getting colds and could not shake off (the GP) referred me to the Gum clinic then asked where I had lived and offered a test and I thought ‘I’ll do it’ thinking it will come back negative as I thought I have not been doing anything, promiscuous and been faithful to my husband

The young one is infected so she goes to the children unit and started the treatment 3 years ago, there was no problem ... I was the one that was the problem. She knows she has HIV, she’s 8, they told her, they ask me if it was ok I wanted to tell her and they told her why you are taking the medication, and one day they just broke the news to her and tell her to keep the medication to stay well, so you have to tell them and tell your feelings they will give us advice”

Testing children

“When offered to test my children I thought that was not the right time, I was not well. I think that if had I tested the child at that particular moment and found out that they were also positive I would not have coped, I thought it would stop my improvement, so they told me recover and after a month, bring the child and we will test her I told my children, ‘Mummy has something wrong with her blood and just wants to know if you have the same thing .’

My elder is not infected ... I had the child tested and although it was negative I am always thinking whether it was a mistake on that day, I still want to take him back, to go back to the same hospital for him to be tested again.

I brought the children and they tested negative and I felt reassured that I am the

only one that is sick and that they are all safe. But as you, every time they are ill or I see something of their skin I am always concerned, so I ask the doctor ...he did say that once they are negative there is no need to retest them but I am always concerned, I know it is bad thinking, but I sometimes want to test them again. I am always looking at them, looking at their skin, but I will take them again just to be reassured but I want to make sure they're ok."

Consent issues and uncertainty of tests administered to children abroad

"They got sick and they were in and out hospital for a year and two and they asked me if I had HIV and I said no but then I found out they tested the children without me knowing and it came back negative, at that time I did not have it, but it may have been routine at that time (in Africa).

I was diagnosed I talked to social services they work with me; they came to my home to test the children. I did not want to take them to the clinic to alert them so they tested them in my home, but now that I am talking...I am just remembering that the girls are not afraid of needles so they allowed them to test them, but my boy would not let them, so the boy never took the test, the reason I had not pressured him was because of his fear of needles.

There is so much to worry about without having to worry if the child is positive, it has got a twist to it, in that it is burden but then it is not a burden. We have the experience that you go to the clinic, you can talk you can express how you feel, but if you do not have them tested you are almost denying them the support and there is a thing about if you can name your enemy then you don't have to be afraid, you know to deal with them. I will always advocate to have the children tested, but all this time I convinced myself that my child is not infected but I don't actually know the girls are not so for me as soon as I go back I will have him tested.

It is very difficult to arrange for testing back home especially when the children are old, we cannot influence them and they can even lie and tell you that they are negative you know they are very clever, especially back home .

I think that we should have women tested twice during the pregnancy. We had a couple of clients who were initially tested early on in the ante natal and then two weeks after the baby was born, baby was really ill and was intensive care and straight away they tested the mother and it came back positive, she was devastated. Sometimes we forget that people have sex during pregnancy and if they tested women at a later stage during pregnancy, women who became infected while pregnant could be given the medication to and care to stop the baby becoming positive."

Support and information

► More support for children (by going to groups and/or at school)

*"When we got told, we did not get the chance to get into group or something."
(young person)*

*"...and my mom was so quick that I was expected to go to all these groups all of a sudden although I did not want to."
(young person)*

"[Children need somewhere] to talk to others in similar situation, like PPC, but I would like them to tell others about PPC.

*Well we don't really talk about this sort of thing but, I'd like to see other children that go there. You feel safe because you meet other children with the same matter; they have sessions if you are HIV positive and give you medical facts so you learn."
(young person)*

*"...I don't want to go to groups and talk about it. Because it makes you feel emotional and I don't like to feel emotional. I used to be like that when my mom used to tell me to go to groups too, when my mum asked me I was, like, why I don't want to go to groups, but it was beneficial."
(young person)*

"I have just discovered that there is a social worker in Scotland whose job is to target the 49 children that are infected and go to their homes and encourage them to go to support group so that is very proactive and brand new. In England there is a lot for children with HIV but I am grateful that I have had the opportunity for my child to go to groups with PPC.

Children need a lot of support and similar events and PPC services really need to be advertised, for instance at school, it is important to educate the teachers so that the children are not mistreated at school.

I am disappointed and in Scotland if you live away from Glasgow and Edinburgh you are completely isolated and the stigma that my some go through at school, for example, which is another story. No HIV community it is difficult to get the services, there is place in Glasgow, there is a place in Edinburgh and there is a place in Aberdeen and they assessed me to get there; that is too far from where I live.

There are no services for children in Ireland. I know that there are not many children but there has to be a way to do something for the children that are there, and also for the parents. We should have the right to go somewhere where it is pre-dominantly gay; I don't think it is appropriate for my children.

More people to help, more support in Ireland, where you can go and discuss, more youth and HIV organisations.” (young people)

“I expect if he had down syndrome he’d get a variety of services.”

Additional support at the point of diagnosis and advocacy needs

“We need some advocacy because some of us are strong now but it takes a long time for people to be able to stand... You have to be strong and tall, you are HIV positive but it does not mean people should walk all over you.

All of the sudden it’s boom you have HIV, and on the phone, and you can imagine how it feels, no-pre-counselling no post counselling, no emotional support nothing and so much to cope with, that it is too much, it is traumatic... you don’t know where to go.

I know of about four AAA, Body and Soul and PPC and it has youth for young people and they have regular activity to be involved and learn about HIV. I have known them since I was 12 and I am growing with the HIV, the biology is important that has made me confident that I am not going to lose my mum so makes you confident about the future, it’s a big or something to worry about but it is not such a big thing. I also knew about Karibu which is now part of PPC. I now know people from all over the world thanks to being part of these groups, so if you have the opportunity, I would say there is a lot of opportunity; you’re supported, uplifted and empowered.”

Tackling discrimination from services

“I went for a smear test I know my diagnosis but at that time it was still shocking. I was trying to cope and work things out, when I went there she read my information on the screen and she went out ‘I have to use a disposable spatula because you are HIV positive and I had to protect..’, and she leaved the information on the screen and walked out and then when I lie down on the bed she put on four pair of gloves (two on each hand) then she does what she had to do and before I have even left the room she takes antibacterial wipes and cleans were I was lying. The information is still on the screen and a lady to collect something in the room and I see looking at the screen I left so dirty, I felt so bad but I needed the service so I just kept quiet and it is only now that I wished I should have done this or that but it is too late.”

The need for personal relationships and intimacy

“With women with HIV don’t date because who can stand their shape but you are denying yourself some interaction.”

“For some of us it is also about the way we look. Just 4 years ago I was beautiful but now they are no longer interested.”

“The [sexual] interest is gone for some women but the way they look is an issue for instance the weight you keep putting on, more and more weight every day.”

“The doctors need to make sure the meds suit us some medication make us get bigger and bigger which men would like me? I cannot undress in front of somebody, and you are denying yourself love and affection.”

“If it was only the stigma then you could find someone who was HIV positive, I don’t know what it is, the medication also changed the way you feel and think in your body, you may lose your libido but also you have to hide the medication and be worried about hiding your treatment and in the end you just decide it is not worth it.”

Support from self-help group

“Attending groups like this one where there is someone like you that speaks always so positively, but the support may not necessarily come from services; some of the support comes from within group like this.”

“I think that we should be doing more of this, there are a lot of people out there that wanted to come but were scared or did not know what that this event was taken place but when we go back we there and say we had a lovely time there and you should have come and next time they will come.”

“If we got organized... let starts a self-help group and stop heterosexuals from hiding in the closet then they will get some power.”

“I am sorry to have to be a bit harsh but I think people should be empower themselves people are not going to come to you go and find and you need to be proactive...”

“We want to stop people affected to seclude themselves and feel angrier, we need to encourage one another.” (young person)

“Some people are not empowered enough or not able to access formal services for support so if you were to offer informal gathering galleries where they could simply come to meet and chat to people similar people like you or me they would.”

“We are fine, I can link with her I can link you with you and her that I will be strong because I am not alone, let exchange number link up, and let our children be in touch and those who want to date they can also start dating, why not.”

The need for information and internet support

“The idea of the website is good because people are looking for information and people are looking for support, for the children they may want to know where you can go if you want this or that.

Give children the opportunity to talk, on a basis of information they can understand. If you have children you may need to know what services are available, information provided in simple language so that the children can take it all in, parents will find it very simple to read.

In other words ... a website that will facilitate disclosure from a print perspective also with information that children can engage with, and to do it in a language that is simple will be helpful.

I realised that there is nothing out there on HIV and childhood illnesses available for parents and support but because he has got HIV, I have to be proactive.

It is important that children can access it themselves, and to actually get used the information on their own and would be very open and simple often about transmission, other people experiences on how it has affected them, and links to other forums where people can feed into or link with, so that they can support each other via the network. Nowadays, children do use the internet a lot and my kid goes straight onto the computer but most of the information they access is inaccurate or is 10 years old, so the information will need to be up to date.

It would be important to update the website but what is important would be to keep the information relevant.

It is important to bear in mind children development as well what is appropriate for a 10 year old may not be and vice versa and there may be a difference in what a 15 year old and what a 10 year may want, I have been on websites that have picture of coffins so we don't want that.

To go a step further will actually mean having children of the target age designing the website rather than adult writing the section of the website aimed at children, that are infected or affected by the HIV virus could create it.

So that it can be a website by children affected and infected by HIV for the general public, as well, aimed at the heterosexual community.

There are children with no mum and dad in foster care they may be completely isolated so finding a way to build bridge with children that are hard to reach.

Bearing in mind the culture, the rebellion, the pornography and peer pressure, young people need information and ways to empower themselves and resist peer pressure, so that they do not fall victims and are unable to protect themselves and make responsible choices, because when infected you have no choice. [Providing] role models, people with HIV that are valuable assets to society and to their communities.”

Current information/knowledge shortage and suggested information/website content

“Kids need information about safe sex that is cool and relevant they all aspire to these celebrities.”

“Use the art, music... but [while promoting a] protective way.”

“Clinical research, not academic but in way that can be understood so that both parents and children can get the message without the clinical jargon, perhaps using cartoon like picture to depict the virus for instance, today’s research papers are so full of jargon that even if you want to read them you get the end you’re so bored and tired because they are so clinical.”

“Some kind of engine search to search the resources out there for instance, information about testing for parents and children who are sexually active, organizing road shows, info about quick testing, about free condoms for children that may be sexually active who are too embarrassed to buy condoms, information on wearing condoms, information on safe sex (including masturbation individual and mutual).”

“I was interested in the experience of parents dealing with childhood illness, chicken pox, rubella...and behavioural difficulties. My child had behavioural difficulties and I am aware that there is little research into children, pre-exposure and I believe that from time to time, there is large load in the heart and brain, he’s not been disclosed and I am wondering when he’s disclosed, and I have several conversation with his paediatrician about his behavioural problem which I think is related to HIV she says it is not.”

► Disclosure and stigma

[Where do I start? Talking to children with HIV about their illness](#)

Baverstock J, Donaghy S, Faulknall W, and Waugh S (2003)

Available to download as PDF from

www.chiva.org.uk/health/publications/talking - accessed 3/5/2011

[Talking to children about their health and HIV diagnosis](#)

Conway M, Donaghy S and Melvin D (2008)

Available to download as PDF from

www.chiva.org.uk/health/guidelines/talking.html

(includes a disclosure grid outlining a knowledge timeline whereby the overall process of explaining HIV to a child is described) - accessed 3/5/2011

[Talking with children, young people and families about chronic illness and living with HIV](#)

Miah J et al (2004)

Provides good practice examples about engaging parents in disclosure.

<http://www.chiva.org.uk/health/publications/chronic> - accessed 3/5/2011

[Give stigma the index finger - Initial findings from 'The People Living with HIV Stigma Index' in the UK 2009](#)

The People Living with HIV Stigma Index (2009)

[Give stigma the index finger – Scotland Report](#)

The People living with HIV stigma index (2009)

<http://www.stigmaindex.org/50/analysis/uk.html> - accessed 3/5/2011

► Testing children

[UK National Guidelines for HIV Testing 2008](#)

British HIV Association, British Association for Sexual Health and HIV and HIV British Infection Society (2008)

<http://www.bhiva.org/HIVTesting2008.aspx> - accessed 3/5/2011

► Services and support

[Developing support services for children, young people and families with HIV: A handbook for service providers](#)

Conway M (2005)

National Childrens Bureau.

<http://www.ncb.org.uk/pdf/HIV%20Handbook%20lo%20res.pdf> - accessed 3/5/2011

[Looking after children: considering the needs of HIV positive looked after children](#)

Ely, A (2008)

National Children's Bureau, London. This report considers how the needs of these children are understood and responded to by the professionals involved with their care as looked after children, and shares the children's views of their experiences. It explores social policy and includes practice recommendations.

www.ncb.org.uk/dotpdf/open_access_2/hiv_looking_after_hiv.pdf - accessed 3/5/2011

[The dispersal process for asylum seekers living with HIV – Advice for health care and voluntary sector professionals](#)

National Aids Trust and British HIV Association (2006)

<http://www.nat.org.uk/Media%20Library/Files/PDF%20documents/NAT-Dispersal-Process-For-Asylum-Seekers.pdf> - accessed 3/5/2011

► General

[Will someone listen?](#)

Children and Young People HIV Network (2004)

National Children's Bureau, London. Summarises key issues raised at national seminars held in 2004 exploring the needs and responses to children and young people living with HIV.

www.ncb.org.uk/hivn/resources/will_someone_listen.aspx - accessed 3/5/2011

[HIV testing guidelines for children of confirmed or suspected HIV-positive parents](#)

Children's HIV Association (2009)

Available to download as PDF from

www.chiva.org.uk/health/guidelines/hiv-testing - accessed 3/5/2011

[Listening to children and young people affected by parental HIV](#)

Cree V.E, Kay H, Tisdall EKM and Wallace J (2006)

Findings from a Scottish study. *Aids Care*, 2006 18 (1) p73-76.

[The Children in Need and Blood-borne Viruses: HIV and Hepatitis](#)

Department of Health (2004)

Aimed at local authorities, the NHS, Primary Care Trusts and other local providers of services. It covers topics such as information about HIV and other blood borne viruses, information about duties to provide services and support and covers areas such as disclosure of information

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4093509 - accessed 3/5/2011

[Action Based Modes of Inquiry and the Host-Researcher Relationship](#)

Gilmore T, Krantz J and Ramirez R (Fall 1986)

Consultation 5.3

[Action Research for Health and Social Care: a guide to practice](#)

Hart E and Bond M (1995)

Buckingham Open University Press

[Afraid to say: The needs and views of young people living with HIV/AIDS](#)

Lewis E (2001)

National Childrens Bureau

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[A handbook for action research in health and social care](#)

Munn-Giddings C and Winter R (2001)

Routledge

[National Study for HIV in Pregnancy and Childhood](#)

based at the Institute of child health, London. www.nshpc.ucl.ac.uk - accessed 3/5/2011

For more information and to receive newsletter with data updates email nshpc@ich.ucl.ac.uk

