

Practice Guidance

Child Protection and HIV

1. Introduction

- 1.1 HIV is never 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 or neglect or occasionally abuse. In other cases, concerns will be directly related to HIV and may be to do with treatment and care. This document builds on guidance produced by the Department of Health, incorporates medical advances and provides advice on those issues particular to families with HIV in the UK, which deserve special mention.
- 1.2 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 and local child protection procedures should all be applied in the same way as they would be to any child, and the interests of the child must be the paramount consideration for all professionals involved with the family, regardless of their specific role.
- 1.3 The advent of combination therapy has brought hope to people with HIV, but it has also brought new moral and ethical dilemmas about treatment and testing, particularly in relation to children. Recent research into the role that ante-natal treatment and breastfeeding play in transmission raises new practice issues about promoting the health and welfare of infants. Parental wishes about treatment for their child may conflict with medical views about what is best for that child's health and development. Parents may fear that child protection procedures will be used to coerce them into making decisions about testing and treatment about which they are unhappy.
- 1.4 Children with HIV who were not expected to survive beyond their fifth birthday are now adolescents beginning relationships with their peers. They need to be able to make informed decisions about their own sexual health and the health of their prospective partners.
- 1.5 The majority of families are from the most affected African communities and, in addition to HIV, may be facing immigration difficulties, separation from their extended family and community, loss and dislocation, cultural and language differences, poverty and racism. The importance of addressing cultural issues and beliefs cannot be overstated.

2. Vertical Transmission

2.1 Background

Most children with HIV are infected as a result of transmission of HIV infection from their mothers. Mother to child (vertical) transmission can occur before or during the birth, or afterwards through breastfeeding. There is clear evidence that the risk of transmission can be greatly reduced by interventions such as anti-retroviral drug treatment, elective caesarean section and the avoidance of breastfeeding. Given that many of these women are from, and may return to, resource-poor countries, the decision to deliver vaginally may be agreed between the family and medical staff as their individual needs dictate. Many women currently deliver vaginally with anti-retroviral cover to reduce the risks of vertical transmission and results are currently promising. The estimated risk of mother-to-child HIV transmission in the UK and Europe, when breastfeeding was avoided, was between 15 and 25%. It has been estimated that breastfeeding more than doubles the risk of mother-to-child transmission of HIV. Together with other interventions as above, when breastfeeding is avoided the risk of mother-to-child HIV transmission can be reduced to less than 5%.

Reducing the risk

- 2.2 Intervention to reduce the risk of vertical transmission can only take place if a pregnant woman is aware of her own HIV infection. The Government has set targets for the increased uptake of ante-natal HIV testing and testing is now offered to all pregnant women, although it is not compulsory. A number of women will decline an HIV test in pregnancy and this is their prerogative. The most rapid spread of HIV infection is now as a result of unprotected heterosexual sex. As a result of these factors, there will be an increase in the number of pregnant women who test positive for HIV.
- 2.3 Once women are aware of their HIV infection, most choose to accept interventions that will reduce the risk of vertical transmission and protect their babies. Most women will agree a plan with medical and midwifery staff for the management of the pregnancy and birth and will agree not to breastfeed. It is essential that women be offered every support to carry out the plans made. For example, assistance may be needed to arrive at a strategy for explaining decisions to partners/relatives in a way that does not breach confidentiality. Women may also need practical or financial assistance in order to carry out the plan e.g. access to bottle-feeding equipment and money for formula milk. This will be particularly important for women who do not have access to public funds. Local health trusts/social care departments may need to develop working arrangements to ensure that culturally appropriate support is offered, including the use of advocates. Within Leicestershire and Rutland

confidential advice, support and advocacy can be accessed through Leicestershire Aids Support Services (LASS).

- 2.3 Pregnancy can be an anxious time and women will naturally be concerned about the health and safety of their baby. Receiving a positive test result during pregnancy leaves little time for a woman to come to terms with the result while having to also consider making a plan for her baby. It is expected that healthcare professionals will do everything possible to agree plans with women that reduce the risk of vertical transmission.

Rejection of medical advice

- 2.4 Children's social care should be consulted where parents appear to be refusing intervention to reduce the risk of vertical transmission. Such refusal may be due to a number of reasons, for example cultural beliefs, concerns about bonding, or in order to maintain confidentiality about HIV status. The referral should be actioned as soon as concerns become evident due to the fact that appropriate interventions are time-limited.
- 2.5 In rare situations, before the birth, 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' (2006) states that children's social care 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 child protection conference, placing the unborn child on the Child Protection Register and agreeing a plan to protect the baby as soon as she/he is born.
- 2.6 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). Consideration may need to be given to 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 breastfeeding where safe alternatives are available.
- 2.7 Whether concerns arise before or after the birth, the first aim 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 parents and this principle should underpin the assistance offered to the family.

- 2.8 There can be no universal guidelines as to the best course of action and each family will require an assessment and decisions made on the basis of:
- the opinion of an Obstetrician/Paediatrician with expertise in HIV infection
 - the nature and degree of harm to the child
 - the general context of parenting
- 2.9 The conclusion of the assessment may be that the baby is at increased risk of being infected with HIV as a result of actions or inactions 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.

3. Testing of Children

Why test?

- 3.1 The PCR (polymerase chain reaction) test can provide accurate information about the HIV status of babies from the first few weeks of life. Given the advances in treatment, there are real advantages in determining the HIV status of children who may have been exposed to the risk of infection. This is particularly the case for children under the age of 1 year, where prophylactic (protective) treatment reduces the risk of life threatening opportunistic infections. If a baby is found not to be infected it prevents him or her being exposed to unnecessary monitoring and treatment with antibiotics.
- 3.2 The most common route of HIV infection in a child is through vertical transmission, but there may also be concern that children may have been exposed to infection where:
- children have received medical treatment in countries without access to sterile equipment or safe blood products
 - children have been sexually abused, or
 - young people are practising unsafe sex or sharing needles
- 3.3 Testing should never be routine and is only indicated on the basis of the child's health needs, rather than to alleviate the anxieties of carers or professionals.

Consent

- 3.4 Consent is always required before a child can have an HIV test. This consent must be both informed and freely given. Where a child has reached the age of 16, she/he is deemed to be capable of giving or refusing consent to their own medical examinations and treatment, but younger children may also be regarded as being capable if they are of sufficient age and understanding. This is known as being Gillick competent and must be explored on a case-by-case basis with the child

concerned. Where children are considered to be too young or otherwise unable to understand the issues, consent must be obtained from a person with parental responsibility. In situations where a child or young person is the subject of Public Law Children Act proceedings, decisions about HIV testing must be referred to the courts. Both parents and children should have access to culturally appropriate information and support to enable them to reach a decision.

Refusal of testing

- 3.5 Where a child is of sufficient age and understanding to be aware of all the issues and refuses to have an HIV test, this decision should be respected, but in the context of an ongoing dialogue with the child in the event of their wanting the test at a later date.
- 3.6 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. It may be that 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. Each case should be considered on its own individual basis and legal advice sought. Again, every effort should be made to work in partnership with parents before considering legal action to override their wishes.

Sexual abuse

- 3.7 Adults who have been raped are offered HIV testing and prophylactic (protective) treatment, but this is not routine practice with children who have been sexually abused. Consideration should be given as to whether such intervention may promote the health and well being of individual children where they have been exposed to the risk of HIV infection. It should also be recognised that children may have fears about HIV infection even where this is unlikely to be a realistic risk, and they should be provided with relevant information and support.

Young people who are sexually active/sharing needles

- 3.8 It is the responsibility of all those working with young people to ensure that they are aware of safe sexual practices and the dangers of needle sharing. Where a young person requests an HIV test, they will need advice or support. Unless there are exceptional circumstances, such requests must be on their own initiative rather than at the suggestion of adults. It is never appropriate to suggest that a young person have an HIV test because they are thought to pose an infection risk to others.

4. Treatment Issues

HIV disease in babies and children

- 4.1 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 the 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 PCP (Pneumocystis Carinii Pneumonia), Candidiasis, Cytomegalovirus or Tuberculosis, or it may take a more non-specific form. Failure to thrive, unexplained persistent fever and diarrhoea are frequent features of this syndrome.

Monitoring and treatment of positive children

- 4.2 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. This is available via the Family Clinic in the Children's Hospital based at Leicester Royal Infirmary. Developmental checks, blood tests and hospital appointments are an important part of this process, and ongoing support is available through the Children's HIV Specialist Nurse.
- 4.3 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 to understand 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.
- 4.4 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 is appropriate to institute child protection procedures and obtain legal advice. In many of these situations where child protection issues arise it will be possible to consider an application to the courts for a Specific Issue Order. It is good practice to consider the need to involve a culturally sensitive advocate who can represent the parents' views and also explain the concerns to the parents.

5. Disclosure Confidentiality

5.1 HIV status should normally only be disclosed with the informed consent of the person concerned. Where the child is infected, their consent to the sharing of information about their status must be sought if they are of sufficient age and understanding. Otherwise, consent should be from the parent or other person with parental responsibility. Consideration should only be given to disclosing an individual's HIV status where there is a clear 'need to know' in order to safeguard the child. Fears about infection risk do not constitute a legitimate reason for disclosing information about HIV status. If a child and/or her/his 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.

Inadvertent disclosure of HIV status

5.2 All workers should take care that they do not inadvertently disclose a service user's HIV status during the course of a child protection investigation, e.g. 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. Only where the HIV status is integral to the concerns raised should it be discussed.

Child protection conferences

5.3 There will be situations in which HIV status is not relevant to the matters to be decided at the child protection conference. In other cases, it may be impossible to decide about concerns regarding a child without mentioning their medical needs associated with the HIV infection, although this may be discussed using alternative terminology for example, 'a medical degenerative condition'. It is good practice for all conference chairs to reiterate confidentiality issues at the outset. Remember that the informed consent of the infected person or their carer can alleviate difficulties around issues of confidentiality.

Disclosure to the child or young person

5.4 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 to an affected child or young person

5.5 A child who is affected does not have a clear right to know information about the HIV status of another person, even though that person may be

their parent or sibling. The right to confidentiality remains with the person who is HIV positive.

Disclosure to an infected child or young person

5.6 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 their parents, whether to tell friends at school). Disclosure needs to be age appropriate, and 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 affects the lives of people with HIV. A child or young person who does not know their status and is on combination therapy may have questions about their medication and hospital appointments. Disclosure can make sense of a situation that has become worrying. Decisions to disclose diagnosis should always be taken with other professionals and the family.

Refusal to allow disclosure

5.7 There may be situations in which a parent or carer is adamant that disclosure should not be made. In such circumstances an ongoing dialogue with the parent or carer should be maintained. Additionally it is possible to provide the child/young person with detailed information about their health and illness without naming their disease.

5.8 While affected children and young people have no absolute right to information about another family member the strain of living with this sort of secret can affect the whole family. Again it is possible to provide appropriate information and support without disclosing the diagnosis of the individual family members.

5.9 If the child is a young adult over 16 or is under 16 but Gillick 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 medical care and to give consent to treatment. In addition, they may be in a sexual relationship or be considering a sexual relationship.

5.10 In the case of a child or young person under 16 who is not Gillick competent, it is the parent or guardian who has the right to make decisions about whether disclosure is made.

5.11 A delicate balance needs to be struck between considering the wishes of the parent or carer and the rights and emotional well being of the young person and if disclosure is considered to be necessary, legal advice should be sought before such disclosure takes place.

6. Conclusion

HIV is rarely a sole cause for child protection concerns. Professionals should maintain collaborative working and refer to existing procedures in order to ensure that the diagnosis of HIV within a family does not prejudice the assessment or outcomes of any child protection/welfare concern.