

# Together



**Supporting families living with  
HIV in the UK**



# Graffiti Wall

Statements by participants at the close of the CHIVA/UK Family Project Practice Sharing Day  
8th March 2011



## The UK Family Project

In 2008, Babs Evans, Grant Manger for the Elton John AIDS Foundation brought together UK based organisations to look at the needs of children and young people with HIV. We discussed how we could work collaboratively to support these needs. Two of the main challenges were, how stigma and discrimination ensures that HIV is treated as a secret in families, effecting communication on HIV, sex and relationships for children and young people, and how we as organisations, spread across the UK, could improve our work together, share good practice and feel part of something bigger.

The UK Family Project then formed; a partnership between Positive Parenting and Children (London), Waverley Care (Scotland) and the Regional HIV Social Work Team (Northern Ireland) of Belfast Health and Social Care Trust, funded by a generous grant from the Elton John AIDS Foundation.

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.

- We achieved our aims through a number of UK wide activities and developments:
- organised two family residentials (October 2009 and October 2011)
- co-ordinated a practice sharing and networking event for practitioners who support families living with HIV, in partnership with CHIVA|
- established a network of support and social care professionals / practitioners
- developed a guide to models and methods of support for families living with HIV
- agreed planning and development that supports the testing of children and young people at risk of HIV
- service development in Northern Ireland
- developed a series of resources for communication and talking about HIV within families called 'It's Good2Talk'. Underpinned by research and evidence based good practice, it has been shaped and informed by parents, young people and practitioners across the UK.

## Acknowledgements

We are particularly grateful to EJAF for funding the UK Family Project and encouraging collaborative working. The collaboration has not been just between organisations but with children, young people and parents who have taught us so much. We would particularly like to acknowledge them and the way they have opened their hearts, talked openly about their personal situation and encouraged us and others along the way.

This document was written and compiled by Victoria Morris, UK Family Project Co-ordinator, Positive Parenting and Children. A big thank you to the project partners, Claire Dallas, Pat Knowles, Jeremy Sandell and Lynne Williamson, colleagues at PPC and to Magda Conway, Amanda Ely and Susanne Lambert (CHIVA).

Special thanks to all the individuals who presented on aspects of their organisational models of supporting families living with HIV at the Practice Sharing Event on 3rd March 2011 at the Princess Diana Memorial Rooms -

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## 1. Introduction

This document is about supporting families living with HIV. It is designed to provide ideas for service development and refinement and should be useful in specialist HIV health and social care settings, and generic services which would like to provide a specialist HIV service. It complements the wide-ranging handbook produced in 2006 by Magda Conway, National Children's Bureau "Developing Support Services for Children, Young People and Families living with HIV" by providing a focus on current provision and developments.

From our work at PPC, Waverley Care and the Regional HIV Team in Belfast, we have learnt to recognise the family as a loose concept, with care of children shared between family members, across households, generations and even countries. By 'families living with HIV' we mean that in the household there is at least one person with HIV. This reflects an approach that we see as essential to effective service delivery, seeing an individual as part of a wider context, and working within this context to make a lasting effect. 'Affected by HIV' means that someone you are close to has HIV.

This document is produced at a time when HIV remains a significant issue in the UK<sup>1</sup>. Whilst those living with HIV seek treatment from clinics to enable them to live a long healthy life, the stigma and secrecy that surrounds the virus means that wider social needs remain a key area of concern. Support that addresses isolation, self-esteem, respite and mental health provide an important aspect of people's care. The June 2011 National Aids Trust report on the impact of social care<sup>2</sup> demonstrates well the value of social support services but also some of the barriers to access. About 40% of people with HIV on the UK are African and Caribbean and for many their immigration status adds complexity to their circumstances often meaning no access to public funds (affecting housing and benefit) and an increased likelihood of living with poverty<sup>3</sup>. Those adults and children 'affected' by HIV by being close by relation or in the same household have long been recognised as having needs in common: caring responsibilities, burden of worries and concerns, keeping the diagnosis to themselves, being unaware of the diagnosis despite its significance. Data collected by CWAC has demonstrated that there are an absolute minimum of 19,200 HIV affected children living in the UK today - an increase of 550% since 1995 when Barnardo's estimated numbers<sup>4</sup>.

<sup>1</sup> In 2009, an estimated 86,500 people were living with HIV in the UK. We cannot tell for certain how many people are living with HIV because this number combines the 64,300 people diagnosed with HIV with an estimated 22,200 who were infected but undiagnosed. Over 23,288 black Africans, and 1,930 black Caribbean people are in the UK living with a diagnosed HIV infection and accessing HIV care. <http://www.nat.org.uk/HIV-Facts/Statistics/Latest-UK-Statistics.aspx>

<sup>2</sup> 'NAT (June 2011)

<sup>3</sup> See NAT and THT 2010 report Poverty and HIV: 2006-2009 for a more detailed account of HIV and poverty, which includes a section on how it affects children <http://www.tht.org.uk/binarylibrary/policy/povertyandhiv.pdf>

<sup>4</sup> CWAC 2009 An Analysis of Affected Children in the UK.

The increase of people living with HIV<sup>1</sup> growing in the regions across the UK and the reduction in local authority specialist HIV social care<sup>2</sup> has meant that more, organisations, social workers and clinical and community health staff are thinking about how these needs can be supported. Often numbers of children and young people with HIV are too low to warrant a whole service and the spread of the families across the area makes delivery a challenge.

At the Practice Sharing and Networking Event, provided by the UK Family Project in partnership with CHIVA on 8th March 2011, current challenges to practice were collated from the attendees. The attendees were all HIV specialists, from 30 different organisations from statutory social care and health/ community and voluntary organisations and larger charities. The main challenges identified were 'disclosure', prejudice and stigma, funding, transition, support and partnership.

In this guide we have drawn together some of the current models being used across the UK to help us consider a range of issues in service development and adaptation. They are by no means the only robust ways in which people in the UK are supported or the only aspect of the services that the organisations provide. These are examples to help stimulate thought and discussion, and were presented at the practice sharing event.

Getting people together who have first-hand experience of the same issue, in a group or through one to one peer support, has been shown to be an effective form of support for many within the HIV sector<sup>3</sup>, and can be run with a relatively small budgets. Some ideas of these interventions are provided.

We also look at how and why practice sharing could be good news for practitioners, professionals and families living with HIV.

Alongside the work of the UK Family Project has been a stream of funding by EJAF to CHIVA. As well as website development and large focus of their work has been to develop quality standards for the sector that provides support to children and young people living with and affected by HIV. A children's rights perspective frames this work and is a reminder for all of us who provide services to parents living with HIV to ensure that we have the child's rights at the centre of our work. The quality standards are explained later in the document.

<sup>5</sup> In the UK, most migrants live in London and the South East. However, the Home Office Border and Immigration Agency's policy of dispersal, means that since 1999 many asylum seekers have been moved to other areas outside the South East until a decision can be made on their asylum claim. Page 2 NAT (April 2008)

<sup>6</sup> p. 3 NAT ( June 2011)

<sup>7</sup> p10-12 Kinouani et al (2011)



## 2. Models of support

The models demonstrated here are examples from across the UK, in a range of social care settings. Each setting is briefly explained with a short summary of a specific area of service development and the contact details of the organisation are provided. A longer case study is provided on the development of services within Northern Ireland offering particular inspiration and encouragement in relation to providing services to a small, scattered community of families living with HIV, to partnership working and to achieving an impact on a small budget.

### 2.1 Disclosure

For most of us working in the sector providing a clear approach and the right support for children, young people and parents in sharing their diagnosis and communicating about HIV is a practice challenge. Many of us are thinking about and discussing how a child's right to know their status and have HIV treated like any other illness may affect our approach and bring more honesty to our service provision. We are considering our use of the concept 'Disclosure'; considering whether such a concept is communicating that the telling of HIV is the revealing of a secret. Are we contributing to the stigma unnecessarily? With other illnesses, do we talk about 'disclosing' the diagnosis? In practice we may use more neutral phrases such as 'talking to children about HIV', 'sharing your HIV diagnosis'. Are we providing an honest and open environment within our services that does not reflect the secrecy and stigma experience of HIV? CHIVA are producing Quality Standards to enable organisations to achieve these aims.

**Setting:** UK children's charity with a specialist project providing support for children, young people and families living with or affected by HIV.

There are just over 90 HIV positive children and young people aged 0-19 years old in Greater Manchester, and Gregory's Place Project works with around 40 of these. A project worker attends the North Manchester General Hospital (NMGH) Family Clinic and the Young People's (transmission) Clinic. The project is also linked in, and works very closely with George House Trust (adult voluntary sector service based in a neighbouring building), CHIVA and a range of other local and national networks/forums. Direct services are provided to children, young people and parents/carers living with HIV and affected with HIV.

In relation to talking about HIV (disclosure), the process starts early. Working closely with HIV positive parents and NMGH to encourage pre-adolescent awareness of their status for children living with HIV. The preparation process with parents/carers can take months/years, however where a parent/carer is fully engaged & ready to talk to their child about HIV, it may be completed within 4 individual sessions.

Once HIV has been named to the child/young person they will be offered one to one HIV specific sessions. These sessions will be pre-booked into the calendar before naming of HIV takes place. Tools are used to discuss matters including HIV and the body, transmission, medication, who to tell, privacy and dealing with stigma and discrimination. When appropriate the child/young person will move to one of two peer support groups (dependant on age) to provide an HIV “safe space”, help build support networks to alleviate isolation and offer participation opportunities (HIV specific sessions and social sessions). This is described as a ‘journey’. The model is also provided for affected young people who will be able to access a separate support group. Parents have their own one to one sessions in relation to support for children and young people living with and affected by HIV, and testing. Peer group support and parenting programmes are also offered.

Gregory’s Place, Barnardos, Manchester

Tel: 0161 273 2901 □ Website: <http://www.barnardos.org.uk>

## **2.2 Testing children for HIV; documentation and support**

Achieving the standard of all children and young people at risk of HIV being tested is an enormous task, however with much hard work and dedication hospitals and clinics are making some headway. All HIV support services need to be involved in making a difference in this area. This example provided by Positively UK shows how an organisation can take responsibility for knowing who of its service users maybe children untested for HIV and be in a good position to support them to access testing.

### **Setting:** UK HIV charity providing peer led support

Positively UK champions the rights of people living with HIV and related health conditions. The organisation provides specialist and peer support, advocacy and information, campaign against discrimination, promote positive attitudes and equitable access to health, and strive to increase the involvement, voice and visibility of people living with HIV.

We provide a helpline, one-to-one and group support through our peer work programme, with specialist groups for women, heterosexual people, African, Caribbean and LGBT communities. We also co-ordinate PozFem-UK, a national network of women living with HIV, which aims to be the national voice of women, influencing decisions, services and policy.

CHIVA's Don't Forget the Children report highlighted that the HIV status of all the children of known HIV positive adults in the UK should be known as a matter of clinical urgency. The report recommendation that all adult HIV care provider and support services, including those in the voluntary sector, must have protocols and referral pathways in place to ensure that all the children of HIV positive parents are tested for HIV. Positively UK practices Good Documentation Practice (GDP) that ensures there are standards by which documents are created and maintained.

Positively UK client documentation procedures ask for information at initial registration of every client to include:

- Number of children
- How many children living in the UK?□
- Were children born after HIV diagnosis?
- Have children been tested – if so what were the results?

Positively UK strongly advises client to proceed with HIV testing of any untested children born subsequent to their HIV diagnosis. The project has around 1,000 registrations per year and 75% of these are women.

Testing of children in families with mothers who are positive is encouraged, and the women are supported through this process. Mothers reported a relief knowing their child's status, especially if it was negative. Positively UK is campaigning for all positive mothers to get their children tested.

To ensure good practise the team work with a tight document procedure where all updates are added in a way that another member of the team can follow-up on work where required.

Furthermore, parents sign a consent form, giving permission for members of the team to share information with other voluntary and statutory organisations where it is necessary for providing the required support.

Positively UK, London

Tel: 020 7713 0444 □ Website: <http://positivelyuk.org/>

## **2.2 Working with families with co-infection**

It is not uncommon for people to have more than one infectious disease at the same time. In the UK tuberculosis (TB), hepatitis C virus (HCV) and the human papillomavirus (HPV) have been common co-infections with HIV. In some areas the issue is sufficiently common for services to develop in response. Waverley Care is one of these organisations and have developed an expertise in supporting families living with HIV and Hepatitis C.

**Setting:** Scottish charity providing support and care to people living with HIV and Hepatitis C

The project is Edinburgh based but covers the whole of Scotland. There has been a shift in focus in Scotland: An estimated 40 000 people are living with chronic Hepatitis C in Scotland – as many of 60% of those are undiagnosed. We now have 'Hepatitis C Scotland' –a government campaign to encourage people to get tested. Statutory and voluntary sectors (including Waverley Care) are extending services to people living with Hepatitis C.

In the 1980's across Scotland there was a large prevalence of co-infected parents presenting with Hepatitis C and HIV. There was a high concentration of addiction issues that involved re-skilling staff to respond to these issues and to support people through the bereavement process. In the organisation there has been a shift in focus towards tackling both Hepatitis C and HIV together, as there are many similar issues. This has brought down barriers between people and encouraged deeper understanding and acceptance of both conditions. Initial research findings indicate a higher mortality rate amongst co-infected people (Statistical Methods in Medical Research, 2008; 1 – 13).

To respond to the reality of these changes there have been developments in ethos and practice, with training to tackle the specific needs presenting. Development in good practice has meant having a sound knowledge of supporting families where there is continuing or past addiction to drugs and/or alcohol use, working with high and complex needs which can be resource intensive, having bereavement skills, working closely with bereavement organisations pre and post and information sharing with other organisations - there are usually numerous organisations involved.

Waverley Care, Edinburgh

Tel: 0131 558 1425 □ Website: <http://www.waverleycare.org/>

## 2.4 Young people

Many HIV organisations and clinics provide support to young people with HIV and affected by HIV. The two examples given below have devised services where meaningful participation of young people is central.

### Youth Participation

**Setting:** UK HIV charity for children, young people and families

Founded in 1996, Body & Soul is a UK charity providing whole family HIV support under one roof. The member base is over 4000 people and each week over 200 individuals access our services. Five interlinked age specific programmes are provided, including Teen Spirit (see below) which offer tailored support to all family members and adults without children. Body & Soul's purpose designed facilities are fully accessible, ensuring that all members are able to access services regardless of physical capacity.

Services include peer support, information workshops, nutrition programme, HIV treatment support, accredited skills development courses, mental health and therapeutic services, legal advice, welfare and immigration services.

### **Youth Services: Teen Spirit**

*"It is so good to know that there are other people exactly the same as me. I had so much bottled up inside that I couldn't share with my friends. Here we can talk openly and don't have to suffer in silence. My confidence has definitely improved. I might be living with HIV but I want to live with it, and I want to make something good out of it. If I can teach one person something about HIV then I'll know I've done well" (Joanne, 17 years old)*

Teen Spirit is a pioneering service for young people aged 13-19 years who are aware about how HIV affects them. Services for young people have been developed and refined over 15 years to ensure they offer 'whole person' support that fully meets the needs of all young people who access them. We identify the needs of the young people through regular member driven needs assessments.

Programmes broadly fall into one of the four key areas. Examples include:

**Physical Health:** HIV information/discussion, sexual health sessions, boxercise, nutrition courses, complementary therapies.

**Emotional Health:** Counselling, peer mentoring, workshops on disclosure, relationships, effects of stigma, loss and bereavement.

**Educational:** Weekly 'Launch Pad' service including tutoring with qualified teachers, careers guidance, college/university applications, employability.

**Social Welfare:** Casework and advocacy (housing, immigration, benefits, looked after young people etc) money management and other life skills.

### **Youth participation model:**

Body & Soul aims to ensure that participation of young people is meaningful and enables them to gain valuable skills. Young people are actively involved in the running of the charity; the Teen Spirit Board of directors meets on a regular basis and members were elected by the wider Teen Spirit group or appointed after showing significant leadership potential. The Teen Spirit Board have responsibility for driving programme delivery, for creative and personal input into Body & Soul campaigns and website and representing the views of their fellow Teen Spirit members on an external or policy level. In addition, two young people also sit on the Body & Soul Board of Trustees.

There is also a comprehensive programme of skills development through volunteering that young people can participate in; this places them as leaders and mentors within the organisation. The programme includes opportunities to train as peer supporters, workshops facilitators and outreach workers (press, conferences, events, schools). Many of these programmes are accredited, adding value to CV's and increasing future employability.

Lastly, young people who are living with HIV can apply to become peer mentors in hospital clinics which are paid roles on a rotating sessional basis. Clinic mentors work with patients around areas such as struggling to adhere to medication, isolation and emotional issues. They are fully trained and supervised jointly by the clinics and Body & Soul.

Body and Soul, London

Tel: 020 7923 6880 □Website: [www.bodyandsoulcharity.org](http://www.bodyandsoulcharity.org).

## Work experience and outreach

**Setting:** UK HIV Charity supporting children and families

Children With AIDS Charity (CWAC) is a UK national charity which exists to help the youngest of those infected and affected by HIV/AIDS since 1993.

CWAC's purpose is to enable them to maintain a good quality of life, engage in social development and look towards a future without prejudice.

There are three core services –

The CWAC Hardship Fund which provides essential items such as clothing, beds and formula milk for children living in severe poverty. This fund supports children infected or affected by HIV, where parent/parents do not have the means to provide the basic necessities for their children. 200 referral agencies are linked into this programme providing the pathways for the finance.

The education programme which produces resources and delivers safer sex workshops to tackle the stigma and discrimination that surrounds HIV.

The outreach and preparation to work programme which works directly with HIV- positive young people who have complex health, educational and psychosocial needs. We provide bespoke individual programs enabling young people to transition to independence.

One to one support is provided to the young person which identifies their main needs. CWAC works with a focus on returning young people to education, work-based training and/or employment. The outreach programme is interwoven into the preparation to work programme and young people are supported socially, emotionally and practically when necessary.

CWAC, London

Tel: 020 7033 8620 □ Website: <http://www.cwac.org/>



## **2.5 Outreach work with families**

**Setting:** South London HIV charity providing support to children, young people and families.

Positive Parenting and Children known as PPC, was formed in the mid-1980s. The organisation provides a range of services to families living with HIV: social work, counselling, family support, parent and young people peer support groups and mentoring, playschemes and respite foster care (support care). PPC works with local authorities, hospitals and primary care teams mainly in south London.

The outreach services allocate individual families in need with a social workers/ practice manager and in some cases a family support worker. The service is mainly provided within the home.

Social workers/ practice managers oversee the case work, link with the statutory services and facilitate more complex direct work using specific tools and methods to address coping with HIV, sharing the diagnosis, bereavement, anger, family relationship issues as well as advocacy and advice. The work of the family support worker is strongly guided by the assessment of the social worker. Together with the family they design the intervention.

The Family Support Service aims to provide:

- opportunities for children to develop peer relationships and support for parent/carer to access and engage with local play facilities
- respite for adult from caring responsibilities
- support the self-esteem and confidence of children
- work with parent to identify and recognise the children's needs, and respond to them
- assistance and support at hospital visits, attend meetings with parent/carer
- reduction in isolation

Referrals are discussed in an allocation meeting and social workers are allocated cases to assess and see what support the family needs. The meeting has post assessment discussions and analysis of presenting issues. The assessment is based on the Common Assessment Framework also includes an exploration of HIV- untested children, planning in relation to telling the children about HIV, how HIV it's perceived, who knows, positive children and their understanding. Referrals are made to other PPC services and outside agencies.

Positive Parenting and Children, London

Tel: 020 7738 7333 □ Website: <http://ppclondon.org.uk/>

## **2.6 Statutory Social Care**

Despite being a shrinking specialism in local authority social care, HIV social work still exists in the UK. More common are generic social workers who specialise or hold HIV cases. This guide is intended to include these individuals and recognise their place in the provision of services to families living with HIV. The example below, and the case study in Northern Ireland (Chapter3), demonstrate how vision and outward looking approaches are key ingredients to the development of their work.

**Setting:** Adult statutory social care with one specialist HIV, support group and management of the children and families HIV hospital social work

The adult and children's HIV support services are managed within generic adult team. There is no specialist children's worker.

There are 900 HIV positive and affected people in the Croydon area and many of those either through diagnosis or relationship history.

The social work model we use is one of 'intimacy' – a state of being close. We ask ourselves questions of the relationship with the service user 'can you be welcomed into their home' 'are you perceived as a friend or foe' 'are you a useful, a tool helping with their needs?' Even with cases where there has had to be statutory (i.e. child protection) intervention, we manage warmth and reciprocity within the relationship.

Croydon provides a regular adult group work session at The Junction in Bromley, refers to Positive Parenting and Children and consults with service users.

In our cases, HIV related brain impairment is a real concern especially where children are involved. Poor adherence to medication, late presentation and immigration issues make for additional complexity. Residential care is expensive. The service holds funding stream to help those who are immigrants but with HIV there is a ceiling.

The work in Croydon involves working closely with the UK Borders Agency (UKBA). UKBA has a large presence in Croydon as it is near to Gatwick. It has been essential for Croydon social services to have a good working relationship with UKBA and be able to influence and prioritise urgent cases. Advocating helps to get the cases to rise to the top and get resolved. It is rare for someone with HIV to be removed.

Adults in Need Team, Croydon Health and Social Care

Tel: 020 8686 4433 □ Website: <http://www.croydon.gov.uk/>

### **3. Case example: 'Few and far between' - service development in a low prevalence area**

**Setting:** A regional statutory HIV social work service based based in Royal Victoria Hospital.

#### **3.1 Summary:**

1. Population of Northern Ireland : 1.6 million
2. Number of people with HIV: approx 800
3. Number of Children and Young People with HIV ◀10
4. Number of affected children and young people – approximately 200
5. Geographical spread of people with HIV: 3 miles – 80 miles
6. Changing patient profile: refugees, asylum seekers and migrant workers
7. Regional HIV Team : 1 Full Time Social Worker and 2 Part Time Social Workers.

The Regional Statutory HIV Social Work Service is based in the Royal Victoria Hospital Belfast, attached to the Genito Urinary Medicine Clinic, which is the Regional Centre for the care of people living with HIV Disease in Northern Ireland.

The Youth Work HIV Support Service is delivered in partnership with A.C.E.T (Aids Care Education & Training) Northern Ireland, a regional division of an international charity.

### 3.2 Issues:

- Widespread belief that HIV is not a problem in Northern Ireland. From the outset there was a need to raise the general level of awareness around the condition.
- Families living with HIV were widely dispersed across the province.
- The profile in Northern Ireland has changed dramatically over the last 5 or 6 years due to the increase in numbers of refugees, asylum seekers and migrant workers, this is expected to continue. As a result there has been an increase in number of families affected by HIV.
- The team found that there were young people living in Northern Ireland both with HIV and affected by HIV and unaware.
- There were young people unaware of their own diagnosis who were no longer babies or toddlers, and concern re the "Rights of the Child" and knowing about their HIV status.
- There were parents who were also concerned and asking for help as to how to talk to their child.

### 3.3 Service development, networking and partnership:

From the point of identifying this growing need for services and throughout the development of support, the need to network and gain through collaboration and input from others became an important aspect of the work.

In **2005** the team became part of the NCB Children & Young Peoples HIV Network and invited Magda Conway to run a "Children First" Training to social workers in Health care and Family and Child Care. They also facilitated a lunchtime seminar for hospital staff and generated extensive media coverage.

In **2006** : Working with NCB, Children & Young Peoples HIV Network and Save the Children an awareness day was provided endeavouring to involve a range of professionals with a focus on education bodies in Northern Ireland entitled....

"It's about Young People....  
It's about support.....  
It's about schools.....  
It's about HIV..... "

At the same time the links with PPC began, using their expertise to aid in our service development and in thinking about the needs of our isolated parents and young people.

Together as PPC and Waverley Care, Edinburgh, the Regional HIV Team NI put a joint business case together to EJAF and became the funded entity The UK Family Project, a two year project to address some of the national issues arising within services support to isolated families affected by the secrecy and stigma of HIV.

The Northern Ireland part of the EJAF funding was used to employ a youth worker from ACET NI (one of our local partners), who keeps direct contact with the young people through text, email, 1-2-1 sessions and group meetings.

In **October 2009** : 2 NI parents attended UK Family Project residential for families living with HIV across the UK. 5 families were due to attend but were restricted because identity papers were not accepted by the airline.

In **November 2009** : We organised workshops and a social activity for our initial meeting of families living with HIV. Here we held a consultation on what they would want from a group and models of service delivery.

We engaged in consultations to decide on service delivery methods which produced a range of intervention options of increasing intensity – text and emailing, group work/meetings, direct one to one work and residentials.

Consultation on group support model	
<u>What parents wanted</u>	<u>What young people wanted</u>
Support for self and family	Be able to talk more openly about how we feel
Family social activities	Confide with someone who has something in common
Make contacts/network	Regular meetings
A 'safe space' to talk about their status	To know more about HIV
Control of their project	HIV is not always the main focus
Quarterly meetings	

The Regional HIV Social Work Team with the support of the ACET Youth Worker have been able to provide group work activities, one to one work and a residential weekend. In addition, young people and parents keep in contact outside of meetings and group activities, in a self-help style.

### **3.4 The residential as a method of support:**

Due to the geographical spread and low prevalence, it seemed logical to bring the parents and young people together for a residential experience. 8 parents and 10 young people came together for a weekend in October 2010.

By travelling together in a mini bus to the venue and by participating the first evening in activities/games about 'trust', the families started to form as a group. The programme provided separate workshops for the adults and young people, with joint outdoor pursuit activities, which made many face their fears, supported by the group of both adults and young people.

## Residential Programme of activities and workshops

Parents and young people	Activities and games about trust
Parents	Parent Teen Communication
Young people	Young People's Relationship
Parents and young people	Outdoor pursuits
Parents	Sharing their HIV Journey

What became apparent from these sessions was that the young people needed more information about HIV and the parents benefited in a very powerful way from sharing their HIV journey.

Here is some of the feedback from that residential:

"I discovered there are people I can trust and connect with"

"That we all have value"

"Strength! Hope! Friendship! Trust! Happiness"

"I discovered that we all need each other on this journey"

"That I am a good Mum, but can be a better Mum"

"Discovered emotions and feelings I had stopped using"

"That I can be fun, I can abseil and I can live without a mobile phone!"

What helped make the residential successful was the **timing** - they had already met several times together, and most of the group knew each other; having a **structured and planned** programme of activities, workshops and outdoor pursuits. The outdoor activities were also deliberately designed for the whole family to participate in and have **quality fun family time together**.

### **3.5 EJAF funding as a catalyst:**

The funding from EFAF for the UK Family Project has enabled service developments in a number of ways in Belfast and Northern Ireland.

1. Developing pathways with the adult clinic in relation to the testing of children of positive parents
2. Developing Care Pathways with Maternity Services in the hospital in relation to mothers living with HIV
3. Addressing issues of isolation of new HIV+ mums and babies, i.e. have acquired funding from Danone for an HIV Mums and Babies Lunch and extending the use of volunteers with families
4. Links with Community Gateway Child Care teams (equivalent to referral and assessment teams) and a range of multi-cultural and children/young people/family agencies and voluntary organisations.

### **3.6 Future Plans:**

- For Parents group to establish itself as a self-help group
- For Parents group to extend invitation to include those who have not yet talked to their children about their status.
- Establish and acquire funding for an annual family residential in Northern Ireland, extending invitation to project partners (funding permitting)
- Have already identified future funding source for continuation of the Youth worker
- Share 'sharing and talking to children about HIV' models – to enhance effective, appropriate support to parents – “gold standard of service delivery”

### **Regional HIV Social Work Team (NI), Belfast Health and Social Care Trust**

Tel: 028 9063 2450 Website: <http://www.belfasttrust.hscni.net/>

## 4. Service development

This section provides ideas and examples of discrete add on services that are designed to complement core services and strengthen family life; they may suit funding applications to smaller funds.

### 4.1 Key considerations:

- Participation from service users from the outset, in consultation, design, implementation and evaluation; support and use of peers will provide encouragement to others and help with engagement. Consultation and participation can enable group to take charge of it's own direction. Networks begin to emerge.
- Groups/ workshops could be one-off but likely to be a need to repeat. Experience from practice has shown that providing the right environment children, young people and parents benefit from being able to discuss matters openly with their peers. It helps those who are coming to terms with their situation and strengthens them to face some of the challenges of living with HIV. Groups will attract individuals who are at different stages of their journey with HIV, and for people, of all ages, who have not been able to access HIV specific support before it can be a great encouragement.
- Facilitative skills, sound HIV knowledge and the ability to provide a safe space are essential. Take time to become familiar with your potential users in order to provide a culturally appropriate service see text box for check list.
- Partnership working can help by sharing expertise and responsibilities, tasks and costs, strengthening the organisational links that will enhance your overall development, provide a better quality of service, make your service more accessible for the service user. Joint health and social care projects make sense in this sector and are not unusual i.e peer mentoring programmes in adolescent clinics.

#### Checklist for a culturally sensitive and accessible service

Do you understand the needs of your local population and individuals?

Do you/staff have opportunities for self-reflection and awareness of their own culture and cultural bias/values? Can you/ they cultural knowledge be broadened? Are you/ they comfortable in communication with people from other cultures?

Are individual service users able to talk about their experiences without feeling judged?

Are individuals able to talk about issues in their own style using aspects of their identity that is integral to their way of thinking i.e. faith, sexuality, culture, age?

Is the publicity likely to attract the hard to reach? What else needs to be done?

Are the barriers to participation and access recognised? Is some outreach worth considering?

Are service users given opportunities to participate, and give feedback?

Are services reviewed and improved on?

## **4.2 Antenatal/postnatal support:**

Aim: to facilitate connections for mothers in the same situation. Unique set of needs that make relating to standard antenatal/postnatal groups difficult. Excellent links with maternity services/hospital essential.

- Annual lunch for all babies born to HIV positive mothers in the year
- Coffee morning for all those who attend antenatal clinic: as above, but for antenatal period, during clinic appointment time.
- Antenatal/postnatal workshop for parents
- One to one peer support (more information from Positively UK who have successfully piloted this model 'mentors mothers' across the UK – Knudsen-Strong (2011))

## **4.3 Sharing your HIV diagnosis with you child:**

Aim: provision of groups to facilitate a discussion forum where parents can talk openly about their experiences, plans, concerns and hopes in relation to being able to talk to their children about HIV. Getting ready for 'telling' is a larger task for parents than the child or young person, but post telling also requires support to ensure the communication within the family is enabled.

- Parents whose children are aware – however they found out. Many services in health and social care have identified that there are still needs around communication post 'telling/ knowing'.
- Parents who are thinking through planning to telling their children – young children, over 10s
- Communication workshop, a basic workshop has been designed by The UK Family Project to bring together parents and to facilitate (UK Family Project (2011))

## **4.4 Young people:**

Aim: to increase the amount of safe spaces for young people with HIV and/ or affected by HIV.

- Group – Ideally this will need to be a regular provision with full participation. However, a quarterly programme could work well. Have a mixture of fun, education and support. Consider the use of incentives to encourage time keeping and attendance. Encourage peer support networks, opportunities for participation and development. Have a clear rationale for joining or separating young people with HIV and affected young people.
- Individual support – this is more costly to resource, but it would be good practice for the young people to have clear pathways to seeking support beyond group events, whether or not they attend, including the range of online opportunities to link up with others (see CHIVA website)
- Visits – in regions where numbers in young people's groups are low, visiting other groups or planning a joint activity/ day trip with the nearest similar group or clinic, can provide the young people with additional peer opportunities and connections that they can maintain themselves via the mobile phone or internet.



#### **4.5 Whole families:**

Aim: to provide opportunities for whole family to be strengthened and address issues together in a safe environment

- In relation to promoting positive relationships between young people and their families, with transition to adult services for young people in mind Hamblin (p.57, 2011) noted several [UK] organisations offer whole-family activities such as day trips (p24-5 Conway (2006)) and even residential to facilitate families spending quality time together. Involving young people in delivering sessions for parents and carers, presenting their concerns and ideas, are another approach sometimes used.
- Residential weekend – the benefits of the residential weekend have been noted in the Northern Ireland example on page . The UK Family Project have run two residential for families across the UK (see Kinouani et al (2011) for the report on the first one). Residential weekends can be infrequent but their impact long lasting. There is a qualitative difference in the level of interactions and connections made when people are in the same place eating and communing.

#### **4.6 Budget headings to consider in costing the provision**

Using partnership opportunities and collaborations may help reduce some of the costs below. For example, your local children's centre may be able to offer meeting space for free or reduced cost.

Staff  
Volunteer expenses  
Training  
Supervision  
Overheads  
Consulting, planning and liaison time  
Venue  
Food and refreshments  
Travel expenses or transport  
Incentives/rewards

## 5. Practice sharing

Developing and improving support services can be enhanced by using practice sharing opportunities. Whether you are developing services from scratch or need to refresh your approach it can help to get ideas and inspiration from others in the same field. We can avoid using precious time and resources re-inventing the wheel, when others have faced similar challenges and devised effective solutions. Even established services can learn from newer services who may be taking a more innovative and succinct approach to meeting the needs of service users.

HIV services are provided across the social care and health sector and from statutory and voluntary sector agencies. Meeting and networking has helped us make progress together on some of the specific challenges of HIV where our focus overlaps.

Opportunities to practice share in relation to supporting families living with HIV come in different shapes and sizes:

- Visiting and meeting other organisations
- Annual CHIVA conference (late spring) and CHIVA parallel sessions at the annual BHIVA conference (autumn) [Chiva - conferences and events](#) and [Bhiva - conferences and events](#)
- Local forums/advisory groups/networks – for example, CHIVA networks; identified multi-disciplinary teams in each UK regional area, [Chiva networks](#)
- Networks in health and HIV are more established than those in social care. 2 new opportunities to network in relation to support issues for families living with HIV were created in 2010. A practice sharing event, [Practice Sharing / Networking event 8/3/10 - Flyer](#) and a practice sharing online forum [UK Family Project Forum](#). Designed to compliment the existing NCB Children & Young Peoples HIV Network
- Funding bodies may provide practice sharing and networking opportunities to those they fund in common. For example, the South London HIV Partnership fund nine community organisations offering a menu of peer support groups and one central management organisation in a hub and spoke partnership arrangement (p.5 SLHP 2011) The facilitators of support groups, both for adults, children, and young people, funded by, meet on a regular basis to share practice ideas in aspects of group work. In 2010 EJAF convened a Learning Event, where they structured a day for all their funded UK projects to present to each other their work, their learning and their future plans, with facilitated questions and answers.

## 6. Quality standards

CHIVA, the Children's HIV Association, is developing quality standards for practice with children and families living with HIV in order to improve the quality of service provision. There will be core standards which would apply generally to any children and family service and specialist standards for specific areas of work with children and families living with HIV. The standards will be available in March 2012 and have been developed in consultation with commissioners and a working group that evolved from the Practice Sharing Event held by CHIVA and The UK Family Project in March 2011. All participants were given the opportunity to complete a questionnaire, and asked to volunteer to become members of a working group. The standards have a social care focus, but a Consultant Clinical Psychologist and a Consultant Paediatric Specialist Nurse joining the group helps to ensure the developments are in tune with current health practice and priorities, and address development needs in health.

The member of the working group are:

Kate Brown	Body Positive, Manchester
Sheila Donaghy	St Georges Hospital, London
Amanda Ely	CHIVA
Jill Hellings	Barnardos, Manchester
Diane Melvin	St Marys Hospital, London
Vicky Morris	PPC London (and UK Family Project)
Michelle Overton	Faith in People with HIV, Leicester
Nimisha Tanna	Body and Soul, London

### **Why develop quality standards?**

- Supports the improvement of quality in services. We know that in the past decade there has been increased pressure on a wider scope of the voluntary sector to support children with HIV and their families across the country.
- Provides the opportunity for quality specialist provisions developed in work with families to be described in sets of standards.
- Enables organisations to carry out reviews of their services against set benchmarks of quality practice
- Commissioners use standards when assessing service provision and are keen on having a one stop shop for standards which they refer to.
- Enables other priorities, such as an outcomes based evaluation process. Services can prove they are having clear benefits and impact on health, wellbeing and other indicators.
- Assists the development of national strategic plans, enabling more consistent, connected and reliable service delivery in areas of needs.

### **Process**

CHIVA planned to develop a set of quality standards in close consultation with professionals working in the voluntary sector and also health professionals. At the practice sharing event

in March 2011, disclosure of HIV to children was overwhelmingly identified as a key practice challenge so was chosen as the first specialist topic for standards, and because a number of services were involved in specialist work in this area, developing resources and practice models.

The initial working group focussed on identifying and describing current practice in this area, with a sharing of practice, resources used and challenges faced. Research has also been carried out into different approaches to work with children with HIV and a study visit to Sweden took place to consider learning from their approach in working with children openly around their HIV status.

The first standard will be called:

**Open and honest practice when working with children.**

The rationale is a child rights based approach which argues that children have a right to know they live with HIV, and that the interests of children affected by HIV are best served when they know about HIV in their family. The standard asserts that children need to be equipped with knowledge about HIV at a young age to enable them to effectively acquire skills to cope and live well with HIV, and to reduce the effects of stigma around HIV.

The standard will give organisations aims to work towards meeting the standard at both a core level and a more developed level. With the defined aim of the standard being the achievement of more open and honest practice in relation to HIV in both health and social care services, addressing the spheres of secrecy which persist around HIV. The standard also aims to give organisations access to tools and resources already developed in order to share best practice already developed, which address work such as supporting communication in families.

The standard will be completed early 2012, when it will be sent around for professional feedback and two organisations will be recruited to pilot the standard.

Further information on the quality standards will be posted on the CHIVA website [www.chiva.org.uk](http://www.chiva.org.uk), contact Amanda Ely, CHIVA Social Care Lead for additional information [Amanda.ely@chiva.org.uk](mailto:Amanda.ely@chiva.org.uk)

## 7. Further resources and websites

The following are very useful websites that will support an update your knowledge. They also contain information resources that can be viewed online and ordered.

**CHIVA** – the Children’s HIV Association – a network for people providing health care for young people and children living with HIV, and a website hub of information, guidance and support for professionals, parents and young people living with HIV. [www.chiva.org.uk](http://www.chiva.org.uk)

**NCB Children and Young People HIV Network** – works to build partnerships with agencies and organisations that have an interest in children and young people living with and affected by HIV. The current focus of its work is transition for young people living with HIV (see Hamblin, E (2011)). The network maintains an email bulletin (send a blank email to: [join-hiv-news@ncb-lists.org.uk](mailto:join-hiv-news@ncb-lists.org.uk)) [www.ncb.org.uk/hivn/home.aspx](http://www.ncb.org.uk/hivn/home.aspx)

**Children in Scotland** – national agency for voluntary, statutory and professional organisations and individuals working with children and their families in Scotland. [www.childreninscotland.org.uk](http://www.childreninscotland.org.uk)

**Children in Wales** - the national umbrella children’s organisation open to individuals and organisations from a wide range of fields with varying interests, but all of whom are interested in improving the lives of children and young people in Wales. [www.childreninwales.org.uk](http://www.childreninwales.org.uk)

**NAM** and **aidsmap** work to change lives by sharing information about HIV and AIDS. NAM provide a comprehensive database for national and international HIV organisations [www.aidsmap.com](http://www.aidsmap.com)

**AVERT** provides AIDS & HIV information, including information about HIV/AIDS infection, HIV testing, prevention, global and African information, AIDS treatment and more [www.avert.org](http://www.avert.org)

**NAT** - the **National AIDS Trust** - is the UK’s leading charity dedicated to transforming society’s response to HIV. [www.nat.org.uk](http://www.nat.org.uk)

**Participation Works** have put together a resource ‘Do the right thing’ a guide of where to find resources and good practice guidance for the development and delivery of participation work. <http://www.participationworks.org.uk/resources?filter1=DoTheRightThing>  
Participation Works is a partnership of six national children and young people’s agencies that enables organisations to effectively involve children and young people in the development, delivery and evaluation of services that affect their lives <http://www.participationworks.org.uk/home>

## 8. References

British HIV Association, Children's HIV Association and British Association for Sexual Health and HIV (2009) **Don't forget the children: Guidance for the HIV testing of children with HIV-positive parents** Mediscript Ltd, London <http://www.bhiva.org/DontForgettheChildren.aspx>

Children with AIDS Charity (2009) **An Analysis of Affected Children in the UK** CWAC, London

Conway, M (2006) **Developing support services for children, young people and families with HIV – A handbook for service providers** National Children's Bureau, London [http://www.ncb.org.uk/media/442293/hiv\\_handbook\\_lo\\_res.pdf](http://www.ncb.org.uk/media/442293/hiv_handbook_lo_res.pdf)

Hamblin, E (2011) **'Just Normal Young People' Supporting young people living with HIV in their transition to adulthood - A report from the Children and Young People HIV Network** NCB, London [http://www.ncb.org.uk/media/496335/hiv\\_network\\_transition\\_report\\_final.pdf](http://www.ncb.org.uk/media/496335/hiv_network_transition_report_final.pdf)

Kinouani, G, Morris, V and Tserpeli, L (2011) **Learning from families living with HIV. UK Family Project residential Report** Positive Parenting and Children, London [http://ppclondon.org.uk/wp-content/uploads/2011/05/PPCsinglepages\\_lowres.pdf](http://ppclondon.org.uk/wp-content/uploads/2011/05/PPCsinglepages_lowres.pdf)

Knudsen-Strong, E (July 2011) **From Pregnancy to Baby and Beyond: Preliminary Findings from an Evaluation of the Pilot Programme** Positively UK

National AIDS Trust **Latest UK statistics** <http://www.nat.org.uk/HIV-Facts/Statistics/Latest-UK-Statistics.aspx>

National AIDS Trust (April 2008) **HIV and the UK Asylum Pathway An overview by the National AIDS Trust of the pathway an asylum seeker takes in the UK from application to either integration or removal** NAT, London <http://www.nat.org.uk/Media%20library/Files/PDF%20documents/HIV-and-the-UK-Asylum-Pathway.pdf>

National AIDS Trust (June 2011) **The impact of social care support for people living with HIV: the results of NAT's snapshot survey of healthcare professionals** NAT, London <http://www.nat.org.uk/Media%20library/Files/Policy/2011/Social%20Care%20Survey%20June%202011%20FINAL.pdf>

National AIDS Trust and Terence Higgins Trust (2010) **HIV & AIDS Help and hope for people in poverty, hardship fund: Poverty and HIV: 2006-2009** NAT and THT, London <http://www.tht.org.uk/binarylibrary/policy/povertyandhiv.pdf>

South London HIV Partnership (2011) **Value: The Bigger Picture 2. Outcomes from the South London HIV Partnership** <http://www.slhp.org.uk/files/file1050075.pdf>

UK Family Project (2012) **It's Good2talk: Communication Workshop for parents and carers - HIV Sex and Relationships** Positive Parenting and Children, London

For the series of resources 'It's Good2talk' go to:  
<http://ppclondon.org.uk/uk-family-project/>  
All links checked 4/1/12



UK Family Project / Positive Parenting & Children (PPC), 49 Effra Road, Brixton, London, SW2 1BZ  
Tel: 020 7738 7333 Fax: 020 7501 9382 PPC is a registered charity. Charity number 328427  
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**UK Family Project**



Belfast Health and  
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