

Looking after HIV: Considering the needs of HIV positive looked after children



Working with children
for children

Updated children's policy overview 2015

Introduction

Looking after HIV: Considering the needs of HIV positive looked after children by Amanda Ely was published by the National Children's Bureau in 2008. The publication from NCB's Children and Young People HIV Network aimed to:

- consider the experiences of looked after children who are HIV positive
- look at policy and practice guidance for looked after children and consider whether this is adequate to support professionals involved in the care of HIV positive children
- offer recommendations for improving practice
- improve general awareness of the issues and risks faced by looked after children living with HIV.

Many of the issues, challenges and recommendations detailed in the original edition remain current. *Looking after HIV* continues to provide clear, practical guidance for professionals to address the specialist needs of children and young people living with diagnosed HIV as well as the risks to young people in the care system of acquiring HIV.

Two new publications will provide updated and additional information to supplement *Looking after HIV*:

- This children's policy overview which supersedes Section 3 of the 2008 edition of *Looking after HIV*, 'Generic children's policy overview'
- *Practice guidance on supporting young people at risk of HIV and other sexually transmitted infections or blood-borne viruses* to be published in early 2016¹.



All resources from the Children and Young People HIV Network, including *Looking after HIV: Considering the needs of HIV positive looked after children* can be downloaded for free from www.ncb.org.uk/hiv.

NCB would like to acknowledge Amanda Ely, the author of *Looking after HIV*, and all those who contributed to the publication.

Keith Clements and Emily Hamblin have produced this updated version of the children's policy overview. This work is part of NCB's role as Health and Care

¹ This document will be updated with a link to the new practice guidance once it is published.

Voluntary Sector Strategic Partner² to PHE, the Department of Health, and NHS England. The Strategic Partner Programme brings together voluntary and community sector organisations to bring the voice and experience of users to the heart of policy making to improve health and well-being; promote equality; and reduce inequalities. It enables increased capability, partnership and joint working within the voluntary and community sectors and with the health and social care systems at national and local levels.

² <http://www.ncb.org.uk/areas-of-activity/health-and-well-being/health-and-social-care-unit/strategic-partnership>

Children's policy overview (Section 3)

This children's policy overview describes a broad children's policy framework, highlighting aspects particularly relevant to the needs of children and young people living with HIV, or at risk of acquiring HIV, who are in the care system. It uses the following headings:

1. HIV
2. Human rights and equality
3. Children's legislation
4. Statutory guidance relating to children
5. Information sharing
6. Other legislation and policy relating to health needs.

Apart from in the first document, there are limited references made to HIV.

1. HIV

Department of Health (2004) [Children in Need and Blood-borne Viruses: HIV and Hepatitis](#)

This document focuses on meeting duties of care in relation to HIV and hepatitis B and C. It is aimed at local authorities, the NHS, primary care trusts (replaced by Clinical Commissioning Groups in 2013) and other local providers. It covers a wide range of areas including HIV prevention and testing and its principles remain current, though some policy, practice guidance and clinical information have changed.³

In relation to information sharing, the guidance stipulates the following:

- The child's consent to disclosure of information about their bloodborne virus status should be sought whenever the child is of an age and understanding to provide it. Parental consent should be sought where the child is not capable of giving informed consent (s5, para 15).
- Where the local authority has parental responsibility, 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. Local authorities will need to liaise closely with other agencies to ensure that their procedures for maintaining confidentiality are appropriate (s5, para 15).
- The local authority should provide full age-appropriate information in terms which the recipient can understand, describing both the advantages and disadvantages of disclosing infection status. Information about the suggested need for disclosure should be non-directive and sensitive to the child's and family's ethnic background, culture and language (s5, para 16).
- If consent to disclosure is withheld, the decision of the child and parents should be followed wherever possible. If the child opposes disclosure, the parents' consent should generally override the child's wishes only if the child is not of an age and understanding to consent. If the local authority officer is concerned that the welfare of the child and/or family is diminished because of their objection to disclosure, further discussions with the family may be appropriate (s5, para 17).

³ NCB's *Practice guidance on supporting young people at risk of HIV and other sexually transmitted infections or blood-borne viruses* (to be published in early 2016) will provide up-to-date information.

- Generally the child's and/or family's wishes should only be overruled if any of the following apply:
 - the child is at risk of significant harm if disclosure is not made
 - there is a legal requirement for the information to be disclosed
 - public interest requires disclosure, for example in order to prevent others being put at serious risk (s5, para 18).
- If it is considered necessary to go against the wishes of the child or parents, they should be told that the information is to be disclosed and to whom, and should be given a full written explanation of the reasons for overruling their wishes. Social workers should always discuss their decision with senior officers and seek legal advice before taking action to disclose in these circumstances, or to disclose information about HIV without seeking the consent of the person concerned, which should take place only in exceptional circumstances (s5, para 19).

2. Human rights and equality

UN Convention on the Rights of the Child (UNCRC)

Ratified by the UK in 1991, the UNCRC sets out the basic rights for children (defined as under 18 years).

The following rights are of interest:

- In all actions concerning the child, the best interests of the child shall be a primary consideration. (Article 3)
- The child who is capable of forming his or her own views shall be assured the right to express those views freely in all matters affecting him/her. (Article 12)
- No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, or correspondence. (Article 16)
- A mentally or physically disabled child should enjoy a full and decent life in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community. (Article 23)
- The child has the right to enjoy the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. (Article 24)
- A child who has been placed by the competent authorities for the purposes of care, protection or treatment of his or her physical or mental health has the right to a periodic review of the treatment provided and all other circumstances relevant to his or her placement. (Article 25)

Equality Act 2010

The Equality Act 2010 legally protects people from direct and indirect discrimination, as well as harassment and victimisation, on the basis of defined 'protected characteristics', which include disability. People living with HIV automatically meet the disability definition under the Act from the day of diagnosis.

The Equality Act 2010 protects disabled people in relation to access to goods, facilities and services (as well as other areas, including education and employment). It also created the Public sector Equality Duty, which requires that public bodies have due regard to the need to eliminate discrimination, advance equality of opportunity, and foster good relations between different people when carrying out their activities.

3. Children's legislation

[The Children Act 1989](#)

The Children Act 1989 sets out local authorities' duties to safeguard and promote the welfare of all children. It provides the legislative framework for planning the individual care of children they look after (or are proposing to look after). This includes a requirement to ascertain the wishes and feelings of the child and give them due consideration before making any decision in relation to their care. The authority should also consider the wishes and feelings of the child's parents or people with parental responsibility and those of any other relevant people (s22, paras 4 and 5). The Act also includes a duty on local authorities to arrange for looked after children's health needs to be met, and places a duty on Clinical Commissioning Groups and NHS England to cooperate with them in this.

[The Children Act 2004](#)

The Children Act sets out requirements for local authorities and other agencies to work together to safeguard and promote the wellbeing of children. It includes the legislative framework for Local Safeguarding Children Boards (LSCBs). It also places local authorities and other local agencies including Clinical Commissioning Groups and NHS England under a duty to cooperate to promote the wellbeing of children and young people.

Section 11 of the Children Act 2004 places duties on a range of organisations and individuals to have clear arrangements for sharing information with other professionals and with the LSCB, in order to safeguard and promote the welfare of children.

Section 11 aimed to promote a culture of appropriate information sharing. As case examples in *Looking after HIV* demonstrate, balancing the need to share information between different agencies and the need to maintain tight control over the sharing of HIV status can present challenges.

[Children \(Leaving Care\) Act 2000](#)

This legislation entitles young people to continued support after they have left care. Young people have a pathway plan which takes over from the existing care plan and must address individuals' health and development, building on the information included in their health plan as well as education, training, career plans and support needed, for example to move into supported lodging. A young person's pathway plan is overseen by a personal advisor who will stay in touch with them until they are 21, or up to 25 for young people in education or training.

In 2013 the Government published its [Care Leaver Strategy: A cross-departmental strategy for young people leaving care](#). This strategy sets out the government's commitment to remove some of the practical barriers that care leavers face as they progress into adulthood. Broad areas of concern covered are education; employment; financial support; health; housing; the justice system; and on-going support.

[Children and Families Act 2014](#)

The Children and Families Act 2014 reforms legislation relating in various areas including adoption and children in care; aspects of the family justice system; and children and young people with special educational needs or a disability.

A [Summary Briefing from the Children's Partnership](#) explains the changes introduced by the Children and Families Act 2014 in relation to adoption, children in care and care leavers.

A [briefing from the Council for Disabled Children](#) explains Part 3 of the Act, which relates to children and young people with special educational needs and disabilities.

4. Statutory guidance relating to children

Department of Health and Department for Education (2015) [Promoting the Health and Wellbeing of Looked After Children](#)

This guidance explains how local authorities and health agencies should carry out relevant duties under a number of pieces of legislation on health and children's social care. Local authorities and health commissioners (Clinical Commissioning Groups and NHS England) must have regard to it when exercising their functions.

The guidance sets out procedures for planning to meet individual children's health needs. For each child that they look after, local authorities are required to arrange for a registered medical practitioner to carry out an initial assessment of the child's state of health and provide a written report of the assessment. This forms the basis of a health plan which must then be reviewed every six months. Health commissioners are required to cooperate in this process which is normally lead by a professional employed by them or a local NHS Trust.

The guidance sets out how, for example:

- Local authorities and health commissioners should take into account the needs and views of looked after children when planning services and ensure adequate resources and provision is in place (para 13)
- Looked after children should not have to wait longer for services, or be treated less favourably, than other children because of uncertain or short placements (para 18)
- Local authorities should consider whether a child's health needs can be met before placing them out of area (paras 78 and 79)
- Social workers, carers and others can support children to stay healthy.

The document includes Principles of Confidentiality and Consent (Annex C), which states that where disclosure of a child's information might reveal information about other individuals (e.g. parents, family), consent should be sought from these individuals as well.

Decisions to disclose information without consent in the 'public interest' must be taken on a case by case basis, and should always be fully documented.

In obtaining consent to seek information from other parties or to disclose information about the child, a key consideration will be determining whether the child is competent

to give consent or whether consent should be sought from a person with parental responsibility. The guidance outlines the principles used to establish children's capacity to consent to medical treatment, and states that the same should apply to consent to information sharing. Where a competent child does ask for their confidence to be kept, it must be respected unless disclosure can be justified on the grounds of public interest e.g. that there is reasonable cause to suspect that the child is suffering, or is likely to suffer, significant harm.

Department for Education (2015) [Guide to the Children's Homes Regulations including the quality standards](#)

This Guide accompanies the Children's Homes (England) Regulations 2015. The Regulations include nine Quality Standards, each containing an over-arching, aspirational, child-focused outcome statement followed by a non-exhaustive set of underpinning, measurable requirements that homes must achieve in meeting each standard. Quality Standards include the health and well-being standard (see regulation 10) and the protection of children standard (see regulation 12). When inspecting children's homes to assess the quality of care being provided, Ofsted must have regard to the Guide.

Other statutory guidance that may be relevant to children and young people living with HIV includes:

- Department for Education (2014) [Statutory guidance on children who run away or go missing from home or care](#)
- Department for Education (2014) [Care of unaccompanied and trafficked children: Statutory guidance for local authorities on the care of unaccompanied asylum seeking and trafficked children](#).

5. Information sharing

The [Data Protection Act 1998](#) and the Common Law Duty of Confidentiality

The Data Protection Act 1998 provides the main legislative framework to ensure that personal information about a living individual is shared appropriately, and informs the government guidance included in this overview. In particular, the Act balances the rights of the information subject (the individual whom the information is about) and the need to share information about them.

The key principle of the Common Law Duty of Confidentiality is that information confided should not be used or disclosed further, except as originally understood by the confider, or with their subsequent permission. Confidentiality can be breached 'in the public interest' in exceptional circumstances.

HM Government (2015) [Information sharing: Advice for practitioners providing safeguarding services to children, young people, parents and carers](#)

This non-statutory guidance aims to support practitioners' decision-making about sharing information to reduce the risk of harm to children and young people. It sets out 'seven golden rules to sharing information', three of which are:

- Be open and honest with the individual (and/or their family where appropriate) from the outset about why, what, how and with whom information will, or could be shared, and seek their agreement, unless it is unsafe or inappropriate to do so.
- Seek advice from other practitioners if you are in any doubt about sharing the information concerned, without disclosing the identity of the individual where possible.
- Share with informed consent where appropriate and, where possible, respect the wishes of those who do not consent to share confidential information. You may still share information without consent if, in your judgement, there is good reason to do so, such as where safety may be at risk.

6. Other legislation and policy relating to health needs

National Institute of Health and Care Excellence (NICE) (2013) [Quality Standard: Looked After Children and Young People](#)

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. The quality standard 'Looked After Children and Young People' defines best practice for the health and wellbeing of looked-after children and young people. It applies to all settings and services working with and caring for looked after children and young people and care leavers, including where they live. It includes a quality statement on 'Support to explore and make sense of identity and relationships', which encourages support for looked after children to understand their health history. Other particularly relevant quality statements within this standard include those on 'Support from specialist and dedicated services' and 'Collaborative working between services and professionals'.

[Care Act 2014](#)

Part 1 of the Care Act 2014 sets out the core legal duties and powers relating to adult social care. Local authorities have duties to assess and meet the needs of adults in need of care and support and their carers. This includes an overarching duty to promote the wellbeing of these individuals, which includes reference to their physical and mental health and emotional wellbeing and their domestic, family and personal relationships, among other considerations.

While main duties in the Act only apply for those aged over 18, it contains a number of provisions on the transition for children's to adults' services including a duty to assess before their 18th birthday the needs of a young person likely to have care and support needs as an adult. It also contains a number of provisions regarding continuity of care across various legal frameworks.

References

Care Act 2014 c. 23. Available from:

<http://www.legislation.gov.uk/ukpga/2014/23/contents> [2 December 2015].

Children Act 1989 c. 41. Available from:

<http://www.legislation.gov.uk/ukpga/1989/41/contents> [2 December 2015].

Children Act 2004 c. 31. Available from:

<http://www.legislation.gov.uk/ukpga/2004/31/contents> [2 December 2015].

Children and Families Act 2014 c. 6. Available from:

<http://www.legislation.gov.uk/ukpga/2014/6/contents> [2 December 2015].

Children (Leaving Care) Act 2000 c. 35. Available from:

<http://www.legislation.gov.uk/ukpga/2000/35/contents> [2 December 2015].

Children's Partnership (2014), *Summary Briefing: Children and Families Act 2014*, NCB & Barnardo's. Available from: <http://thechildrenspartnership-knowledge.org.uk/media/1032/1303-c-and-f-act-2014-revised.pdf> [2 December 2015].

Council for Disabled Children (2014), *The Children and Families Act 2014 Part 3: Children and young people with special educational needs and disabilities – A briefing from the Council for Disabled Children*, NCB. Available from:

<http://www.councilfordisabledchildren.org.uk/resources/summary-of-the-children-and-families-act> [2 December 2015].

Data Protection Act 1998 c. 29. Available from:

<http://www.legislation.gov.uk/ukpga/1998/29/contents> [2 December 2015].

Department for Education (2014), *Care of unaccompanied and trafficked children: Statutory guidance for local authorities on the care of unaccompanied asylum seeking and trafficked children*, DfE. Available from:

<https://www.gov.uk/government/publications/care-of-unaccompanied-and-trafficked-children> [2 December 2015].

Department for Education (2014), *Statutory guidance on children who run away or go missing from home or care*, DfE. Available from:

<https://www.gov.uk/government/publications/children-who-run-away-or-go-missing-from-home-or-care> [2 December 2015].

Department for Education (2015), *Guide to the Children's Homes Regulations including the quality standards*, DfE. Available from:

<https://www.gov.uk/government/publications/childrens-homes-regulations-including-quality-standards-guide> [2 December 2015].

Department of Health (2004), *Children in Need and Blood-borne Viruses: HIV and Hepatitis*, DH. Available from:
http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4093509 [2 December 2015].

Department of Health and Department for Education (2015), *Promoting the Health and Wellbeing of Looked After Children*, DH & DfE. Available from:
<https://www.gov.uk/government/publications/promoting-the-health-and-wellbeing-of-looked-after-children--2> [2 December 2015].

Department of Health and NHS England (2015), *Future in mind: Promoting, protecting and improving our children and young people's mental health and wellbeing*, DH & NHS England. Available from:
<https://www.gov.uk/government/publications/improving-mental-health-services-for-young-people> [2 December 2015].

Equality Act 2010 c. 15. Available from:
<http://www.legislation.gov.uk/ukpga/2010/15/contents> [2 December 2015].

Government Equalities Office (2015), *Equality Act 2010: guidance*. Available from:
<https://www.gov.uk/guidance/equality-act-2010-guidance> [2 December 2015].

Health and Social Care Information Centre (2013), *A guide to confidentiality in health and social care: Treating confidential information with respect*, HSCIC. Available from:
<http://systems.hscic.gov.uk/infogov/confidentiality> [2 December 2015].

HM Government (2013), *Care Leaver Strategy: A cross-departmental strategy for young people leaving care*, HM Government. Available from:
<https://www.gov.uk/government/publications/care-leaver-strategy> [2 December 2015].

HM Government (2015), *Information sharing: Advice for practitioners providing safeguarding services to children, young people, parents and carers*, HM Government. Available from:
<https://www.gov.uk/government/publications/safeguarding-practitioners-information-sharing-advice> [2 December 2015].

National Institute of Health and Care Excellence (2013), *Quality Standard: Looked After Children and Young People*, NICE. Available from:
<https://www.nice.org.uk/guidance/QS31/chapter/Quality-statement-4-Support-to-explore-and-make-sense-of-identity-and-relationships> [2 December 2015].

United Nations (1989) Convention on the Rights of the Child. Available from:
<http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx> [2 December 2015].



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