

# **HIV/AIDS Policy Good Practice Guidelines**

**Working with Children and  
Young People infected and  
affected by HIV/AIDS**

**HIV, Sexual Health and  
Substance Use Team**

**Leeds Social Services Department**



**Leeds**  
CITY COUNCIL



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## **HIV, Sexual Health and Substance Use Team**

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Based in Leeds Social Services Department, the team has a corporate remit to coordinate and develop the Council's response to HIV/AIDS, Sexual Health and Substance Use through commissioning, policy development, consultation and training.

The team also has a role across the City as a partner in a number of strategic, development and commissioning fora.

If you have any queries or concerns about an adult or child that you are working with in relation to our subject areas you can contact the team on the numbers below.

### **The team's core aims are as follows:**

- To develop policies and staff guidelines relating to our three areas of work
- To provide high quality support and training to LCC employees
- To participate in the strategic development of services within the Council and partner organisations
- To provide up-to-date information to LCC employees on our three areas of work
- To promote HIV prevention, sexual health education and substance use/misuse harm minimisation within Leeds City Council
- To continuously develop our practice as a team

### **Resource Library**

The Team has a large Resource Library covering its remits and related issues. Anyone can join the library free of charge and can access resources on a lending basis. We have a wide range of leaflets, which can be taken away for distribution, on a small scale.

## Introduction

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Leeds Social Services Department is committed to protecting the rights of service users living with HIV/AIDS and ensuring that its service provision is sensitive and non-discriminatory in its delivery.

The Department's HIV, Sexual Health and Substance Team based within Social Services are available to provide professional advice; guidance and support to ensure staff's knowledge and skills are kept up to date.

These guidelines are based on the wide range of issues that have arisen in practice. Issues arising out of an individual's HIV situation vary widely and can be very complex, the HIV Team is available to provide professional advice, guidance and support to ensure staff's knowledge and skills are kept up to date.

It should be noted that these Guidelines are intended as guidance only and any staff member who is unsure about any particular case should consult their manager or the specialist agencies listed in the Appendix.

This document should be read as a whole in conjunction with other corporate policies on HIV and AIDS.

Where the document uses the term 'people affected' it is intended to include partners, relations, and friends; formal or informal carers of people living with HIV or AIDS; and those who have concerns about HIV. All those affected by HIV are potential users of services.

## Purpose and Scope of the Children and Young People's HIV/AIDS Policy and Guidelines.

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- The purpose of these guidelines is to establish key principles and practice of Leeds Social Services Department response to Children and young people affected by HIV.
- Ensure that young adults and children affected by HIV do not experience discrimination or stigma as users of the Council's Services.
- Ensure the principles of confidentiality relating to HIV are practiced at all times.
- Develop and promote appropriate and sensitive responses to young people and children affected by HIV/AIDS.
- Ensure that knowledge around HIV/AIDS is uniform and up-to-date across the Department.

## **Section One: The Facts about HIV and AIDS**

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**1.1** HIV (Human Immunodeficiency Virus) is a virus that damages the immune system and exposes it over time, to the risk of severe infections and certain cancers.

AIDS (Acquired Immune Deficiency Syndrome) is a diagnosis or description given to someone when they have acquired HIV infection and is experiencing ill health due to a number of specified infections affecting them.

It is important to be clear about the differences and terms between the diagnoses of HIV and AIDS because of the misinformation and factual inaccuracies concerning the virus. For example, there is no such thing as an 'AIDS virus' or 'full blown AIDS' as the virus is HIV. Someone cannot be an 'AIDS Carrier' because this would mean they are 'carrying' a diagnosis. In addition, people do not die from AIDS but an HIV related illness.

The Department recognises that HIV is not easily transmitted and the majority of infections have taken place through unprotected sexual activity; an HIV infected mother to her unborn baby via the placenta, delivery or breast-feeding and through contaminated blood or blood products via an injection.

There is no evidence to indicate that HIV can be transmitted by casual contact in any social, domestic, school or hospital setting in the absence of blood or bodily fluids, or through sharing of crockery or cutlery.

### **1.2 What is HIV (Human Immuno-Deficiency Virus)?**

HIV is an infection, which replicates the body's own cells and then damages the immune system, weakening the body's defences against infections. The virus proceeds to damage the immune system over a period of years, which can lead to a pattern of medical problems (AIDS) that can be potentially fatal.

### **1.3 What is AIDS (Acquired Immune Deficiency Syndrome)?**

The acronym AIDS is used to describe the condition of a person whose immune system is damaged as a result of HIV infection.

When diagnosed with this condition, the body is unable to protect itself against specific 'opportunistic' infections. Infections are called opportunistic because they are caused by organisms which are normally controlled by the immune system but which 'take the opportunity' to cause disease if the immune system has been damaged.

There is currently no vaccine against HIV. The only treatment to stem the progress of the infection in preventing damage to the immune system is by the use of anti-retroviral medications for life.

## **1.4 How is it Transmitted?**

In order for transmission to take place, three conditions need to be in place:

- Live virus has to be present either in the body of an infected person or in a contaminated body fluid or body tissue.
- There needs to be a sufficient amount of virus present.
- It has to get into the body of an infected person through an effective route for transmission to take place.

## **1.5 What are the Routes of Transmission?**

There are four proven routes of transmission:

- Unprotected (without using a condom) penetrative sex (vaginal or anal) with someone who is infected with the virus.
- Sharing injection equipment, which has been previously used by someone who is infected.
- Injection or transmission of contaminated blood or blood products and donations of semen (artificial insemination), skin graft and organ transplants taken from someone who is infected.
- From a mother who is infected to her baby; this may be through the course of pregnancy, at birth or through breast-feeding.

## **1.6 Preventing HIV Infection**

The transmission of HIV can be greatly reduced by taking the following precautions:

- Using good quality condoms bearing the British Standard kite mark.
- HIV positive women can prevent transmitting HIV to their baby by taking anti-retroviral drugs during pregnancy, having a planned caesarean section and avoiding breast-feeding. Anti-retroviral drugs are drugs that attack HIV cells. They work by interfering with the way the virus tries to reproduce itself inside a human cell hence reducing the chances of infected cells producing new HIV particles which could go on to infect even more cells.
- Anyone injecting drugs legally or illegally should use clean needles, spoons, filters and syringes. Never share any injecting equipment and dispose of used paraphernalia carefully in a sharps bin.
- Applying universal precautions. This is when exactly the same precautions are taken in each and every instance, which is likely to involve direct contact with potentially infectious material and treating all bodily fluids as potentially infectious. Universal precautions are the most effective way to ensure that the risk of HIV infection is minimised.

# **Children and Young People HIV Policy**





## **Section Two: Children and Young People's HIV/AIDS Policy**

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### **2.1 Children, Young People and Confidentiality**

Information about the HIV status of a child should only be disclosed on a need to know basis in the best interests of the child.

- Fears about infection risk do not constitute a legitimate reason for disclosing information about HIV status.
- Where a child or young person is HIV positive, their consent to the sharing of information about their status must be sought in writing if they are of sufficient age and understanding. Otherwise, consent should be from the parent or other person with parental responsibility.
- Where there is shared responsibility between the Local Authority and parents, via an interim care order or permanent care order, a joint decision about sharing of information relating to the child's or young person's HIV status, should be reached if possible. In the event of the parents withholding consent, the Department may override this decision if disclosure is in the best interest of the child. This decision must be referred to the Chief Officer Children.
- In any meeting convened by the Department, discussion of a child's or parent's HIV positive status should only take place if absolutely necessary for a full consideration of the need to protect and support the child.

### **2.2 HIV Testing Children and Young People**

It would be appropriate to consider testing for HIV in circumstances where children and young people may have been exposed to HIV through any of the following risk factors:

- Children with clinical symptoms of infection such as weight loss and oral thrush – medical advice necessary
- Children or Young people who have received medical treatment in countries without access to sterile equipment or safe blood products.
- Children or Young people who have been exposed to contaminated injecting equipment.
- A child or young person who may have had vaginal and oragenital sex with an infected person

Testing a child or young person for HIV should only be carried out with the welfare of that child or young person being of paramount consideration. There must always be clear reasons about why a test is deemed necessary and that the test result is essential for the appropriate care support and treatment of that child or young person.

Any decision regarding testing a child or young person will require full and informed consent. If the young person is aged 16 or over they must give consent before the test can take place. If a child is under 16 and is of sufficient age and understanding then the child's informed consent must be given before a test can take place. This is known as *Fraser* competency. If the child is deemed not to have the necessary level of maturity, then consent must be sought from a person with parental responsibility.

Wherever possible, where there are concerns that a child or young person may have been exposed to HIV via mother-to-baby transmission, the mother should be approached to be tested. In this situation, the mother should be provided with appropriate information and support to enable her to make an informed decision.

Where a child is 'accommodated' by the Local Authority, and parental responsibility remains with the parents, the decision to test remains with the parents.

If the child is on a care order or interim care order, the Chief Officer Children may overturn a parent's decision about testing if it is in the interests of the child, following legal advice.

If a child or young person has been placed for adoption but has not yet been adopted, only the Local Authority holds parental responsibility. In this case, neither the parents nor the prospective adopters can consent to HIV testing. In this situation, the Chief Officer (Children) makes the decision for a test, following advice from the Adoption Panel Medical Adviser and a county court order must be applied for.

Children and young people are entitled to age and culturally appropriate information before and after testing. Arrangements must be made to ensure that the results of the test are fed back to the child and their family in a planned and sensitive way and that ongoing support is available.

Terrence Higgins Trust (THT) Yorkshire and the African Communities Service can both offer support, as can the HIV, Sexual Health and Substance Use Team within the Department.

Where a child or young person is of sufficient age and understanding to be aware of the issues and refuses to have a HIV test, this decision should be respected, but in the context of an ongoing dialogue with the child or young person in the event of them wanting to test at a later date.

### **2.3 Fostering and Adoption**

All foster carers should receive basic awareness training on HIV within the general induction training. This should include universal precaution awareness and the importance of standard hygiene precautions used for everyone.

Testing will never be carried out solely at the request of foster carers or prospective adoptive parents as a routine examination prior to fostering or adoption.

Where a child is HIV positive and thus receiving medical care, the foster carers will need to be informed so that the child's or young person's needs are met adequately.

Foster carers caring for a child living with HIV should have access to appropriate information and support to enable them to adequately be involved in the child's or young persons care.

Families who wish to foster or adopt a child with HIV need to be assessed in exactly the same way as any family who is prepared to look after a child with a long-term condition. The child's health needs need to be discussed, together with the implications of treatment and possible deteriorating health.

Possible reactions to the child's HIV status from family, friends, schools and the wider community should be discussed before placement. As should, the pros and cons of disclosing the child's HIV status on a need to know basis.

Where the history of the birth parents give rise to serious concern that a child may have been exposed to HIV, the adoption panel should seek advice from the Adoption Panel Medical Adviser and the HIV, Sexual Health and Substance Use Team.

Where a child or young person known to be HIV positive is placed for adoption, a specific plan for training, care and support needs to be drawn up. The adoptive parents should be given information and counselling about the implications of caring for a child or young person living with HIV and the availability of services.

## **2.4 Looked After Children**

All residential care staff should receive basic awareness training on HIV within general induction training. This should include universal precaution awareness, issues around confidentiality, stigma and prejudice and services within the city.

Staff should have access to resources and supported in accessing further training and updating their knowledge around HIV.

Young people who express concerns around HIV should be supported in accessing relevant and appropriate information.

Looked After Children who are living with HIV, and also those who have been affected within the birth family should be supported in accessing support services within the city.

Looked After Children who are living with HIV should be made aware of their rights, in line with their age and understanding. Where appropriate, they should be made

aware who has a 'need to know' about their HIV status. Regular meetings should take place, whereby the young person has the opportunity to discuss their needs and any issues, which arise.

## **2.5 Prevention, Training and Information**

The Department recognises the need for its staff to be informed and continually updated with accurate information about HIV and AIDS. The HIV, Sexual Health and Substance Use Team will provide training and resources to staff.

The Department will endeavour to meet general and specific training needs so that all employees can work comfortably, sensitively and appropriately with people infected or affected by HIV.

The Department aims to ensure HIV/AIDS information and resources are culturally and linguistically appropriate to the needs of Leeds diverse communities.

The Department will continue to work in partnership with statutory and voluntary sector agencies to develop preventative strategies to ensure prospective service users are accurately informed.

## **2.6 Discrimination**

The Department will continue to challenge the prejudices surrounding children and young people with HIV/AIDS and combat the discrimination that arises for them in the provision of services.

Discrimination or prejudice by an employee against any service user with HIV/AIDS will not be tolerated and may lead to disciplinary action being brought against the person concerned.

The Department recognises that particular groups of people, e.g. diverse communities, gay men and intravenous drug users have long been subjected to increased victimisation as a result of HIV/AIDS and being used to "justify" other forms of prejudice. The Department will undertake to challenge these prejudices.

The provision of appropriate services for Black and Minority Ethnic Communities requires recognition of the diversity, linguistic, cultural, religious and ethnic make up of local communities. The department will endeavour to provide information in appropriate language and formats where it is realistically possible.


## **2.7 Health and Safety**

The Department will ensure infection control policies are regularly reviewed and incorporate accurate up to date information regarding universal precautions and HIV infection.

## **2.8 Policy Implementation and Monitoring**

All complaints about services or discrimination against HIV positive people can be addressed to the complaints' officer who by law all Social Services Departments must employ.





**Good Practice Guidelines for  
Working with Children and Young  
People**



## **Section Three: Confidentiality**

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### **3.1 Children and Confidentiality**

Information about the HIV status of a child should only be disclosed on a need to know basis in the best interests of the child. Fears about infection risk do not constitute a legitimate reason for disclosing information about HIV status

Where a child or young person is HIV positive, their consent to the sharing of information about their status must be sought in writing if they are of sufficient age and understanding. Otherwise, consent should be from the parent or other person with parental responsibility.

Where there is shared responsibility between the Local Authority and parents via an interim care order or permanent care order, a joint decision about sharing of information relating to the child's or young person's HIV status, should be reached if possible. In the event of the parents withholding consent, the Department may override this decision if disclosure is in the best interest of the child. This decision must be referred to the Chief Officer Children.

If a child and or their family are opposed to the disclosure of HIV status, they should only be overruled if a failure to do so would place the child at risk of significant harm and/or there is legal requirement to disclose or there is an overriding and legitimate public health risk.

### **3.2 Inadvertent Disclosure of HIV Status**

Workers should take care that they do not inadvertently disclose a service user's HIV status during the course of a child protection investigation. For example, a number of families will not have disclosed their HIV status to their GP. A worker unfamiliar with HIV work might not know this and might inadvertently disclose the client's HIV status to the GP as part of a routine check.

### **3.3 Case Conferences Convened by Social Services**

There will be situations in which HIV status is not relevant to the matters to be decided at the case conference. In other cases it may be impossible to decide about concerns regarding a child without mentioning HIV because, for example, the concerns are about medical issues.

If HIV is not directly mentioned but is likely to be inferred from the discussion, it would be better for the conference chair to make a specific statement about confidentiality and blood-borne viruses at the beginning of the conference. This gives the chair an opportunity to place a duty of confidentiality on conference members at the outset. Mention of HIV should be avoided wherever possible in the conference minutes.

### **3.4 Disclosure to the Child or Young Person**

Disclosure to the child or young person is a very sensitive issue. Parents and carers may have strong views about when disclosure should take place. These views may not always fit with professionals' ideas about best practice. Each family needs to find the time and the way that is right for them. Culturally sensitive professional support should be offered to families to help them tackle this difficult task. Disclosure should be seen as a process rather than a one-off event.

A child who is infected has a clear right to know information about their own medical situation but parents and carers may want to protect their child from some of the consequences of knowing (fear, concerns about the health of their parents, whether to tell friends at school). Disclosure needs to be age appropriate; the child needs to be able to understand what they are being told. They also need some understanding of wider issues, like prejudice and confidentiality that affect the lives of people with HIV. A child or young person who does not know their status and is taking combination therapy will have questions about their medication and hospital appointments.

Disclosure can make sense of a situation that has become worrying. Disclosure may not be appropriate if a child or young person is very ill, if they have no support network or if they're living situation is unstable. If the child is a young adult over 16, or under 16 but Fraser competent and it is their own health that is affected, there may be compelling reasons for disclosure to take place. A young person of 16 has a right to make decisions about their own medical care and to give consent to treatment. In addition, they may be in a sexual relationship or be considering a sexual relationship.

### **3.5 Looked After Children**

When working with Looked After Children, fostered or accommodated children who have been affected by HIV within the birth family, it is useful to think about the following issues:

- Is the young person aware of the HIV within the family? If so, are they aware of who is or was infected?
- Have any family members died? If so, has the child or young person received any support.
- Which staff members 'need to know' about the history of HIV within the child young person's family?
- Is the young person living with HIV? Have they been tested? If they are HIV-positive are they linked with any services like THT or Barnardos for example?
- Has the young person been provided with age-appropriate information?

### 3.6 School

There is no legal requirement for parents to inform the school authorities of a case of HIV infection. Where a parent, carer or child seeks advice about whether they should inform a school or other educational establishment about HIV, they should be informed of this. They should, however, be helped to explore whether or not disclosure would be in the best interests of the young person on the basis of ensuring that the child's physical, emotional and educational needs are met fully. Where a child or young person is of sufficient age and understanding they should be included in these discussions

If the discussion results in a parent, carer or young person deciding to inform the school about their HIV status, further consideration will be given as to whom to inform in the school. This should normally be the Head Teacher unless a school has elected a named member of staff with specific responsibility for HIV.

It is important to establish exactly which family members are aware of any HIV infection. Children and young people may be unaware of their own or a parents/sibling's status.

### 3.7 ESCR Guidance Statement

**As the ESCR system is not currently set up to restrict access to case files, (with the exception of child protection) the HIV, Sexual Health and Substance use team have produced the following guidance statement to record HIV and Hepatitis B and C status.**

Due to the stigma and discrimination, which surrounds blood borne viruses it is essential that information concerning an individual's HIV or Hepatitis status be given the highest respect in terms of confidentiality. This means that only individuals who have a clear need to know the information have access to it. Steps need to be taken to ensure that information regarding a person's HIV or Hepatitis status is protected.

A service user's HIV or Hepatitis status should **never** be recorded on electronic files. It is possible to record the issues that are being dealt with without mentioning HIV or Hepatitis.

When recording information regarding an individual's health status, the extent of the information that needs to be recorded should be fully considered. This is especially important in the light of current access to ESCR.

## 4 Testing Children and Young People

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Testing a child or young person for HIV should only be carried out with the welfare of that child or young person being of paramount consideration. There must always be clear reasons about why a test is deemed necessary and how the test result is essential for the appropriate care support and treatment of that child or young person.

Where the child, parent or workers have raised HIV as an issue, it is important to access specialist medical advice to consider if there has been a real risk of infection and whether there is anything to gain from testing.

There is a need for discussion before any test takes place to clarify access to the results. If a child/young person is of sufficient age and understanding to give informed consent then the result will either be given to them directly, or to who ever gave consent for the test. Even if workers have been involved in the initial discussions, they do not have automatic access to the results.

All babies born to HIV positive mothers will have maternal HIV antibodies in their blood up to the age of 18 months; therefore a HIV antibody test will be unable to establish whether a child is infected in its own right.

Advances in the last few years have seen the introduction of a test known as the PCR (Polymerise Chain Reaction) test for the diagnosis of HIV in infants under 18 months, This test means that in most cases, a child's infection status can be established within 3 or 4 months. For children aged over 18 months, a standard HIV antibody test can be done.

It should be remembered that a test on a child/young person might provide deductive diagnosis of the mother's HIV status. It is therefore strongly recommended to obtain the mothers' consent before testing the child/young person and to consider how the information will be used or shared. Wherever possible, where there are concerns that a child or young person may have been exposed to HIV via mother-to-baby transmission, the mother should be approached to be tested. In this situation, the mother should be provided with appropriate information and support to enable her to make an informed decision.

Children and young people are entitled to age and culturally appropriate information before and after testing. Arrangements must be made to ensure that the results of the test are fed back to the child and their family in a planned and sensitive way and that ongoing support is available.

THT Yorkshire and the African Communities Service can both offer support, as can the HIV, Sexual Health and Substance Use Team within the Department.

## 4.1 Consent

Consent is always required before a child can have a test for HIV. This consent must be both informed and freely given. If the young person is aged 16 or over, s/he is deemed to be capable of giving or refusing consent to their own medical examinations and treatment. Younger children may also be regarded as being capable of giving informed consent if they are of sufficient age and understanding; this is known as being Fraser competent and must be explored on a case-by-case basis with the child concerned. If the child is considered to be too young or otherwise unable to understand the issues, consent must be obtained from a person with parental responsibility.

Unless a child is on a Care Order it will be for their parent to decide whether the child should be tested or not, unless the child is of sufficient age and understanding to make their own decision. Under the Children Act 1989, there may be several parties with parental responsibility for the same child.

Whether or not the Local Authority has full parental responsibility or shares this with parents, the birth parents and any other person with parental responsibility should always be consulted, unless the Local Authority has decided that such consultation would not be in the best interests of the child.

If the child is on a care order or interim care order, the Chief Officer (Children) may overturn a parent's decision about testing if it is in the interests of the child, following legal advice.

However, when a child is not in the care of the Local Authority and the parents refuse consent to testing, the Local Authority may apply for an appropriate court order (e.g. a section 8 specific issue order) to make the case for testing, if they judge that it would be in the child's best interests.

If a child or young person has been placed for adoption but has not yet been adopted, only the Local Authority holds parental responsibility. In this case, neither the parents nor the prospective adopters can consent to HIV testing. In this situation, the Chief Officer Children makes the decision for a test, following advice from the Adoption Panel Medical Adviser, and a county court order must be applied for.

The Department will not support testing of a child for any reason other than the child's own welfare. In particular children will not be tested at the request of prospective foster or adoptive parents.

Young people considering whether or not to be tested require specialist counselling. Discuss all such cases with the Department's HIV, Sexual Health and Substance Use Team who can advise about where suitable counselling can be obtained.

## **4.2 Refusal of Testing**

Where a child is of sufficient age and understanding to be aware of all the issues and refuses to have a test, this decision should be respected but in the context of an ongoing dialogue with the child in the event of their wanting to be tested at a later date.

Where a parent refuses permission for their child to be tested, this may be considered to be a child protection issue if it denies the child access to suitable health care. The age and health of the child are important considerations. There are more pressing reasons for knowing the HIV status of vulnerable children under the age of one year and/or children who are unwell than older children who are in good health. Again, every effort should be made to work in partnership with parents before considering legal action to override their wishes.

## **4.3 Reasons Why Parents May Refuse to Consent to Testing**

Some parents decide not to test their child/young person because they would need to tell their family if the child was positive and this would disclose their own status.

Parents may not want to consent to testing of a child/young person because they want to treat them as negative and this will give them 'something to live for'. In cases where the child/young person turns out to be positive, it destroys their hopes for the child/young person as well as facing the issues about witnessing their own child going through illness.

Some parents have expressed concern because medical treatments for children/young people are still being researched and effectiveness is not conclusively proven. They may not want to subject their children to severe side effects from some of the medicines and therefore reduce the quality and normality of their child's life.

Parents may feel unable to cope with the discrimination after disclosure of the child's status to, for example schools, GP's, and foster carers as this has implications for their own confidentiality in the long term.

## **4.4 HIV Positive Mothers**

In the UK, the most common route of infection for children is through mother to child transmission, often referred to as vertical transmission. Since 1999, universal testing for HIV during pregnancy has been recommended by the Department of Health as part of standard antenatal care, together with appropriate information about the implications of the test result. For women, who are aware of their diagnosis, either before or during pregnancy, and are able to start interventions, the rate of mother to child transmission is now around 1%.

The recommended interventions are:

- Anti-retroviral treatment
- Careful obstetric management during pregnancy and birth, including caesarean section
- Avoiding breast feeding

In some situations, a vaginal delivery may be an option depending on the progression of the virus.

In rare situations, a pregnant woman may decline some or all of the interventions offered, or may indicate that she intends to breastfeed. Under UK law, unborn children do not have any legal status and pregnant women cannot be compelled to have an HIV test, to accept medication or to undergo a caesarean delivery. However, the Department of Health in "Working Together to Safeguard Children" (1999) states that Social Services should become involved where there is concern that an unborn child may be at future risk of significant harm. Such involvement can include convening a pre-birth case conference, placing the unborn child on the Child Protection Register and agreeing a plan to protect the baby as soon as s/he is born.

Following the birth, the baby has rights of her/his own, including a right to "the highest attainable standard of health and to facilities for the treatment of illness" (**UN Convention on the Rights of the Child: Article 24**).

Again, Social Services may need to consider whether the baby is suffering, or is likely to suffer significant harm (Children Act 1989: Section 47) and whether action is needed to safeguard the baby.

In practice, concerns will arise at this stage where parents are declining anti-retroviral medication for the baby following the birth, or breast-feeding where safer alternatives are available.

Whether concerns arise before or after the birth, the first aim when Social Services receive a referral regarding the risk of vertical transmission must be to work in partnership with the parents to reduce the risk to the baby. In almost every case it is in the child's best interests to be cared for by the parent/s and this principle should underpin the assistance offered to the family.

There can be no universal guidelines as to the best course of action and each family will require a full assessment and decisions made on the basis of:

- the opinion of a Paediatrician with expertise in HIV infection;
- the nature and degree of harm to the child;
- the general context of parenting.

If the conclusion of the assessment is that the baby is at increased risk of being infected with HIV as a result of actions by the parents, a decision will need to be made whether this constitutes a risk of significant harm, and therefore whether child protection procedures and legal intervention are indicated.

The importance of providing the parents with accessible and appropriate information and support cannot be underestimated. It is essential that workers involved act in partnership with the parents to understand why they may refuse intervention. Such refusal may be due to a number of reasons including cultural beliefs, concerns about bonding, or in order to maintain confidentiality about HIV status.

## **5 Child Protection**

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HIV is not in itself a child protection issue. However, there will be a small number of families affected by HIV in which child protection issues arise, as they do in other families where there may be concerns about children. In some instances concerns will be nothing to do with HIV and will be about parenting ability, neglect or occasionally abuse. In other cases concerns will be directly related to blood borne viruses e.g. concerns about treatment and care, or risk of infection from contaminated injecting equipment.

Children from families affected by HIV are entitled to the same support and protection by the Local Authority as children from other families. The Children Act, Department of Health Guidance (1999) and local child protection procedures should all be applied in the same way as they would be to any child. The interests of the child must be the paramount consideration for all professionals involved with the family regardless of their specific role.

### **5.1 Caring and supporting Children and Young People living with or affected by HIV**

In the UK, the majority of children and young people infected with or affected by HIV are of African origin and face a number of disadvantages such as poverty, uncertain immigration status and unsettled housing.

Many experience social isolation, which is aggravated by HIV still being the subject of considerable stigmatisation within society at large and particularly within some African communities. It is essential that services are sensitive and responsive to the cultural needs of the young person and their family. Support can be offered from the African Communities Team based at Barnardo's Castle project.

Children living with HIV/AIDS may have particular medical needs but they also have emotional, social and intellectual needs, which are equally important. A child

with HIV should be viewed as a child not as a disease. For the child with HIV, play and contact with other children are an essential part of keeping generally 'healthy'.

To a certain extent, HIV affects all children by what they see on TV and on posters, or what they find out about by talking and listening to others. HIV directly affects some children; they, their family or their friends may be HIV positive. Some may have experienced death or separation of a parent or carer or someone who is of significant importance in their lives. Childcare workers are often in the unique position of being there for a child who is going through painful or difficult times. Childcare workers have always had to deal with challenging situations on occasion; it is important not to feel de-skilled by HIV and to use the skills and experiences gained in other areas to support children and young people affected by HIV.

## **6 Treatment Issues**

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Without any treatment, HIV infection in children may result in chronic disease and about 20% of HIV infected children develop AIDS or die in the first year of life. By the age of 6 years, about 25% of HIV positive children will have had some illness because of their infection. The long-term picture is unknown, but it is likely that most children with HIV will benefit from early life-prolonging treatment. HIV may manifest as AIDS defining illnesses such as Pneumocystis Carinii Pneumonia (the most common opportunistic infection in infants), Candidiasis, Cytomegalovirus or Tuberculosis, or it may take a more non-specific form; failure to thrive, unexplained persistent fever and diarrhea are frequent features of this syndrome.

### **6.1 Monitoring and Treatment of HIV Positive Children**

The progression of HIV disease is not the same in children as in adults and the range of drugs used to treat children is not as extensive. Children and young people who are positive will require careful monitoring to ensure that the appropriate treatment options are considered at the right time. A specialist treatment centre usually oversees this. Developmental checks, blood tests and hospital appointments are an important part of this process.

Medication suitable for children is often made up as a liquid. This means that it has a short shelf life and prescriptions have to be made up more frequently than is the case for tablets. If medication is missed resistance to the drug can develop. Parents and carers may need help in understanding the importance of regular medication and practical assistance in getting supplies. Some parents and carers may not want to give powerful drugs, whose long-term effects are not yet known, to a child who appears to be healthy.

Parents need access to good quality information in order to make informed decisions. Every situation involving a child where the giving or not giving of

medication has become a cause for concern for professionals needs to be considered individually. These cases are unlikely to have simple solutions. Where a child's health is going to be adversely affected by the withholding of treatment, it may be necessary to convene a child protection conference to consider whether a protection plan is needed. It is good practice to consider the need to involve a culturally sensitive advocate who can represent the parents' views and also explain Social Services' concerns to the parents.

### Local Services

#### **Barnardo's African Communities Service**

The Serious Illness team works with families in which someone has a serious illness, including HIV. Main focus on how the illness affects the child in the family. African Communities Team offers a service to African families and individuals affected by HIV.

Low Wood  
Clarence Rd  
Horsforth  
Leeds LS18 4LB  
☎ 0113 2589290

#### **Black Health Initiative**

Provides confidential advice, information and support to African and African Caribbean service users on issues of sexual health and substance use.

☎ 0113 307 0300

#### **Infection and Travel Medicine Unit**

Services for people affected by HIV infection, including same day HIV testing.

Ward 16, Gledhow Wing  
St James hospital  
Leeds LS9 7TF  
☎ 0113 206 5716

#### **Leeds Centre for Sexual Health - Leeds General Infirmary**

An outpatient clinic specialising in providing sexual health services. Service includes: investigation and treatment of all sexually transmitted infections including HIV. Sexual health advice, information, education and counselling available.

Sunnybank Wing  
Leeds LS1 3EX  
[Health.advisor@leedsth.nhs.uk](mailto:Health.advisor@leedsth.nhs.uk)  
☎ 0113 392 6724/6725

#### **Terrence Higgins Trust Yorkshire**

Care, support and information for people living with and affected by HIV.

2 Oxford Place  
Leeds LS1 3AY

☎ 0113 2364720

[Info@thtyorkshire.org.uk](mailto:Info@thtyorkshire.org.uk)   [www.tht.org.uk](http://www.tht.org.uk)

### **National Services**

Children with AIDS Charity

Lion House  
3 Plough yard  
London EC2A 3LP

☎ 020 7247 9115

[www.cwac.org.uk](http://www.cwac.org.uk)

### **Positively Women**

347-349 City Rd  
London EC1V 1LR

☎ 020 7792 0222

[www.positivelywomen.org.uk](http://www.positivelywomen.org.uk)

### **Positive partners and Positively Children (PCP)**

Unit 67 Euro Link Business Centre  
49 Effra Rd  
London SW2 1BZ

☎ 020 7738 7333

### **Body and Soul**

9 Tavistock Place  
London EC1V 7QE

☎ 020 7383 7678   [www.bodyandsoul.demon.co.uk](http://www.bodyandsoul.demon.co.uk)

### **The Children and Young people HIV Network**

☎ 020 7843 1911 [www.ncb.org.uk](http://www.ncb.org.uk)

### **Health Initiatives for Youth: UK (HIFY-UK)**

[www.hify.org.uk](http://www.hify.org.uk)

## **For Further Information and confidential support within LCC Contact:**

The HIV, Sexual Health and Substance Use Team  
Department of Social Services  
Merrion House  
110 Merrion Centre  
Leeds LS2 8QB  
☎ 0113 247 8670

### **LCC Safety Health and Welfare Unit**

☎ 0113 224 3405

### **LCC Needles Collection Help line**

☎ 0800 1386227

## **Useful Resources available from the HIV, Sexual health and Substance Use Team Library**

Talking with children about illness and HIV

Meet Fatima, a girl who has HIV

HIV/AIDS and Young Children – an information guide for workers and carers

Afraid to Say – the needs and views of young people living with HIV/AIDS

Getting help – when someone in my family has an illness called HIV

Produced by  
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