

HIV in Schools

A good practice guide to supporting children living with and affected by HIV

Magda Conway



The Children's HIV Association (CHIVA)

CHIVA manages a network for professionals committed to providing excellence in the care and support of children, young people and families living with HIV. It provides medical guidelines for NHS care, supports practice development, and undertakes direct work. CHIVA has an active youth committee of young people living with HIV.

CHIVA aims to:

- Enhance the health and social outcomes for children, young people and families living with HIV
- Reduce the isolation of children and young people living with HIV
- Ensure that the voices of children, young people and families living with HIV are present in service and practice development
- Reduce the stigma faced by children, young people and families living with HIV
- Facilitate knowledge about HIV and thus empower young people with HIV to become more independent.

National Children's Bureau

The National Children's Bureau (NCB) is a leading charity that has been working to improve the experiences and life chances of children and young people across England and Northern Ireland, especially the most vulnerable, for over 50 years.

We play a strategic support and leadership role across the sector by:

- Initiating partnerships and projects involving, for example, mental health and emotional well-being, and disability, which aim to improve the lives of children and young people
- Sustaining the effectiveness and efficiency of our specialist networks, including the Council for Disabled Children, the Sex Education Forum, the Anti-Bullying Alliance, and the Childhood Bereavement Network
- Championing the use of evidence, and the involvement of children and young people, to shape and improve national policy and local services
- Building the skills, knowledge and networks of practitioners and voluntary groups working with children and young people.

Every year, we reach more than 100,000 children and young people through our links with organisations including local authorities, children's service providers, academic bodies, schools, and voluntary organisations. For more information, visit www.ncb.org.uk.

Children and Young People HIV Network

The Children and Young People HIV Network is a national network for organisations and professionals concerned with children and young people who are living with and/or affected by HIV, from conception to adulthood. It is based at the National Children's Bureau and aims to:

- Provide an effective voice for children and young people who are living with or affected by HIV
- Challenge the stigma and discrimination associated with HIV
- Build child-centred policy and practice recommendations.

The Network has a long history of influencing national and local policy; developing and disseminating good practice, information and resources; and participation work.

This reissue updated and published by the Children's HIV Association. Original edition published by the National Children's Bureau in 2005.

National Children's Bureau, 8 Wakley Street, London EC1V 7QE

Tel: 020 7843 6000

Website: www.ncb.org.uk

Registered charity number: 258825

© National Children's Bureau 2015.

British Library Cataloguing in Publication Data

A catalogue record for this book is available from the British Library

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system or transmitted in any form by any person without the written permission of the publisher.

The views expressed in this book are those of the authors and not necessarily those of the National Children's Bureau.



Contents

Acknowledgements

Foreword

Terminology

<u>Summary of guidance</u>	8
<u>Introduction</u>	12
<u>Facts and understanding HIV</u>	15
<u>Living with HIV</u>	17
<u>Working towards an HIV-friendly school</u>	20
<u>Disclosure and confidentiality</u>	24
<u>Right to education</u>	28
Appendix 1: Further Information	
<u>Appendix 2: References</u>	31

Acknowledgements

In the original edition published in 2005 by the National Children's Bureau, the following people and organisations were instrumental in ensuring that this document met the needs of schools:

Author and editor Magda Conway, then coordinator of the Children and Young People HIV Network at the National Children's Bureau, with contributions from Dylan Buckle (Camden LEA), Beulah Gordon (Positively Women, now Positively UK), Mark Jennett (Health Development Agency) and Kevin O'Dell (Education of Vulnerable Children Team, Department for Education and Skills).

Help and support was also provided by Betty Layward Primary School; Sheila Donaghy, paediatric HIV consultant nurse specialist; Gill Frances, National Children's Bureau; Neil Gerrard MP, chair of the All Party Parliamentary Group on AIDS; Steve Howell, National Children's Bureau; Helen James, Tower Hamlets LEA; Elizabeth Kawonza, Sutton and Merton PCT; CHIVA Executive Committee members; Dr Linda Lazarus, EAGA Secretariat; Laycock Primary School; Christine Lenehan, Council for Disabled Children; Juliet Ramage, manager, Health Through Action (now Gregory's Place); Dr Andrew Riordan, paediatric consultant; Richard Rudd, vice principal, Bacon's College; Dr Mike Sharland, paediatric HIV consultant, chair of the Standing Committee of the Royal College of Paediatric and Child Health; Jonathan Stanley, National Children's Bureau; Linda Toocaram, National Children's Bureau; Dr Gareth Tudor-Williams, paediatric HIV consultant, chair of CHIVA; Helen Wheatley, Council for Disabled Children. The young people from Positively Women (now Positively UK).

The 2015 update was written and edited by Magda Conway, now Manager at the Children's HIV Association. Many people were involved in this process, with special thanks going to:

Emily Hamblin, National Children's Bureau; Dr Steve Welch, paediatric HIV consultant; Alastair Hudson, Family Planning Association; Andrew Fellowes, Council for Disabled Children; Angelina Namiba, Positively UK; Gunes Kalkan, Barnardos; Judy Ellerby, National Union of Teachers; Naomi Sheppard, Brook; Kat Smithson, National AIDS Trust; Maureen Kiwanuka; Michael Brady, Terrence Higgins Trust.

Thank you to ViiV Healthcare for funding the consultation and update of this guidance.

Foreword

As Chair of the Children's HIV Association (CHIVA), it gives me great pleasure to endorse this clear and practical guidance to be used by schools, to help support children living with or affected by HIV.

Schools are experienced in providing support to children living with many chronic illnesses. However, the stigma surrounding HIV means that families are reluctant to disclose the diagnosis because of concerns about confidentiality, and are therefore unable to access this support. In the UK, there are approximately 1,000 children in mainstream schools living with HIV and over 25,000 children who live in families affected by HIV. The vast majority of these children have not notified their school, due to lack of confidence in the response.

Through a series of case studies looking at the real experiences of children and families in schools, this publication provides those involved in education with an insight into the issues for, and the impact of inappropriate practice on, the lives of those affected.

It is in the interest of all children that schools provide accurate information about HIV, including how to avoid acquiring infection as part of Sex and Relationship Education; therefore, it is essential that teachers and staff are equipped with accurate knowledge and understanding about HIV and routes of transmission. A recent survey commissioned by CHIVA showed that this knowledge could be improved. Increasingly, children living with or affected by HIV will be among those being taught about HIV and HIV prevention in schools, and there is a duty of care to ensure that this information is provided without perpetuating stigma and prejudice against those living with HIV.

This guidance provides the information and resources for schools to ensure that a pupil who discloses their HIV diagnosis will be supported in a non-judgmental way. If teachers or other staff become aware that a child in the school is living with HIV, they need to understand that this poses no risk to others, and should ensure that confidentiality is respected and maintained. Staff will consequently be in a far better position to understand and support the children in their schools who are infected with, or affected by, HIV, whether or not the diagnosis has been disclosed to them. The number of HIV infections in the United Kingdom is rising. Schools might not know whether an individual child (or staff member) is living with or affected by HIV, but having a supportive approach to HIV can benefit all pupils, staff, the school, and wider society.

Dr Amanda Williams

Chair, Children's HIV Association for the UK and Ireland (CHIVA)

Terminology

Throughout this document the following terms are used:

Living with HIV refers to children and young people who are living with HIV infection

Affected refers to children and young people who have a close family member they live with who is infected with HIV.

Parent/carer(s) denotes those with parental responsibility and care of a child or young person.

Child refers to any child or young person in nursery or full-time education, up to the age of 18 years.

School denotes all educational settings for nursery and school-age children.

School community includes all those working and interacting with a school, such as headteachers, advisors, governors, religious and local community leaders, parents, teachers, support staff and pupils.

SUMMARY OF GUIDANCE

Children living with and affected by HIV are attending UK schools. In January 2015, a survey of paediatric HIV health teams showed that in 89% of cases, schools had not been informed that they had a pupil living with HIV. Of those schools that were informed, 33% had been without the consent of the child or family and 46% initially responded in a negative way towards the child (CHIVA 2015).

A survey of teachers undertaken by Ipsos Healthcare, showed that although over 80% were concerned about the pastoral care needs of pupils living with HIV, there is a considerable amount of misunderstanding of how HIV is passed on, with 52% listing spitting/biting as a route of transmission, and only 40% correctly identifying the main ways children living with HIV in UK schools have acquired HIV (Ipsos Healthcare 2014).

A child living with HIV in a school:

- **Poses no risk**
- **Presents no additional insurance issues**
- **Requires no additional resources**

What they do face is a high level of stigma, the impact that this stigma can have on their well-being, and the additional complications that managing a long-term health condition may present to a family.

'Notifiable diseases' are those that people are legally required to report, as coming into everyday contact with someone with one would pose a risk of onward infection. HIV is a 'non-notifiable' disease because all people living with HIV, including pupils and staff in schools, present no risk of onward transmission in every day contact. If there were any concerns about people in the school community posing a risk of onward infection, HIV would not be a non-notifiable disease and pupils and staff would be legally required to report their HIV status.

Following this guidance is simple, effective, and does not incur any costs for a school. Everything that a school needs to do in order to effectively support children living with HIV already exists within established systems. The key is understanding the realities of living with a highly stigmatised illness, and working with children and families to meet their needs and uphold the level of confidentiality that they want and that is legally afforded to them.

Key Facts: There are just over 1,000 children living with HIV in the UK and Ireland (National Survey of HIV in Pregnancy and Childhood 2015), and over 25,000 who live in a family with HIV (CHIVA 2015).

HIV CANNOT be passed on through normal daily contact, which includes playing and normal childhood interactions.

- The vast majority of HIV positive pupils in education in the UK acquired HIV from their mothers during pregnancy, birth or breast-feeding.
- A pupil (or teacher) living with HIV poses no risk to the school community.
- There has NEVER been a case identified of a child passing HIV to another child, teacher or member of the school community within a school.
- People living with HIV are able to live long, healthy lives.
- Confidentiality is critical to people living with HIV, due to the stigma that is still present in society.

Stigma

The term stigma is often used when talking about HIV. Stigma refers to the devaluing, shaming, blaming or punishment of particular individuals or groups. Stigma taps into existing prejudices and often further marginalises people. For HIV, stigma comes from HIV being associated with sex, disease and death, and with illegal or culturally taboo behaviours such as drug use.

Stigma is harmful to the individual and can lead to HIV positive or affected children feeling shame, guilt and isolation. It can also lead individuals or institutions to discriminate, causing direct harm or violating children's legal and human rights, such as by denying services or entitlements.

What schools have to do (the law)

Children living with HIV are legally defined as 'disabled' and are therefore protected against discrimination in education by the **Equality Act 2010** (further information P.28)

The Children and Families Act 2014 sets in law a duty to support pupils with medical conditions in maintained schools, academies, free schools and Pupil Referral Units (PRU) (further information P.29)

This guidance will help you meet your legal duties in various relevant areas:

- Equality
- Confidentiality
- Health and Safety
- Bullying
- Statutory duties to promote children and young people's wellbeing
- Supporting pupils at school with medical conditions

What schools need to do

School should be a place that every child can access without fear of discrimination and where children and families can seek support. Those living with HIV may experience associated physical and mental health issues and take a strict daily regime of medication that often leads to side effects. Children living with HIV have often faced bereavement and poverty, and can have additional caring responsibilities in their home.

School needs to be a place where it is safe to be living with HIV and where families feel safe to share this information. An HIV-friendly school can be achieved through a holistic approach that promotes a caring, supportive and inclusive environment. As those with HIV fear negative judgements, direct reference to HIV in schools' policy documents and other relevant communications with parents/carers (along with other health conditions) will ensure that all those in the school community are aware of the school's position in wanting to support a child living with or affected by HIV. Examples of these policies and statements that could be included, are found on P.20.

What schools want to do

Schools want to be places where all children are safe and able to equally access education. They are places where children's attitudes and understanding of the world are developed; therefore schools should model an educated and calm response to HIV, as they would with any other health condition.

What schools should do when an HIV disclosure is made

This model follows the format and statutory guidance provided by the DfE regarding children with medical conditions in schools: (Annex A)

School is informed about child or families HIV status

Research has shown that 33% of disclosures to schools happen through a third person without the families consent. If this happens, the first step is to establish whether that person has the family's consent, and if not, to speak with the family, in order to inform and reassure them.



The headteacher designates a staff member to co-ordinate a meeting with the parent/carer, child and HIV health or social care practitioner, to discuss the child's medical and/or pastoral support needs.



Draw up agreed support plan, to include confidential information storage and sharing, and dates to review this plan.



Consider the information or training needs of the designated staff member, to improve their knowledge and understanding of HIV. This could be reading this guidance in full, or a conversation with a paediatric HIV practitioner.

If a child tells you about their own or their parent/carer's HIV infection, reassure the child that this information will be kept confidentially amongst specific staff in the school, and agree who will inform the parent/carer that this information has been shared (further information, p.24).

It is important that all staff discuss, and are aware of, the procedures for HIV disclosure, before it happens. This presents the opportunity to: ensure that staff's HIV knowledge is up-to-date; reassure staff by repeating information about routes of transmission; and firmly establish the need for confidentiality. It may be helpful to get support from a local health promotion unit, health advisors from local sexual health clinics, or a local paediatric infectious diseases nurse or doctor.

Checklist for developing an HIV Friendly School

To develop policies for supporting children living with or affected by HIV, start by asking the following questions:

- Is HIV mentioned in school policies – such as policies for inclusion, and sex and relationships education (SRE) policies – and in school documents such as the prospectus or mission statement?
- Are you following universal first aid procedures?
- Who are your named first aiders and when is their training review date?
- Do all staff, including teachers and support staff, have a basic understanding of HIV transmission and an awareness of the stigma faced by those living with, or affected by, the virus?
- Is HIV awareness part of your school development plan?
- Can opportunities be created in your school to promote HIV awareness across the school community?

These questions could be considered in a whole staff meeting or by governors as a way of raising awareness of the key issues for schools in becoming HIV friendly.

If you need further information or support, please contact the experts in this field and they will be happy to help you. This could be a local HIV support service; paediatric HIV healthcare providers or the Children's HIV Association, who can either help you directly or put you in touch with local contacts (www.chiva.org.uk).

INTRODUCTION

Case study one (2012)

A child was not taking their antiretroviral therapy (HIV medication) and their health team was very concerned about this. The paediatric HIV nurse obtained the mother's permission to approach the school for support. The nurse met with the Health Welfare Worker and the Head of year, and ensured that they had a good understanding about HIV and confidentiality. The school was very keen to support the child and work with the health team. Together, they set up a system where a member of the child's health team could come to school each day and administer Direct Observational Therapy (DOT). The school also ensured that the child could eat directly after taking the medication, which is important for that particular medicine. The school were extremely supportive, responded calmly and upheld excellent confidentiality, liaising with the health team and ensuring that the needs of the child were met.

Facts

- In 2015, there are just under 1,000 HIV-positive children under the age of 19 living in the United Kingdom and in mainstream education (NSHPC, 2015).
- The number of affected children is not known, but can be estimated at over 25,000 (Conway, 2015).
- **There is no known reported case of HIV transmission occurring in a UK school.**
- Because HIV cannot be transmitted through normal daily contact, it is a non-notifiable disease, which means that parent/carers or children may choose to not inform the school.
- Due to stigma and discrimination faced by people living with HIV, confidentiality is essential when knowing an individual's HIV status.

Purpose of this guide

This guide provides schools, governing bodies and local authorities with practical information and suggestions on ways to support the needs of children living with HIV. It addresses schools' concerns about HIV and sets out some simple ways in which a school can provide a supportive environment for a child living with, or affected by, HIV. This is set in the context of the pastoral support that schools already provide, including all pupils with health needs.

The guide is relevant to all schools, including: academies, free schools, maintained nursery, primary, secondary and special schools, independent schools, and PRUs. It is for all the staff who work in them – including local authority personnel, governing bodies and school leaders – and external bodies who have regular contact with schools. It will also be of use to those providing services to children, such as youth

workers and early years practitioners. This guide has been developed in consultation with a number of schools, local authorities, parent/carers, and children living with HIV.

Research on teachers' knowledge of HIV

In November 2014 an Ipsos Healthcare poll was conducted across the UK with 500 secondary school teachers, to look at their knowledge of HIV and their understanding of its impact in an education setting.

Although over 80% were concerned about the pastoral care needs of pupils with HIV, understanding of how HIV is passed on varied. Although respondents were typically aware of how HIV is transmitted, many also identified incorrect routes of transmission. These included: spitting/biting (52%), kissing (18%), and a small number who incorrectly noted sharing toilets, baths, swimming pools and holding hands. A poor understanding of HIV amongst staff will mean misinformation being passed on to pupils, and unnecessary concern about the possibility of pupils living with HIV attending the school.

When asked about the most common way children living with HIV became infected, 40% understood that the majority of children living with HIV acquire the virus from their mother during pregnancy, birth or breastfeeding, but 60% listed incorrect sources including sexual transmission (29%), injecting drug use (18%), and even spitting/biting (1%). This lack of understanding of the demographic of pupils living with HIV demonstrates low levels of understanding of family HIV.

Research in the experiences reported by paediatric HIV health care teams

In January 2015 the Children's HIV Association published an audit that was undertaken with paediatric HIV healthcare providers. It concluded that:

- In general, schools are not told that they have an HIV positive pupil, with only 11% of HIV positive children attending a school that knows their diagnosis.
- Of this 11%, 64% of children and families decided to tell schools; the other 36% had a third person disclose without the child or family's consent.
- 82% of the schools told, were mainstream schools.
- 46% of schools initially responded negatively leading to a bad experience for the child and family, with 78% of these then responding supportively, following interventions from outside practitioners. 22% of schools that initially responded badly, continued this response, even after interventions from outside practitioners (CHIVA 2015).
- Following an intervention from outside practitioner, 78% of schools then responded supportively, whilst 22% continued to respond negatively (CHIVA 2015)

Why should schools support children living with or affected by HIV?

Schools are an important part of a child's life and provide a supportive, caring environment. Yet still in 2015, the reactions of staff, parent/carers or pupils, to a child who is living with or affected by HIV, have in some cases led to the child feeling unable to remain at that school. This may be due to a lack of knowledge about how HIV is transmitted or media stereotypes relating to those who are living with the virus.

Creating supportive and inclusive school environments through policy and practice, will make a real difference to the lives of children living with and affected by HIV. It will prevent the exclusion and bullying that children living with HIV tell us that they often face or fear, and will encourage educational development, thus improving these children's health, well-being and opportunities. It will enable schools to meet their legal duties, and to promote equality and diversity across school communities.

FACTS AND UNDERSTANDING HIV

Case study two (2013)

A family arrived in the UK as asylum seekers in 2013 and had a number of different agencies supporting them. The children were placed in mainstream school and one of the community workers disclosed that two siblings were living with HIV to the school without the families' consent.

The school contacted a national teaching organisation for support. They were advised to suspend the siblings and put a risk assessment in place. This was not necessary action to take, but it also had the backing of Social Services and a multi-agency strategy meeting was called. The family's GP raised concerns with the school about the approach they had been advised to take and contacted the family's specialist paediatric HIV healthcare provider to ensure they attended the meeting. It was clear that up to this point accurate knowledge of HIV and risk had been absent from the process, despite the school contacting external agencies for support.

After this meeting, it was decided that the suspension should be stopped. The children went back to school quite quickly. Crucially, information was kept about their HIV status to a few members of staff. Both a nurse and an HIV specialist social worker, based at a local HIV support service, worked directly with the teachers who knew. The initial breach of confidentiality and subsequent actions have had a big impact on the family. However, despite having been initially incorrectly advised, there is now improved knowledge of HIV among the teachers and the school is very supportive to the family.

Key Facts:

- **HIV cannot be passed on through normal daily contact**
- **The vast majority of pupils living with HIV in education in the UK acquired HIV from their mothers during pregnancy, birth or breast-feeding**
- **HIV is a non-notifiable disease because a pupil (or teacher) living with HIV poses no risk to the school community.**

HIV is a blood-borne virus that was first identified in 1983. HIV can be transmitted through blood, breast milk and sexual fluids (e.g. semen, vaginal fluids). HIV is not passed through saliva. Since 1985, all donated blood and organs in the UK have been screened for infections. Almost all infections in the UK occur through unprotected sex, from mother to baby and, more rarely, the sharing of injecting equipment. Transmission is only possible if there is a sufficient quantity of the virus entering the bloodstream directly, so exposure to HIV does not make infection inevitable.

If a child living with HIV has a cut, this should be dealt with in the normal manner, following universal first aid procedures and standard hygiene practices. This will be effective in preventing transmission of all blood-borne infections, including HIV.

Having a child living with HIV in school poses no risk to staff or pupils. As stated before, there is **no known case of an HIV transmission occurring in a school in the United Kingdom.**

Children being injured by or playing with injecting equipment should receive medical attention; however, HIV presents **very limited risk** in this scenario, with the main risk of blood-borne virus transmission coming from hepatitis B and C. Due to the success of needle exchange schemes, HIV prevalence is low in intravenous drug users (Public Health England, 2014).

HIV is a sexually transmitted infection and sex and relationships education (SRE) should provide pupils with the knowledge and skills to protect themselves against acquiring the virus through using safer sex practices. All schools will have pupils who are at risk, either now or in the future, of acquiring HIV in their lifetime.

It is important when teaching SRE to be aware that there may be pupils living with or affected by HIV in the room and to ensure the correct information is provided in a non-stigmatising manner.

LIVING WITH HIV

Case study three (2015)

The school was informed about a pupil's HIV diagnosis at a professionals' meeting. A copy of this guideline was provided, with clear instructions on how the information must be handled. Three staff members were allocated by the school to provide support for the child and training was offered, although it was felt to be unnecessary, as much information had already been provided to the staff.

A month later a member of the child's paediatric HIV health care team was invited to a meeting at the school. During the meeting the healthcare worker was asked questions by a number of school management staff regarding the 'risk' of having a child living with HIV in the school. Clear advice on the routes of transmission was given again to the senior management staff and it was reiterated that the child presents no 'risk'.

Following this meeting, contrary to the advice given, senior management decided that all staff should be told. The Headteacher also had reputational concerns and claimed that 'if the press found out, it would be a problem'. The Headteacher made the decision to disclose the child's HIV status to the whole staff team without family consent. On this occasion the pastoral care lead for the child resigned from the school, citing this breach in the child's confidentiality and misuse of advice as their reason.

At this time there was a change in the child's care and it was decided that the child would move school. The child and their healthcare team are reluctant to share this information with a school again, as the risk to the child's well-being is too high. This means that the child will not be able to benefit from any additional support a school might provide to them.

Virtually all children living with HIV are completely healthy during their school career. With regular clinical check-ups and advances in antiretroviral therapy (HIV medication), the majority of these children in the United Kingdom are reaching adulthood, with a number now over 30 years of age. In general, daily medication regimes do not interfere with the school day, and only become a consideration when the child attends school trips or residential. The fear that many families have of schools finding out, can mean that they opt to either have the child manage their own medication whilst away or, more often, the child is not given permission to participate. If a school is told and agrees to manage a pupil's medication, as with any medication, a robust system should be in place to manage this in a safe and confidential manner (DfE 2014).

Although a child living with HIV has a compromised immune system, there is no greater risk to their health in an educational setting than there is for any other child. Compared to non-affected children, children living with or affected by HIV are more likely to be marginalised and fall behind with their work, due to periods of their own, or a family members' ill health, hospital appointments, or caring responsibilities at home.

Children with HIV will need to attend regular hospital appointments, and the school may become concerned about attendance, asking for information about the reasons for regular appointments. Due to the fear of stigma and disclosure, this information is often not shared.

Children's knowledge of their own HIV

A child living with or affected by HIV is at risk of isolation, discrimination and bullying from his or her peer group and other members of the school and wider community, which is why the majority choose not to share information about HIV in their family.

Fear and experiences of discrimination mean some children living with and affected by HIV may not know about their own or their family members' HIV status. It is not unusual for primary school aged children to take medication and attend hospital appointments without having HIV named to them. This is due to parent/carer and health providers fearing the child will accidentally share this information and their desire to keep the child from experiencing discrimination. Both national and international practice is changing regarding this, attempting to lessen the impacts of secrecy and stigma on the child, but it illustrates the depth of fear people living with HIV face about the reactions of others.

With children affected by HIV, research has shown that the majority find out before they are officially told, causing the child great fear and anxiety that can be exhibited in challenging and inappropriate behaviour (Miah, 2004). This can add complex dynamics when having pupils living with or affected by HIV in a school.

The majority of families living with HIV tell us that the fear of discrimination leads them to decide against telling schools

If a school wants to support a pupil living with or affected by HIV, they need to first provide parent/carers with the reassurance that information will be kept confidential, and only discussed on a need-to-know basis, with consent. Parent/carers need to be aware of, and have access to, the school's policies – and these should include upholding confidentiality and the actions that will be taken if this is breached.

There have been many examples of school communities reacting inappropriately to the disclosure of a child's or parent/carer's HIV status, such as pupils being excluded,

confidentiality not being kept, and pupils being forced, in one way or another, to leave the school. However, the alternative – non-disclosure – means that the child may not receive the emotional and educational support that they may need in order to reach their academic potential, and that HIV remains something that the child thinks is ‘bad’ and must be kept hidden.

The harm to a child caused by inappropriate reactions, underlines the importance of schools having policies and practice in place to reassure the child, parent/carers and teaching staff. These will protect the child from negative reactions and enable them to receive the care and support that they need, in order to thrive and achieve their academic potential.

A whole-school approach to supporting those living with HIV in schools

The number of HIV infections in the United Kingdom is rising, with 81,512 people in the UK accessing HIV treatment in 2013, and an estimated additional third of those infected, not yet having been tested. Schools may not know whether an individual child (or staff member) is living with or affected by HIV, but having a supportive approach to HIV can benefit all pupils, staff, the school, and wider society.

A whole-school approach to being HIV-friendly, as set out in the next section, will challenge the attitudes and misconceptions of the school community and wider society. As adult rates of HIV increase annually, this is an issue that cannot be ignored. By putting in place a few simple systems, schools can protect and support these more vulnerable pupils, as well as HIV positive staff and parent/carers.

WORKING TOWARDS AN HIV-FRIENDLY SCHOOL

“If the school had a policy saying that they do not discriminate and that they are supportive. And if that policy listed HIV amongst other long term illnesses”
(A suggestion from a mother living with HIV of what would support her to tell her child’s school about her status, 2015)

An HIV-friendly school can be achieved through a holistic approach that promotes a caring, supportive and inclusive environment, and which is embedded throughout school practice, activities and procedures. An HIV-friendly school is a school that includes HIV issues throughout the various school policies (medical needs, inclusion, bullying, SRE, and so forth) and documents, demonstrating that HIV is considered in the same light as other medical conditions, but acknowledging the impacts of stigma and families’ fears. This would be preferable to schools developing a separate HIV policy.

In simple terms, this is about language and having HIV referred to by name, alongside other health conditions and disabilities in school policies. This will help to destigmatise the virus and show families living with HIV that they will be treated well. Direct reference to HIV will ensure that all those in the school community are aware of the school’s position in wanting to support the child living with, or affected by, HIV. Below are suggestions and examples of some school policies where HIV could be mentioned. There may be other, equally appropriate policies that are not mentioned here.

First aid

The Health and Safety (First Aid) Regulations 1981 require employers to provide adequate equipment, facilities and trained first aid personnel. Schools should make an assessment of first aid needs and have first aid procedures in place. It is not necessary for schools to know whether a pupil has HIV; universal first aid procedures and standard hygiene control measures should effectively prevent the possibility of transmission of HIV in accidents where the spillage of blood is involved.

General first aid and health education for pupils in schools, as part of the curriculum, will address issues of blood-borne infection and common sense measures to protect against these. Universal first aid precautions were specifically established to prevent the spread of infections. This includes all blood-borne viruses such as HIV, and acknowledges the fact that an individual’s blood-borne virus status is not always known by themselves or others. Ideally, as many staff as possible should be trained in basic first aid, and should use universal first aid practice at all times, with the entire school community. More details can be found in *Guidance on First Aid for Schools: A good practice guide* (DfE 2000, updated 2014), which sets out how this should be done.

Equal opportunities and social inclusion

Equal opportunities and social inclusion policies could acknowledge the stigma and discrimination that surrounds HIV, and should state that the school actively promotes awareness and inclusion, and provides support to children living with, and affected by, HIV.

Sex and Relationships Education policy

DfES Sex and Relationship Education (SRE) Guidance (DfES 0116/2000) require that: pupils clarify their knowledge of HIV and sexually transmitted infections; they are taught assertiveness skills for negotiating relationships and that they are enabled to become effective users of services that help prevent and treat sexually transmitted infections and HIV. SRE is compulsory for all maintained secondary schools, academies, free schools and PRUs, which should all have a policy that covers these aspects and promotes a climate that counters stigma, discrimination and social isolation. Although this SRE guidance has not been updated since 2000, Brook, the PSHE Association and the Sex Education Forum, supported by DfE, produced supplementary guidance in 2014 which updated this. This can be found at <http://www.brook.org.uk/our-work/sre-supplementary-advice> and is fully endorsed by the National Association of Head teachers, Association of Teachers and Lecturers and National Union of Teachers.

Medical needs policy

School governing bodies, academy proprietors and PRU management committees should have policies in place for managing medicines in schools and supporting children who have medical needs, including issues of confidentiality. What is important is that pupils living with HIV are included as children with medical needs; this should be reflected in the wording of this policy.

The school prospectus

To encourage disclosure, parent/carers need to be reassured about the ethos of the school and feel in control of information sharing and confidentiality. Schools have a responsibility to tackle prejudice and discrimination and, by openly promoting HIV acceptance, will offer an alternative perspective on an illness that is often negatively portrayed.

In order to promote acceptance and support for pupils living with or affected by HIV, it would be helpful to include a statement on supporting pupils with medical needs in the school prospectus, and for the mission statement to promote the acceptance of these pupils by highlighting the school's supportive ethos.

For example:

[Name of school] will seek to support any child that has a medical or health condition, such as diabetes, asthma, HIV or hepatitis, in order to ensure their health, safety, welfare and inclusion in school life.

Additionally, the prospectus could state:

[Name of school] aims to meet the needs of all pupils, regardless of medical need, illness or disability, and we will not tolerate discrimination and bullying. We promote a whole-school approach to tackling the stigma and discrimination faced by people living with HIV.

Where particular illnesses or disabilities are listed, be sure that HIV is included. For example:

A child with medical needs, which includes allergic reactions, anaphylaxis, asthma, diabetes, epilepsy, hepatitis and HIV...

There could be a statement that specifically identifies a member of staff (such as the headteacher or a senior manager) as someone with whom parent/carers can confidentially discuss medical issues or conditions. For example:

[Name of school] respects a pupil's right to confidentiality, in relation to medical information. If you have any concerns relating to a medical issue or condition, please arrange a meeting with the headteacher. All discussions of this nature will be strictly confidential and taken no further, without the consent and involvement of the parent/carer and, where appropriate, the pupil.

Case study seven (2013)

A child came from a family who were very cautious about disclosing their HIV status to external agencies, and had always maintained that they did not want the school to know. The child went on a residential school trip for 5 days, taking their medication with them. The family did not provide any explanation to the school of what the medication was for. The child's paediatric HIV nurse received a distressed call from the mother saying that she had withdrawn her child from the school trip, as she had been asked to attend a meeting at the school to explain why her child was taking medication.

Through further discussions, it transpired that the teachers running the trip had questioned the child about the medication during the previous evening. The child did not want to disclose their HIV status, but felt that they had to answer truthfully to a teacher.

The paediatric HIV nurse worked with the headteacher and other staff who had been informed, to develop their HIV knowledge and inform them about confidentiality. The school response was very positive, demonstrating that they understood the importance of confidentiality. The school was clear in their communication that they wished to do whatever they could to support the family in the most appropriate way. The nurse also supported the mother and the child to rebuild their confidence in, and relationship with, the school.

The outcome of these actions was positive. The child returned to school and their confidentiality was maintained. Nothing was documented on the school record about HIV; the incident was recorded as a disagreement with the mother that led to the temporary withdrawal of the child from school.

DISCLOSURE AND CONFIDENTIALITY

Case study four (2014)

A child was in the middle of their exams and feeling incredibly stressed, worried and emotional. The teacher noticed the increased anxiety of the child and asked if there was anything else that was bothering them. The child broke down and disclosed their HIV status.

The teacher was the Deputy Head and managed the disclosure calmly. They met with the mother (who was extremely anxious) and reassured her that the information would be kept confidential and the teacher just needed to tell one other person in the school. The mother requested the teacher liaise with clinical staff and information and guidance was shared.

The outcome was very positive with the child now feeling supported at school and the clinical staff having a positive relationship with the teacher. The main person that still has concerns is the mother, reflecting her fear of the stigma she believes the family might have to face if their HIV status is widely disclosed in the school.

This section gives an example of good practice protocol in relation to the disclosure of a pupil or family member's HIV status. It is important to establish the protocol before an HIV disclosure, agreeing individuals' roles, acknowledging the need to uphold confidentiality and establishing who actually 'needs to know' within the school community.

Ensuring that all staff discuss, and are aware of, the procedures for HIV disclosure presents opportunities to bring staff's HIV knowledge up to date, to reassure them, and to firmly establish the need for confidentiality. It may be helpful to obtain support from a local health promotion unit, health advisors from local sexual health clinics, or local paediatric infectious diseases nurse.

Who needs to know?

Realistically, no more than two members of staff need to know. One would normally be the headteacher and the other, a designated staff member, ideally chosen by the pupil and parent/carer, who can oversee the child's education and pastoral care. The headteacher and staff should treat this medical information confidentially. Agreement should be reached between the headteacher, the parent/carer and the pupil (where appropriate), on who else should have access to records and other information about the pupil (DfE 2014).

The role of the headteacher will be to support the designated staff member, to discuss any issues with them, to instigate any discussion between parent/carers and

the school on issues that arise concerning the pupil's education or well-being. They have overall responsibility for the development of child's individual healthcare plan.

The role of the designated staff member will be to unobtrusively oversee the pastoral care of the pupil and deal with any day-to-day issues that may arise, such as hospital appointments, periods of lateness due to the side effects of the child's medication, or caring responsibilities.

The school or family may feel that in the case of a pupil living with HIV, they would like the school nurse to be involved. It may be useful to include the school nurse when developing protocols for disclosure. The school nurse could also be a link between the school and paediatric HIV practitioners, to ensure that communication flows between all those involved in meeting the child's medical, educational and support needs. **Please note that consent from the family will need to be gained to share this information with the school nurse.**

The above roles should be discussed and agreed with the parent/carer and child concerned. Depending on the child's needs, an optional Education, Health and Care (EHC) plan may be drawn up (DfE 2014). Alternatively, the school may decide that their protocols will include a 'care plan' establishing the support that the child wants and needs, and regular meetings to review the support during the academic year. The recording and storing of this information needs to be agreed with the parent/carer and child at the time, so as to reassure them further that this information will be kept confidential.

To cover the issue of staff protection and liability, the designated staff member should keep some form of confidential records. The format and storing of this information can be agreed when developing the schools protocols. Again, reassurance needs to be given to the parent/carer and child that no one will have access to these records without their consent.

Living with, or being affected by, HIV is not a child protection issue. However, as with any medical condition that either a child or their family has, it may impact on the child's well-being. The Children Act 2004 established protocols for sharing information with health, social care and education professionals. It is essential that the issues of confidentiality, stigma, and who needs to know and why, are at the forefront of any decision to share information on an HIV infection. It is paramount that the child and parent/carers are involved in these decisions, which is a right afforded to them by the Children and Families Act 2014.

When disclosure happens

Families will not have taken the decision to disclose lightly. At the point of disclosure and throughout the process of agreeing any support, reassurance and agreement will be needed on:

- What personal information will be recorded
- How information will be stored and retrieved
- Who will have access to information
- The child and parent/carers rights in consenting to information sharing.

Information about individual or family HIV status should not normally be added to a pupil's record. Families have complained that, following disclosure to one school, the information is passed on to subsequent schools, without consent. If the school feels that it is essential to include this information on the child's record, parent/carers should be given the option of having it removed before a child transfers schools. Additionally, the school needs to consider who has access to the child's records, and whether they can guarantee this information remains confidential, if it is included in the school records system.

Quick reference to an HIV disclosure in a school

This model follows the format and statutory guidance in Annex A of Supporting pupils at school with medical conditions (DfE 2014).

School is informed about child or families HIV status

Research has shown that 33% of disclosures to schools happen through a third person, without the families consent. If this happens, the first step is to establish whether that person has the families consent, and if not, to speak with the family, in order to inform and reassure them.



Either the child/family tell a staff member or the school is informed by a third person. The child/family are reassured and the headteacher is informed.



The headteacher designates a staff member to co-ordinate a meeting with the parent/carer, child (where appropriate) and HIV health or social care practitioner, to discuss the child's medical and/or pastoral support needs.



Draw up an agreed support plan, to include confidential information storage and sharing, and dates to review this plan.



Consider the information or training needs of the designated staff member, to improve their knowledge and understanding of HIV. This could simply be reading this guidance in full, or a conversation with a paediatric HIV practitioner.

The meeting should address and reach agreement on, the following issues:

- Confidentiality and reassurance that the child will not be treated differently.
- Arrangements on attendance due to hospital appointments, illness or caring responsibilities.
- The level of educational and pastoral support needed, and how this will be reviewed.
- How confidential records will be kept on the child's health and these meetings.
- Where the child is HIV positive, decide how any important health information that may affect the child - such as changing medication and its side effects – will be shared with the school.

RIGHT TO EDUCATION

Case study five (2014)

A nine-year-old child disclosed their HIV status in an unplanned way to their headteacher. The headteacher was very supportive and a decision was taken to contain the information to a few members of staff. A series of brief workshops were run by a paediatric specialist HIV nurse, for those staff that had been told this information. These sessions ensured full understanding of the condition, confidentiality, and that the child's needs were recognised by the school.

This action has helped to build a positive relationship between the school and the child's clinical team, which has since been maintained. It has been very useful for this child living with HIV to have staff in the school who know their status and are well informed of the facts. This has ensured that the child has people in the school to turn to for support.

There are many ways a school provides support:

- By responding to the needs of the child
- Respecting confidentiality
- Providing pastoral care
- Making allowances for hospital appointments;
- Promoting an ethos of understanding; tackling discrimination (such as bullying)

Children living with or affected by HIV have the same right of admission as all other children to maintained schools, academies and free schools, and to education and associated services. Where a school is aware that a child is living with HIV, the following laws afford the child the right to their information being handled in the strictest confidence, as well as full consideration being given to the child's additional support needs, where necessary.

The Equality Act 2010 protects people in England, Scotland and Wales from being discriminated against on grounds such as race, sexual orientation and disability. HIV is defined as a disability from the point of diagnosis, which means that it is illegal to discriminate against people living with HIV. This law explicitly offers protection from discrimination in a variety of settings, including education.

Full details of how the duties in the Equality Act apply to disabled children in schools are set out in the Council for Disabled Children's *Disabled Children and the Equality Act 2010* (Stokes 2015).

The Public Sector Equality Duty was created under the Equality Act. It states that

public sector organisations (which include maintained schools, academies, free schools and PRUs) must have due regard for the need to:

- Eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the Act
- Advance equality of opportunity between people who share a protected characteristic and those who do not
- Foster good relations between people who share a protected characteristic and those who do not.

The Equality Act explains that having due regard for advancing equality involves:

- Removing or minimising disadvantages suffered by people due to their protected characteristics.
- Taking steps to meet the needs of people from protected groups where these are different from the needs of other people.
- Encouraging people from protected groups to participate in public life or in other activities, where their participation is disproportionately low.

The Equality Act checklist

Schools should demonstrate how they have anticipated the needs of pupils with HIV. Questions that a school could address to explore this, include:

- Are all staff and voluntary helpers aware of the Equality Duty, including managers, teaching staff, learning support assistants and others involved in providing or supporting learning?
- Have all or some staff been trained to understand the needs of pupils with HIV?
- Has the school reviewed, or begun to review, policies covering admissions, education and associated services, and exclusions, to ensure that these do not place pupils with HIV at a substantial disadvantage?

Section 100 of the **Children and Families Act** (2014) places a duty on governing bodies of maintained schools, proprietors of academies, and management committees of PRUs, to make arrangements for supporting pupils with medical conditions at their school. This new duty aims to ensure that all children with medical conditions, in terms of both physical and mental health, are properly supported in school, so that they can play a full and active role in school life, remain healthy, and achieve their academic potential.

Section 19 makes clear that local authorities, in carrying out their functions under the Act in relation to disabled children and young people and those with special educational needs (SEN), **must** have due regard to:

- The views, wishes and feelings of the child or young person, and the child's parents.
- The importance of the child or young person, and the child's parents, participating as fully as possible in decisions.
- The need to support the child or young person, and the child's parents, in order to facilitate the development of the child or young person and to help them achieve the best possible educational, and other, outcomes.

This Act places the onus on local authorities to identify children and young people in their area who might have special educational needs or disabilities, strengthening the case for schools to ensure that they are HIV-friendly, so that families feel more able to share this information..

As HIV is a disability, the Special Educational Needs and Disability (SEND) code of practice applies to HIV positive pupils.

Case study six (2012)

A six-year-old child was in receipt of Disability Living Allowance (DLA). Their DLA form was faxed to the school for an educational update. It is uncertain where the agency processing the DLA got the school's information from, as the family had not provided this. The fax from the agency went to the school's reception and as a result, all reception staff saw the information about the child's HIV status. Reception staff went on to tell the headteacher.

This breach in confidentiality had the potential to have negative consequences for the child and their family. In this case, a specialist HIV nurse was contacted, who came into the school to run some training about HIV with all the staff that were aware of the information. As well as accurate information about HIV and how best to support the child, the importance of confidentiality was stressed. These sessions went well, and the child was able to remain in the school.

APPENDIX I: FURTHER INFORMATION

The following organisations and websites provide useful information about HIV and are arranged under relevant subheadings.

I. General

AVERT: a charity providing information on HIV, including information and quizzes for young people, and news and statistics about HIV and other sexually transmitted infections. Visit: www.avert.org.

Children and Young People HIV Network: based at the National Children's Bureau, the Network develops national policy and good practice for issues relating to children living with and affected by HIV. Visit www.ncb.org.uk/hiv.

Children's HIV Association for the UK and Ireland: a membership network of practitioners providing health and social care to children and families living with HIV, which produces current medical guidelines for the NHS and runs some services for HIV positive children. Visit: www.chiva.org.uk.

National AIDS Trust: the United Kingdom's leading HIV policy development and advocacy organisation. Visit: www.nat.org.uk.

Positively UK: a national charity that offers support and information for HIV positive individuals and their families. They can provide positive speakers for schools. Visit: <http://positivelyuk.org/>.

Terrence Higgins Trust: a national charity that offers advice and help to those living with HIV, and works to reduce the spread of HIV. Visit: www.tht.org.uk.

2. Education resources

HIV Facts (National AIDS Trust 2014):
<http://www.nat.org.uk/HIV-in-the-UK.aspx>

Life in my shoes (Body and Soul 2014):
<http://lifeinmyshoes.org/>

Positive? Awareness and attitudes towards HIV (FPA 2014):
<http://www.learningpositive.com/>

School visits by Terrance Higgins Trust:
<http://www.tht.org.uk/our-charity/Resources/Training/Who-we-train>

Studying with HIV

Web-based guidance on meeting the needs of young students in further and higher education who have HIV:

<http://ncb.org.uk/studying-with-hiv>

Supporting young carers in families affected by HIV.

This document has a section for education professionals:

<http://www.youngcarer.com/resources/families-affected-hiv>

3. Useful guidance

Advice for Employers: HIV at work (NAT 2012):
http://www.nat.org.uk/media/Files/Publications/Jul_2012_HIV@Work_Advice_for_employers.pdf

Advice on statutory policies for schools (DfE 2014):
<https://www.gov.uk/government/publications/statutory-policies-for-schools>

Disabled Children and The Equality Act 2010 for Schools.
(Council For Disabled Children 2015):
<http://www.councilfordisabledchildren.org.uk/resources/disabled-children-and-the-equality-act-2010-for-schools>

Guidance on First Aid for Schools: A good practice guide. (DfE 2000, updated 2014):
<https://www.gov.uk/government/publications/first-aid-in-schools>

Guidance on infection control in schools and other childcare settings. (Public health England. September 2014 version 2):
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/353953/Guidance_on_infection_control_in_schools_11_Sept.pdf

Health Conditions in Schools Alliance (2015):
<http://medicalconditionsatschool.org.uk/>

HIV and Recruitment: Advice for employers (NAT 2012):
http://www.nat.org.uk/media/Files/Publications/Jul_2012_HIV_and_recruitment_Advice_for_employers.pdf

Schools: Guide to the 0 to 25 SEND code of practice. Advice for school governing bodies/proprietors, senior leadership teams, SENCOs and classroom staff (September 2014):
<https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

Shooting Up: Infections among injecting drug users in the United Kingdom (Public Health England updated November 2014):
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/370707/Shooting_Up_2014.pdf

Statutory Guidance: Supporting pupils at school with medical conditions. (April 2014). Department of Education:
<https://www.gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions--3>

APPENDIX 2: REFERENCES

CHIVA (2015) *CHIVA Paediatric Nurses Audit: experiences of HIV positive children in UK schools*, CHIVA, Bristol.

CHIVA (2015) *Data on HIV affected children living in the UK*, CHIVA, Bristol.

Department for Education (September 2014) *Supporting Pupils at school with medical conditions: Statutory guidance for governing bodies of maintained schools and proprietors of academies in England*, DfE.

Ipsos Healthcare (December 2014) *HIV in schools: Uncovering the unmet needs in management of children affected by HIV*.

Public Health England (updated November 2014) *Shooting Up: Infections among people who inject drugs in the United Kingdom 2013*, Public Health England, London.

McDonald, S (2011) *HYPNet adherence audit*, BHIVA, London.

Miah, J et al. (2004) *Talking With Children, Young People and Families About Chronic Illness and Living With HIV*, National Children's Bureau, London.

Stokes, P (2015) *Disabled Children and the Equality Act 2010*, Council for Disabled Children, London.

