Contents: Children Living with HIV

Rights and Responsibilities

Outcome: Children and young people infected by or affected by HIV:

- **are treated as children in need**
- **are protected**
- **receive a relevant service**
- **receive the best care and treatment available as a fundamental right.**

This policy raises the main issues that will arise when working with a family. Many of the questions we need to ask ourselves are the same as with any other case. The key to an effective service is being confident in our ability to answer them with the added HIV dimension.

1.1 Rights and Responsibilities

Rights

- We will seek to make sure that children who have specific needs arising from their HIV status enjoy the same life chances as all other children locally.

- We will seek to make sure that children whose parents have specific needs arising from their HIV status (children affected by HIV) enjoy the same life chances as all other children locally.

Responsibilities

- HIV is a social exclusion issue and needs to be addressed as such. There is a rising trend of infection and a recognised link between sexual ill health, poverty and social exclusion. — NCB HIV Forum

- The discrimination and prejudice faced by children infected and affected by HIV is still evident throughout our society. The challenge for staff and carers is to maintain professional clarity and dedication to the needs of the child in the face of fear and anxiety that prejudice brings. — Natnl Strat for Sexl Health+HIV, Dept of Health 2002

- When the local authority holds parental responsibility for a child, as corporate parents we will:
  - act as a good parent
  - act in the best interests of the child
  - listen to the wishes and feelings of the child
  - act in partnership with parents, carers and other parental

Rights and Responsibilities

responsibility holders
- work in partnership with other agencies.

- Treating all children the same, irrespective of their known or suspected HIV status, will not only help to reduce transmission of other infections but will also eliminate the alienation or ostracism of those who may be infected with HIV.

- If we treat an HIV positive child differently, other carers, parents and children may suspect that 'something is different' about that child. Gossip and mistrust could be generated, which would be damaging for the child.

Rights and Responsibilities

Your notes and comments

Introduction

- HIV and other potentially dangerous viruses such as hepatitis may be difficult to diagnose in young children and may remain undetected or unsuspected in many people.

- Paediatric HIV infection is a field with rapidly changing knowledge and a range of complex clinical problems. There have recently been improvements in the area of early diagnosis of infection in young infants.

- Actual numbers of children and young people living with HIV in the family are not known because they have not been recently updated since the emergence of highly active anti-retroviral therapies (HAART) in the late 1990's. These have prolonged the lives of parents infected with HIV, who are living longer and having more children.

Children in Scotland 2002

2.1 What is HIV?

- HIV stands for **H**uman **I**mmuno-deficiency **V**irus. It is a virus that damages the immune system so that it is less able to protect the body against some infections.

- A child or young person may be infected with HIV and be perfectly well with no symptoms for months or years. The longer a child or young person has HIV, the more likely it is that damage to the immune system will lead to severe infections or tumours.

- The term AIDS stands for **A**cquired **I**mmune **D**eficiency **S**yndrome. AIDS is sometimes used to describe someone with HIV who has developed opportunistic infections or tumours.

- Once infected with HIV a child or young person remains infected for the rest of their life. As yet there is no vaccine or cure but treatments can reduce the damage caused by HIV and greatly improve the quality of life for people with HIV.

- With advances in treatment, children and young people with HIV are able to concentrate on living longer and healthier lives, viewed as having a chronic rather than a terminal illness.

2.2 How is HIV transmitted from one person to another?

- HIV may be present in infectious quantities in the following body fluids:
  - semen

Introduction

- vaginal and cervical secretions
- blood and blood derived products
- breast milk.

- HIV is hardly present (in negligible / not significant) quantities in:
  - tears
  - blister fluid
  - saliva (only ever detected in very small quantities in a very small number of people).

- HIV is **not** present in:
  - urine
  - faeces
  - vomit
  - sweat

  but **may** be present in **blood-stained** urine, faeces, vomit or sweat.

- HIV /AIDS is **not** a notifiable (to Environmental Health) disease.

- The only proven routes of transmission are…
  Mother to baby transmission which may happen:
  - during pregnancy where the baby is infected across the placenta
  - at birth where a baby may be infected by a mother's cervical secretions or blood during delivery
  - through breastfeeding.

  Most children with HIV are infected as a result of transmission of HIV from their mother.

  The rate of mother-to-child transmission is about 5 to 15% among HIV infected women who do not breastfeed and 25 to 45% among HIV infected women who do. The following measures can reduce the risk of mother-to-child transmission to around 1%:
  - anti-retroviral drug therapy for the mother and child
  - avoiding breastfeeding
  - choosing a caesarian section.

  Section 4.2
  NCB Forum

  Sexual transmission through unprotected sex with someone who is infected. This is sex without a condom or femi-dom and is 'penetrative', which means a penis, cut finger or tongue going into the body through the anus, vagina or to a lesser extent the mouth with someone who is infected.

Introduction

Blood transmission by:
- sharing injecting equipment that has previously been used by someone who is infected
- medical treatments that transfer infected blood products.

Since 1985 in the UK all such blood products have been treated to prevent such infection.

2.3 How is HIV not transmitted?

- HIV cannot be transmitted by the following:
  - touch
  - ordinary social contact such as shaking hands, cuddling and playing
  - coughing and sneezing
  - cups, cutlery and food
  - towels
  - toilet seat
  - pets
  - mosquitoes and other insects
  - sharing baths and showers
  - swimming pools
  - kissing
  - bites that bruise rather then cut the skin.

- In summary, HIV is a relatively delicate virus and not easily passed from one person to another. The most frequent means of transmission is unprotected sex and sharing contaminated needles. There is no risk of transmission in ordinary day-to-day contact with an HIV positive adult or child.

Introduction

Your notes and comments

Confidentiality

HIV and confidentiality need not be a confusing issue if we focus on the health and social needs of the child or young person when thinking about who **needs** to know.

- Confidentiality is a fundamental principle on which good social work practice is based.
- Ideally, we will seek the consent of the person infected or affected by HIV before information is shared.
- We will take the feelings and wishes of the child into account in sharing any information.
- Children and young people may not want their school to know they have HIV in the family, for fear the information will be leaked out in an uncontrollable way and they will be ostracised.
- Children may fear being ostracised by their friends for HIV connections, so may choose not to share their 'secret', bearing it alone.

Children in Scotland / Univ of Edinburgh, 2002

- Who needs to know information related to HIV will be passed primarily on a sound assessment of the **needs of the child**, not the community or other agencies.
- We will make sure we have a clear and consistent approach to confidentiality locally.
- As a department, we will establish who should be involved in receiving information on a child's HIV status.

Caldicott Principles

- Information will not be disclosed only because it is thought it might help protect those involved in the care or treatment of a child with HIV infection. Good hygiene precautions should be in place and will protect such people. Schools do not have a need to know the HIV status of children.
- Social Services' position is that where a child is infected or thought to be at risk of HIV infection, information will be made available to:
  - carers and staff who are responsible for the child's health and social well-being, especially those involved in personal care
  - meet the department's legal responsibility for health and safety.

COSHH case law

Confidentiality

In this instance, the information is treated as if it is in the domain of Social Services, not an individual member of staff. It is not reliant on the consent of the child or young person using the service or their parent.

- Social Services will inform people using the service so they are aware of the principles of confidentiality. — Data Protection Act 1998
- It is strongly recommended that this principle be extended to other traditionally complex areas of confidentiality and HIV, such as adoption, involving parents, education and day care providers.
- Safeguarding the sharing of personal information in the Social Services Department will be raised at the beginning of all child protection meetings and reviews.
- Recorded information must only be disclosed in carrying out the Department's duties and responsibilities.
- Any breach of agreed confidentiality procedures will be considered most seriously and staff are highly likely to be disciplined because of the potentially drastic consequences of others learning someone's HIV status. — Disciplinary Procedure

3.1 What will be done before disclosing information about HIV?

- Factors we will share for consideration before giving consent include:
  - what are the advantages and disadvantages for the child and / or family resulting from the disclosure?
  - who will have access to the information if it is disclosed?
  - what confidentiality procedures are in place to protect the information after transfer?
  - the disclosure would be in the best interests of the child and would benefit the family or disclosure would protect an individual at risk of infection
  - the person / agency receiving the information is aware of its confidential nature and is able to maintain confidentiality on the information provided.
- Before disclosing information about HIV to any agency or individual, social services staff and foster carers will be satisfied that all of the following are fulfilled:
  - the child and / or the child's parents have given written consent to us passing the information on. Parental consent

Confidentiality

will be obtained where the child is not capable of informed consent - we make sure the person is fully aware of the implications of them agreeing to us disclosing the information **before** their consent is given.	
• Parental consent will be sought where the child is not capable of giving informed consent, unless it had been decided that consulting them would not be in the child's best interest.	Section 33(2) Child Act 1989
• Senior managers and Legal Services will be consulted before a decision **not** to consult parents is made.	
3.2 What will be done if consent is withheld but it is necessary to disclose the information? • If consent is withheld, the decision of the child and parents should be followed wherever possible.	
• If the child opposes the disclosure, the parent's consent should generally over-ride the child's wishes **only** if the child is not of an age and understanding to consent.	
• The consent of the child or parents should **only** be overridden in the following circumstances: - the child would be at risk of significant harm if disclosure were not made - there is a legal requirement for the information to be disclosed - the public interest requires disclosure to prevent others being put at risk.	Children Act 1989
• If a young person wants information to be kept confidential from their parents, their wish for privacy will only be overridden if the conditions above apply. **Social Services staff must always discuss such a decision with senior managers and seek legal advice before overriding a young person's wishes.**	Article 8 on privacy, Human Rights Act 1998
• If it is decided to go **against** the wishes of the child or parents, they should be told that the information is to be disclosed and who it is to be given to and given a full written explanation of the reasons for this. **Social Services staff must always discuss their decision with senior managers and seek legal advice before acting on such a decision.**	Article 8 Human Rights Act 1998

Confidentiality

- Particular difficulties may arise where a child's behavior may increase the risk of others being infected. In exceptional circumstances, such as when a child is making deliberate attempts to infect others through activities that involve direct exchange of infected blood, there may be a need for a wider group of staff and carers to be aware of the child's HIV status.

- If the decision is made to override a young person's wishes, the issues should be discussed fully with the young person and they should be given the option of making the disclosure themselves.

- The recording and supervision policies will apply.

- The recording of information regarding HIV testing and status should be treated with particular sensitivity.

Schedule 3 Data Prot Act 1998

Confidentiality

Your notes and comments

Prevention

Working effectively and consistently on the issue of HIV demands a whole approach which must include prevention.

- We will promote the good sexual health of young people and families. Social Services has existing policy on sex education and personal relationships, which is accompanied by some training and resource materials for use by staff with young people.

Teenage Pregnancy

4.1 Good Practice Hygiene

We refer to 'good practice' rather than 'infection control procedures' because special precautions are not necessary when caring for someone who has HIV, so long as we keep to ordinary good hygiene practice.

Commonsense precautions will protect carers and others against a range of infections that may be transmitted by blood or body fluids.

- Good **hygiene** practice includes:
  - keeping cuts and sores that break the skin covered by a waterproof dressing (plaster)
  - washing hands thoroughly before and after carrying out First Aid procedures involving bleeding or broken skin
  - washing hands after accidental contact with blood or other body fluids.

Dept of Health

- If there is an **injury**:
  - wear disposable rubber gloves while treating the wound, wash it immediately, applying a suitable dressing
  - wash off blood splashed onto the skin immediately with soap and water. Wash out splashes of blood in the eyes or mouth immediately with plenty of water
  - after accidents, clean hard surfaces with blood or other body fluids on them like furniture with hot soapy water or Trigene (bleach substitute).

- Do not **share** razor blades, toothbrushes and other items that may become contaminated with blood.

- Store and dispose of **needles** used for intravenous therapy in appropriate containers supplied by the Health Service. Take all necessary safety precautions to prevent injuries with a needle.

- Follow these principles when **cleaning**:
  - use normal cleaning methods. No special disinfectants are

Prevention

necessary for either the bath or toilet
- use disposable cloths with a separate ones for the kitchen, bathroom and toilet
- throw away paper towels, disposable gloves and aprons
- wash clothing or other materials, for example terry nappies, sheets and towels which have been soiled with blood and body fluids as normal in a washing machine. Wear rubber gloves If hand washing of soiled clothes is unavoidable
- there are no special measures needed to wash crockery and cutlery.

- Follow these principles when **disposing of waste**:
  - flush items that have been soiled with blood or body fluids like tampons down the toilet if disposable or put them into a plastic bag into the dustbin like paper towels, disposable nappies, sanitary towels
  - flush vomit, faeces and body fluids down the toilet wash potties with detergent or antiseptic and hot water and dry with paper towels.

- Social Services staff and foster carers will make sure that good hygiene is universally practised.

4.2 HIV and Breastfeeding

Women who are HIV positive before becoming pregnant or become HIV positive during pregnancy should receive advice from a well-informed **midwife**, doctor or health visitor on the risks of breastfeeding so they can make well-informed decisions.

Newham Maternity Services

- Breastfeeding is a significant route of HIV transmission, formula bottle-feeding is safer for the baby of an HIV-infected mother.

- The rate of mother-to-child transmission is about 5 to 15% among HIV infected women who do not breastfeed and 25 to 45% among HIV infected women who do.

- The risk of transmission of HIV from an infected mother to her infant through breastfeeding is increased if the mother is newly infected during the breastfeeding period.

- Poor breastfeeding techniques may result in cracked nipples, inflammatory conditions and / or bacterial infections such as mastitis, all of which may increase the risk of mother-to-child transmission of HIV.

Prevention

• There is no evidence that the milk produced in the first few days after birth (colostrum) poses a greater or lesser risk of transmission than later milk. If breastfeeding is unavoidable, the following will reduce the risks to the child: - breastfeeding should be supplemented with formula milk or other drink - early stopping of breastfeeding is strongly advised as the longer the duration of breastfeeding the greater the additional risk of HIV transmission through breast milk.	
• Some women find it difficult to avoid breastfeeding. For example, complications may arise if the woman is part of a community where breastfeeding is the cultural norm and women who do not breastfeed signal their HIV status. By revealing this, such a woman may face stigma, isolation or violence and so may not be prepared to avoid breastfeeding.	
• There are physical medical reasons other than being HIV positive why a woman should not breast feed. With the help of Health and Social Services staff, a woman may be able to explain her avoidance of breastfeeding in this way and so protect her confidentiality.	
• For some parents on very low income, such as asylum seekers, the cost of commercial formula milk may be a key reason for choosing to breastfeed. In such circumstances financial support from Health and Social Services may resolve the issue.	Enfield and Haringey Joint Health and Social Services
• Asylum seekers without access to public funds will get money to buy infant formula	Refugee Council
• Asylum seekers in receipt of support from National Asylum Seekers Support Service will receive an increased weekly allowance with the birth of their child.	David Blunkett v. Asylum Seeker
• Free bottled milk sterilisers may be issued by Sure Start.	
• The best interests of the infant will be at the centre of considerations. Where there is disagreement between an HIV positive mother and Health / Social Services over breastfeeding and a child is at significant risk of HIV infection, we will seek legal advice. Despite several child protection cases highlighting this issue in court:	Department of Health

Prevention

'…there has been no legal direction on this point and a further court decision is awaited for clarification'. advice Sept 2001

Clear health advice to the Court on the risks to the child of breastfeeding will be very important in such a case.

Prevention

Your notes and comments

Testing

The HIV Test, although a simple blood test, needs to be accessed through specialist routes.

- Testing for HIV will be to safeguard the health requirements of the child. Staff will record clear reasons informing the decision whether or not to test.

- The paramount consideration in a decision whether to test or not to test must be the **welfare of the child.** It must be clear that the test result is essential for the planning of care for the child or young person's future.

- For assessment, when considering the testing of a child for HIV, it is important to treat the issue of why we shouldn't test with the same weight and importance as why we should test.

- Allaying the anxieties of prospective carers (temporary or permanent) should not in itself be a reason for testing.

- There may be pressures from other agencies to pursue testing a child that is not based on health grounds, for example for forensic evidence in child abuse cases. These will be resisted.

- We acknowledge that prejudice, fear and discrimination still exist around HIV. The decision to test or not to test a child needs to address the social and emotional impact of testing.

- The decision whether to pursue a test or not is to be made by the Group Manager. This decision will be made with clear reasons.

- Fully record a decision to test or not to test a child, to make sure the intricacies of testing have been fully considered as a matter of good practice.

- In some cases the testing of a child or young person may suggest the HIV status of one or both of their parents. Sisters and brothers should be considered.

- Any assessment of whether to test or not to test a child for HIV may be revisited if justified by sufficient changes in circumstances, for instance changes in the health of the child, at the child's request or following disclosure of previous risks.

Testing

- Consider strategies for working with the child now and as they get older in core assessment action, assessment records and ongoing care planning.

5.1 Process for considering an HIV Test

Why is the issue of an HIV test being considered?

- This process will only apply to children for whom the local authority has parental responsibility. In all cases, advice should be sought from Legal Services as an application to court may be necessary. Examples:
  - Mother is HIV positive
  - forensic evidence in child protection cases
  - sexual abuse
  - health needs of the child
  - the child or young person is exhibiting HIV related illness
  - the child or young person requests a test
  - intravenous drug use by the child or young person or their parents
  - knowledge that a young person is having unprotected sex.

5.2 Testing Policy: Newborn to 16 years old

Counselling and testing will be **offered** by health staff to children and young people by following the following criteria:

- presenting with needle stick injury
- at any age if their mother is found to be infected
- at any age if the mother is untestable and her medical history can't be found and her sexual partner is found to be infected
- who present signs and symptoms suggesting potential HIV infection
- who have been sexually abused by a known HIV positive perpetrator or a high risk perpetrator (stranger rape, perpetrator with known risky behavior, multiple abusers)
- who have been sexually abused and have evidence of other sexually transmitted infections
- young people involved in high risk behaviour.

- Children and young people who have been sexually abused or who are strongly suspected to have been abused and present concerns outside these criteria should be followed up and / or discussed with a team member of the Community Paediatric HIV Team.

- Children and young people who request an HIV test and fall outside these criteria should be referred to the Community Paediatric HIV team for counselling.

Testing

5.3 Procedures for Testing: Newborn to 16 years old

- Newborn babies of mothers diagnosed HIV positive in pregnancy will be tested by the Acute Sector / primary care trust medical team (Midwife, Health Visitor, GP) according to current policy. This includes notifying the Community Paediatric HIV team of any positive results.

  S. Derbys Community Health Services Test Protocol

- Testing of children presenting with signs and symptoms suggesting potential HIV infection will be tested within the Acute Sector. The Consultant will inform the Community Paediatric HIV Team of any positive results.

  Appx 12.2

- Young people in high risk behaviour should be referred to the Department of Genito-Urinary Medicine.

  William Macdonald Clinic DRI

- Any concerns about testing procedures can be discussed with any member of the Community Paediatric HIV Team

  Appx 12.2

Testing

Your notes and comments

Assessment and Working Together

6.0 Assessment and Working Together

- HIV is a complex medical condition and health services will be involved with the family. The social needs of the child are and will remain the responsibility of Social Services where the local authority has parental responsibility.

- To make sure a whole assessment is made, staff will seek and consider the views of other key professionals, particularly Health.

- There may be a wide variety of professionals involved in the care and support given to the individuals within the family. To ensure a coordinated approach that is least intrusive to the family, an appropriate key worker will be identified.

- As a principle of good practice, Social Services staff will always consider what are the best interests of the child in any case. This may involve wishing to share information with other professionals outside of Social Services. The reasoning for this will be shared with the child or their carers and formal consent gained from them.

- In some cases, over-ruling the wishes of the child or carer will become an option but in all such cases we will seek legal advice on the process for considering disclosure.

- The principles of confidentiality identified apply. Other agencies may have different policies with regard to information sharing, which will be respected.

  Section 3 Confident-iality

- Due to advances in treatment available to infected infants, involving carers is of paramount importance. This will not be at the expense of the needs of the child or for the benefit of other adults.

- We will seek and include the views of the child or young person where we can get them.

- A situation where many different people hold information that would benefit the child if pooled together but do not do so under a misunderstanding of confidentiality should be avoided if ‘what is in the best interests of the child?’ is held.

- The effective management of a child or young person’s situation involving HIV may include advice and support from

Assessment and Working Together

agencies outside the usual lines of agreement.	
• Social Services will seek to work in partnership with Education to make sure children and young people are encouraged to discuss and actively learn about HIV and AIDS from an early age, including the potential outcomes of unprotected sex.	NCB HIV Forum
6.1 Children in Need	
• Where a child is **affected** by HIV because their parents or carers are infected, they are seen as a child in need and are required to have an assessment of their needs within the context of the family as a whole. This is particularly relevant to staff whose primary role is to work with adults.	
• Refer affected children from adult health services through to children's Social Services for a 'Child in Need' assessment.	
• Children adversely affected by the chronic long-term illness of their parent or carer will be regarded as children in need.	Children Act 1989
• A child or young person whose parent or carer is HIV+ is likely to become a young carer. Refer them to the Young Carers' Project for an initial assessment as a child in need.	Children Act 1989
• Children caring for their HIV+ parents may become involved with: - making more tea and washing up when their parent is ill - housework and cooking - helping the parent to bath - helping them in and out of bed - cleaning the bed - looking after younger siblings - continuing care role – keeping a 'watchful eye' on levels of illness, tiredness, pain, medication, weight loss, phoning for medical help, accompanying on hospital trips.	Listening to Children / Young People Whose Parent / Carer is HIV+, Children in Scotland 2002
• Children affected by HIV, for example their parent is HIV+, have health needs for their own well-being, including mental health.	Children in Scotland 2002
• All children will be regarded as potentially living with HIV and their level of knowledge researched. We will discuss positive and negative aspects with them, balancing facts with social awareness.	NCB HIV Forum

Assessment and Working Together

- Staff will upgrade themselves regularly on their knowledge of HIV and AIDS issues and developments.

6.2 Needs of Refugees and Asylum Seekers

- Children seeking asylum may become sole carers for parents with HIV because of a lack of extended family to share the care. They will be referred to the Young Carers' Project for an initial assessment as a child in need. — Young Carers' Project

- Some women find it difficult to reduce the chances of transmitting HIV infection to their baby by avoiding breast-feeding. For example, complications may arise if the woman is part of a community where breastfeeding is the cultural norm and women who do not breastfeed signal their HIV status. By revealing this, such a woman may face stigma, isolation or violence and so may not be prepared to avoid breastfeeding.

- There are physical medical reasons other than being HIV positive why a woman should not breast feed. With the help of Health and Social Services staff, a woman may be able to explain her avoidance of breastfeeding in this way and so protect her confidentiality.

- For some parents on very low income, such as asylum seekers, the cost of commercial formula milk may be a key reason for choosing to breastfeed. In such circumstances financial support from Health and Social Services may resolve the issue. — Enfield and Haringey Joint Health and Social Services

- Asylum seekers without access to public funds will get money to buy infant formula — Refugee Council

- Asylum seekers in receipt of support from National Asylum Seekers Support Service will receive an increased weekly allowance with the birth of their child. — David Blunkett v. Asylum Seeker

- Free bottled milk sterilisers may be issued by Sure Start.

6.3 Children in Public Care

- All assessments for children in public care will consider the possibility of HIV health concerns where there is a possible risk of:
  - sexual abuse
  - unlawful sexual intercourse
  - young people involved in intravenous drug use

Assessment and Working Together

- children involved in prostitution

- Reviewing Officers will consider HIV as a standard agenda item under the broader banner of sexual health.

- Children still need to be protected regardless of the health of their parents and carers.

- We will introduce the HIV dimension in all child protection conferences and reviews where there is a possible risk of infection for example:
  - sexual abuse
  - unlawful sexual intercourse
  - young people involved in intravenous drug use
  - children involv4ed in prostitution.

- We will seek legal advice.

Section 4.1 Good Practice Hygiene for Residential Social Workers and foster carers

Assessment and Working Together

Your notes and comments

Services for Children and Parents who are HIV Positive

A child infected with HIV falls under the definition of a 'child in need'. — Children Act 1989

7.1 Community Paediatric HIV Services (Health) — Appx 12.2

We can offer:

- Information and advice about blood-borne viruses including HIV and their effects on your child at home, in school and in the community
- Regular medical checks
- Regular development checks
- Behaviour management advice
- Special needs assessment for educational purposes
- Testing of children and young people for HIV and other relevant infections
- Counselling about HIV infection, illness, grief and bereavement
- Education and training.

7.2 Telling Children About HIV and Supporting Them

- The process of telling children about HIV in their family and their understanding and coming to terms with the knowledge is like a journey. Individual families and children will be at different stages between no knowledge and full understanding. Knowing about HIV does not ensure understanding and **telling without appropriate support structures can be damaging for children**. Young children may believe their parent is about to die. The most vulnerable time may be as they enter adolescence. — Children in Scotland 2002
- Counselling will be available for the child or young person and those with parental responsibility.
- The main difficulties associated with parental HIV for children and young people is the stigmatised and life-threatening nature of the illness and their struggle to cope with it. — Children in Scotland
- Children and young people want to be treated as 'normal' — Children in

Services for Children and Parents who are HIV Positive	
people and treated fairly, not to be singled out and treated differently to their peers.	Scotland 2002
• Parents often have mixed feelings about explaining HIV to children and may need help and information to do it.	S. Derbys Paediatric HIV Team
• Parents gave many reasons for wishing to postpone telling their children about HIV status, such as: - concerns about discrimination and stigma and fears that the child may not be able to keep the secret - children being too young to understand and adverse effects upon their well-being - parents not having come to terms with living with HIV.	
• A recent study found that children often felt angry and hurt when they learn that a member of their family had HIV but they were not told.	National Children's Bureau
• Some children were given partial knowledge of HIV in their family. For example: - being aware that a parent needs to take medicine every day but being uncertain what it is for - accompanying a parent to a clinic and not being told 'formally' about HIV in their family but know much more than adults thought.	
• Research found feelings of isolation were common amongst families with HIV. Children's access to social and leisure activities may be limited because: - there are additional pressures on parents as a result of their caring role - barriers and stress may be caused by the need to keep secrets and fears of disclosure. Most children were skilled at negotiating who they could tell and trust - financial pressures on families where parents are not able to work because of their illness - children with a partial knowledge may have no space to talk about HIV. Specific HIV support groups and respite trips can give them a safe space to discuss these issues.	National Children's Bureau
Schools - 90% of children affected by HIV reported being bullied, affecting their confidence and motivation to attend school. Peer solidarity to deter bullying was often not available for	National Children's Bureau

Services for Children and Parents who are HIV Positive

such isolated children. Appropriate school support is often dependent on school's awareness of the family's HIV status but fear of discrimination or lack of trust was often a barrier to telling schools.

- Young people may not be able to concentrate at school for fear their HIV+ parent may become taken ill while they are away from home.

- Childen and young people affected by HIV may not be able to participate in sex education at school for fear of being seen to know too much about the topic. They may not get their genuine queries addressed, particularly if the teacher does not make a realistic assumption that someone in the class may be affected by HIV in the family.

- Children and young people may voluntarily give up precious respite activities that help them forget their worries to assist their ill parent.

Children in Scotland 2002

- Children and young people want their parents to be viewed as normal parents and not be criticised or discriminated against because of their illness.

- Family conflict can centre around how much the young carer is expected to do at home.

- If nerve damage grows, some parents could lose their balance and their memory, becoming numb or in pain. In acute illness some may have difficulty breathing or swallowing and eating. Depending on the exact nature and stage of their illness, their parental judgement can fail, they can become irritable and angry, forget things and make mistakes on times and dates and have difficulty in controlling money.

- Few young people are able to talk about parental death without a great deal of difficulty. Those that are tend to:
  - be older
  - be told of parental HIV by their parents by 11 or 12 years old
  - have received counselling in childhood and early teenage years
  - have usually been involved in care-giving in the last stages of their parent's illness.

Services for Children and Parents who are HIV Positive

- When a parent dies, young people may not be able to face school and wish to stay close to the surviving parent. They may fall behind and school may seem less relevant.

- Children may find it helpful to spend time with their parents at specialist HIV agencies, where they can learn gradually about HIV 'as and when' they are ready to learn more. These young people experience less shock when they come to understand the implications of their parent's HIV illness. — Children in Scotland 2002

Social care workers will: — Children in Scotland 2002

- be clear about the purpose of contact with the young person
- be as constant a force in the lives of young people as they can manage
- not expect children to trust them with their anxieties before they are ready
- not expect children and young people to understand the value of talking just because they do
- not keep asking questions
- only want to talk about problems
- take time to build up a relationship with young people
- be prepared to have a laugh with young people
- talk of things of interest to the young person
- allow the young person to decide the issues that are worrying them
- organise activities that enable to young person to meet other young people in a similar situation to them
- not talk of 'needs' or 'support services' as these do not have sufficient meaning for young people.

Services for Children and Parents who are HIV Positive

Your notes and comments

Sources

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- Department of Health (January 2002) **Children In Need and Blood-Borne Viruses: HIV and Hepatitis**

- Helen Kay, Viviene E. Cree, Kay Tisdall and Jennifer Wallace (2002) **Thinking Positively: Listening to Children and Young People Whose Parent is HIV Positive** Children in Scotland and University of Edinburgh

  - Factsheet 1: HIV Education and Support in Scottish Secondary Schools

  - Factsheet 2: Social Work Provision for Children Affected by HIV

  - Factsheet 3: Health Service Provision for Children Affected by HIV

  - Factsheet 4: Interviews with Children and Young People

  www.childreninscotland.org
  tel. 0131228 8484

- HIV Forum for Children and Young People, Issues for Discussion **Meeting the Needs of Children and Young People Living with HIV: HIV Antenatal Testing and Beyond**
  Janine Jolly, Co-ordinator
  National Children's Bureau
  8 Wakley Street,
  London EC1V 7QE
  tel. 020 7843 1911
  hivinfo@ncb.org.uk

- Derbyshire County Council Social Services Department (September 2000) **Policy and Guidance for Children Infected and Affected by HIV**

- Nigel Shipley (January 2002) **HIV and Children: Guidance and Policy for Social Services Staff, Foster Carers and Adopters** South Gloucestershire Council and NHS Trust

Sources

- Teenage Pregnancy Unit **Guidance for Field Social Workers, Residential Social Workers and Foster Carers on Providing Information and Referring Young People to Contraceptive and Sexual Health Services**
  www.teenagepregnancyunit.gov.uk
  020 7972 4574

- Department of Health 'Quality Protects' **The Best Chance in Life: Improving the Quality of Services for Children**
  www.doh.gov.uk/qualityprotects

- **Data Protection Act 1998** Schedule 3 Conditions Relevant for Purposes of the First Principle: Processing of Sensitive Personal Data

- Southern Derbyshire NHS Health Authority **Welcome to the Community Paediatric HIV Team**
  tel. Dr Ann Brammer, Associate Specialist Community Paediatrician
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  0115 930 5599 extension 213
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Confidentiality Flowchart HIV and AIDS