

HIV in Schools



Good practice guide to supporting
children living with and affected by HIV

Magda Conway

About CHIVA

CHIVA's mission is to ensure that children, young people and families living with HIV become healthier, happier and more in control of their own futures.

CHIVA works to ensure young people living with HIV have the treatment and care, knowledge, understanding, skills and wider support needed to live well and achieve their greatest potential.

For more information see www.chiva.org.uk

About the National Children's Bureau

For more than 50 years, the National Children's Bureau has worked to champion the rights of children and young people in the UK. We interrogate policy and uncover evidence to shape future legislation and develop more effective ways of supporting children and families. As a leading children's charity, we take the voices of children to the heart of Government, bringing people and organisations together to drive change in society and deliver a better childhood for the UK. We are united for a better childhood.

Our membership groups draw partners together to drive change in key areas where we need to make childhood better. These include the Anti-Bullying Alliance, Council for Disabled Children, Childhood Bereavement Network and Schools' Wellbeing Partnership.

In 1992, NCB established a network to address the impact of HIV on children in the UK through policy and practice development. HIV continued to be a specialist area of NCB's work into the 2010s.

For more information see www.ncb.org.uk

Published by the National Children's Bureau
National Children's Bureau, 23 Mentmore Terrace,
Hackney, London E8 3PN

Website: www.ncb.org.uk
Registered charity number: 258825

© National Children's Bureau 2005, updated 2015. Latest update 2022

ISBN 1 904787 47 9

British Library Cataloguing in Publication Data
A catalogue record for this book is available from the British Library

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

The following organisations support this guidance.



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Acknowledgements

In 2005, the following people and organisations were instrumental in ensuring that this document met the needs of schools:

This guidance was written and edited by Magda Conway, coordinator of the Children and Young People HIV Network, 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; the CHIVA Executive; 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; Dr Linda Lazarus, EAGA Secretariat; Laycock Primary School; Christine Lenehan, Council for Disabled Children; Juliet Ramage, Barnardos; 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 in 2005; Helen Wheatley, Council for Disabled Children. The young people from Positively Women (now Positively UK).

Many people were involved in the 2015 update, funded by ViiV Healthcare in particular:

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

This guidance was further updated in 2022 by Amanda Ely, CHIVA. Thanks to Emily Hamblin, Octavia Holland, Matthew Dodd and Richard Newson at the National Children's Bureau for support with this update.

Foreword

As Chair of 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 share the diagnosis with schools because of concerns about confidentiality and are therefore unable to access this support. The vast majority of children living with HIV have not notified their school, for fear of the response.

Through a series of case studies looking at the real experiences of children and families living with HIV, this publication provides those involved in education with an insight into the issues for those affected, and the impact of current practices.

It is in the interest of all children that schools provide accurate information about HIV as part of relationships and sex education. It is therefore essential that teachers and staff are equipped with accurate knowledge and understanding about HIV and routes of transmission. A survey commissioned by CHIVA to support the 2015 update of this guidance showed that this knowledge was lacking. Increasingly, children living with or affected by HIV will be among those being taught about HIV 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 educators and schools to ensure that a pupil who shares information about 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.

CHIVA has also published an education toolkit, *Empowering Students: End HIV Stigma*, which enables teachers to educate young people with the facts about HIV in an engaging way.

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 of CHIVA

Supportive quotes

Florence Eshalomi MP for Vauxhall, Co-Chair of the All-Party Parliamentary Group HIV and AIDS said, *“Schools who follow this guidance will be well equipped to support any children living with HIV. This alongside CHIVA’s education toolkit, will provide schools with the ideal package of resources to empower a generation of teachers and students with the knowledge needed to end HIV stigma. This fully aligns with the APPG’s aims to ensure that all people living with HIV have a good quality of life, free from stigma, discrimination and fear.”*

A member of CHIVA’s Youth Committee explains why the support of her school has helped her. *“I am lucky enough to live in an area with great HIV support and facilities, and to go to a school where HIV is handled with confidentiality and care. Year 10 has been quite a stressful and difficult year for me and one of the only education years where HIV has been a struggle for me. I was struggling to stay in school the whole day or even turn up. The school was quite concerned and had ideas that something deeper was going on. With the support of my doctor, we were able to talk to the school about my HIV, and with this new knowledge the school finally understood. If HIV was properly taught as part of the curriculum, then support could be given to other young people in my situation.”*

Terminology

Throughout this document, the following terms are used:

Living with HIV refers to children and young people who have been diagnosed with, and are living with HIV.

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

Parents/carers 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.

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/carers, teachers, support staff and pupils.

Introduction

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 support that schools already provide to 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, parents/carers, and children living with HIV.

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 in 2014, showed that although 80% saw pupils living with HIV as having associated pastoral care needs, understanding of how HIV is passed on was poor, with 52% listing spitting/biting as a route of transmission, and only 49% understanding how the majority of children living with HIV in UK schools have acquired HIV.

In addition, a survey on public knowledge and attitudes about HIV conducted by the National Aids Trust (NAT) in 2021 found that most of the public don't hear very much about HIV and that knowledge held is often outdated and patchy, with most mistakenly identifying at least one way in which HIV cannot be acquired (NAT 2021).

It's important for schools to be aware that a child living with HIV in a school:

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

HIV is NOT a notifiable disease

'Notifiable diseases' are those that people are legally required to report, as coming into everyday contact with someone would pose a risk of onward transmission. 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 everyday contact.

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

- The vast majority of children and young people living with HIV in education in the UK, acquired HIV vertically 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 who are on effective treatment 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.

Children living with HIV face a high level of stigma, which can affect their wellbeing and can lead to 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 diagnosed with HIV are legally defined as 'disabled' and are therefore protected against discrimination in education by the **Equality Act 2010** (further information on 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 the following 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

People living with HIV may experience physical and mental health issues associated with the condition and take a strict daily regime of medication that can lead to side effects. There are additional complications that managing a long-term health condition may present to the child and their family. 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 every child can learn without fear of discrimination, it is safe to be living with HIV and where children and families feel safe to share this information with staff and seek support. 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 a school's 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.21.

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 they are told a pupil is living with HIV

This model is informed by the statutory guidance, *Supporting pupils at school with medical conditions*, provided by the Department for Education (DfE 2015).

School is informed about a child or family's HIV status

Research has shown that in 33% of instances where a school is told that one of their pupils is living with HIV, this happens through a third party, without the family's 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.



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 whether an IHCP (see p.26) is required (in most cases this will be appropriate).



Level of support required is identified and documented and must include details of 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, or CHIVA.

If a child tells a teacher about their own or their parent/carer's HIV status, the teacher should 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.25).

It is important that all staff discuss, and are aware of, the procedures for managing HIV information, before it is received. This presents the opportunity to: ensure that staff's HIV knowledge is up to date; reassure staff by repeating information about how HIV can be transmitted; 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, the general school, sex and relationships education – 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 an all-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 contact CHIVA directly. (www.chiva.org.uk).

HIV in Schools

Case study

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 a mainstream school and one of the community workers told the school that two siblings were living with HIV, without the family's consent.

The school contacted the National Association of Head teachers (NAHT) for support. They were advised to suspend the siblings and put a risk assessment in place. Not only was this an unnecessary action to take, but it also had the misguided backing of Social Services, and a multi-agency strategy meeting was called. The GP raised concerns with the school about the approach that they had been advised to take, and contacted the family's specialist paediatric HIV healthcare provider, to ensure that 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. The school invited an appropriate representative to the meeting.

After this meeting, it was decided that the suspension should be stopped. The children went back to school quite quickly. Crucially, information about their HIV status was kept 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 great impact on the family. However, despite having been initially incorrectly advised, there is now improved knowledge of HIV amongst the teachers, and the school is very supportive of the family.

Facts

- HIV cannot be transmitted through normal daily contact; therefore, it is a non-notifiable disease, which means that parents/carers or children may choose not to inform the school.
- Due to stigma and discrimination faced by people living with HIV, confidentiality is essential when a school is made aware of an individual's HIV status.

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 80% saw HIV as a pastoral care issue, understanding of how HIV is passed on was poor. Incorrect routes of transmission noted by participants included: spitting/biting (52%), kissing (18%); and a small number 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 how a child acquired HIV, 40% understood that the majority of children living with HIV acquire the virus from pregnancy, birth or breastfeeding, but 60% identified it to be via sexual transmission (29%), injecting drug use (18%), and even spitting/biting (1%). This demonstrates low levels of understanding of HIV in the context of families.

Research on the experiences reported by paediatric HIV health care teams

In 2015, CHIVA published an audit that was undertaken with paediatric HIV healthcare providers. It concluded that:

- In general, schools were not told when they had a pupil who was living with HIV, with only 11% of children living with HIV attending a school that knew their diagnosis.
- Of this 11%, 64% of children and families decided to tell schools; the other 33% had a third party share the information without the child or family's consent.
- 82% of the schools told, were mainstream schools.
- 46% of the responses by schools, initially led to a bad experience for the child and family.
- Following an intervention from an outside practitioner, 78% of schools then responded supportively, whilst 22% continued to respond negatively.

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 for children. However, if the reactions of staff, parents/carers or pupils, to a child who is living with or affected by HIV are inappropriate, this can be harmful to the child and their family. Such prejudice is caused by a lack of knowledge about how HIV is transmitted, and stereotypes of 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 exclusion and bullying that children living with HIV tell us they have faced or fear, and will encourage educational development, thus improving these children's health and wellbeing 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

A child was not taking their antiretroviral therapy (HIV medication, ART) 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 of 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 was extremely supportive, responded calmly, and upheld excellent confidentiality, liaising with the health team and ensuring that the needs of the child were met.

You cannot get HIV from kissing, cuddling, or sharing drinks, plates or toilet seats.

HIV is a blood-borne virus that was first identified in 1983. HIV can only be passed between people via: semen and vaginal fluids; blood; vertical transmission (mother to baby during pregnancy or labour); or through breast milk.

Outside of the body, HIV can't survive for very long. Even if a person living with HIV cuts themselves, there is a very low risk for HIV transmission if someone else comes into contact with their blood. The skin is a protective layer. Unless the other person has a cut or broken skin at the same time, there is no risk of transmitting the virus between them.

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 the transmission of all blood-borne infections, including HIV.

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.

HIV can be transmitted through sex, and relationships and sex education (RSE) in schools 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 of acquiring HIV in their lifetime.

It's important to note that there are very good medicines that people living with HIV take, called antiretroviral therapy (ART). People living with HIV who are on effective HIV treatment can live a long, healthy life.

A person living with HIV who is taking ART may have an 'undetectable HIV viral load'. This means they still have HIV, but ART has reduced the amount of HIV in their blood to such low quantities that it can no longer be detected by a standard blood test. If their HIV is undetectable, there is zero risk of transmitting the virus to sexual partners. The phrase U=U (undetectable = untransmittable) is now widely used.

It is important when teaching RSE to be aware that there may be pupils living with, or affected by, HIV in the room, and to ensure that the correct information is provided in a non-stigmatising manner. See CHIVA's Education Toolkit, '*Empowering Students: End HIV Stigma*', for more information.

Living with HIV

Case study

The school was informed about a pupil's HIV diagnosis at a professionals' meeting. 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 a great deal of 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 once again given to the senior management staff, and it was reiterated that the child presented 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 prior consent. On this occasion, the pastoral care lead for the child resigned from the school, citing this breach of 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 to another school. The child and their healthcare team are now 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 that a school might provide for them.

Virtually all children living with HIV are completely healthy during their school years. Although a child living with HIV may have a compromised immune system, there is no greater risk to their health in an educational setting than there is for any other child. With regular clinical check-ups and treatment with antiretroviral medication (HIV medication), the vast majority of these children in the UK are living well with HIV into adulthood, with a number of young people, now over 30 years of age, and many are having their own children.

However, 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 HIV stigma, this information is often not shared. Children living with or affected by HIV are more likely to be marginalised and fall behind with their work if they or their family members' have periods of ill health, as this can mean additional time out from school to attend hospital appointments or to carry out caring responsibilities at home.

In general, daily medication regimens do not interfere with the school day, and only become a consideration when the child attends school trips or residential excursions. 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 2015).

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 that some children living with and affected by HIV might 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 as their health condition. This is due to parents/carers and health providers fearing that the child will accidentally share this information, and their desire to keep the child from experiencing discrimination.

This is not considered good practice, and guidance illustrates the benefit and right for children to have full knowledge and understanding of their HIV, in order to lessen the impacts of secrecy and stigma. (WHO 2011, Ely 2012). However, the issues surrounding telling children about their HIV illustrate the depth of fear about the reactions of others, faced by people living with HIV.

In 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 there are 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 the school.

If a school wants to support a pupil living with HIV, they need to first provide parents/carers with the reassurance that information will be kept confidential, and only discussed on a need-to-know basis, with consent. Parents/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 examples of school communities reacting inappropriately to learning about a child's or parent/carer's HIV status historically, 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 where schools are not informed 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, parents/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 full academic potential.

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

In 2020 106,890 people were living with HIV in the UK, with just over 5,000 people estimated to be unaware of their HIV status. (UKHSA 2021). 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 will challenge the attitudes and misconceptions of the school community and wider society. By putting in place a few simple systems, schools can protect and support these more vulnerable pupils, as well as staff and parents/carers living with HIV.

Working towards an HIV-friendly school

Case study

A child came from a family who were very cautious about informing the school about 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 4-5 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 residential course had questioned the child about the medication during the previous evening. The child did not want to tell the teachers about their HIV 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's 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 a 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 trip.

"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, behaviour, RSE, 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. Schools could state in their policies (e.g. behaviour policy) that students talking about certain medical conditions, such as HIV, in an offensive way is strictly forbidden and that sanctions will apply. 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 a blood-borne infection; universal first aid procedures and standard hygiene control measures should effectively prevent the possibility of transmission blood-borne viruses, 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 the guidance on *First aid in schools, early years and further education* (DfE 2022) which sets out how this should be done.

Equal opportunities and social inclusion

Equal opportunities and social inclusion policies should 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.

Relationships and sex education policy

Statutory guidance on relationships and sex education (RSE) and health education (DfE 2021) requires: that pupils understand transmission of sexually transmitted infections including HIV; that they are taught how to recognise the characteristics and positive aspects of healthy one-to-one intimate relationships; and that they understand how to get further advice, including how and where to access confidential sexual and reproductive health advice and treatment. They should also be taught about U=U (see page 18).

RSE is compulsory for all pupils receiving secondary education. (*with parents/carers being permitted to withdraw pupils from sex education but not relationships and health education).

Medical needs policy

School governing bodies, academy proprietors and pupil referral units (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 sharing information, parents/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 pupils living with or affected by HIV, 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.

Information sharing and confidentiality

Case study

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 told the teacher they had HIV.

The staff member was the Deputy Head and managed the situation professionally. They met with the mother (who was extremely anxious) and reassured her that the information would be kept confidential, and that the teacher just needed to tell one other person in the school. The mother requested that 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 that she believes the family might have to face, if their HIV status is widely shared in the school.

This section gives an example of good practice protocol in relation to schools being informed about a pupil or family member's HIV status. It is important to establish protocols in advance, 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 receiving information about HIV relating to a pupil or member of their family 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, a local paediatric infectious diseases nurse or CHIVA directly.

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 2015).

The role of the headteacher will be to support the designated staff member, to discuss any issues with them, to instigate any discussion between parents/carers and the school on issues that arise concerning the pupil's education or wellbeing. They have overall responsibility for the development of the 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 sharing information. The school nurse could also be a link between the school and the child's 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, in order to share this information with the school nurse.**

Judgements will be needed about how best to support children living with HIV in education, based on medical evidence and consultation with parents. Children are likely to benefit from an individual healthcare plan (IHCP) (DfE 2015) establishing the support that they want and need, with meetings to review 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.

The purpose of individual healthcare plans, and how they should be developed and used, is explained in the statutory guidance on *Supporting pupils at school with medical conditions* (DfE 2015). Some children may also have special educational needs (SEN) and may have a statement, or Education, Health and Care (EHC) plan which brings together health and social care needs, as well as their special educational provision. The relationship between statements, EHC plans and IHCPs is set out in the statutory guidance. (DfE 2020)

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 school's 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 wellbeing. 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, who needs to know and why, are at the forefront of any decision to share information on a child or family member living with HIV. It is paramount that the child and parents/carers are involved in these decisions, which is a right afforded to them by the Children and Families Act 2014.

When information is shared, families will not have made the decision lightly, 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 providing information about HIV to one school, the information is passed on to subsequent schools, without their consent. If the school feels that it is essential to include this information on the child's record, parents/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 that this information remains confidential, if it is included in the school records system.

Right to education

Case study

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 sessions 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.

There are many ways in which 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; and 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, and 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 guide on the *Disabled Children and the Equality Act 2010*.

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 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/carers
- The importance of the child or young person, and the child's parents/carers, participating as fully as possible in decisions
- The need to support the child or young person, and the child's parents/carers, 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 able to share this information.

HIV is defined as a disability within the Equality Act. The Special Educational Needs and Disability (SEND) code of practice applies to pupils living with HIV.

Case study

A nine-year-old child shared information about their HIV 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.

Quick reference to receiving information about a pupil who has HIV in a school

This model is informed by the statutory guidance, *Supporting pupils at school with medical conditions*, provided by the Department for Education.

School is informed about a child or family's HIV status

Where a school is told that one of their pupils is living with HIV through a third party, establish whether that person has the family's consent, and if not, 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 whether an IHCP is required (in most cases this will be appropriate).



Level of support required is identified and documented and must include details of 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, or CHIVA.

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 on the meetings in regard to this
- Where a child is living with HIV, 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.

Appendix 1: Further Information

The following organisations and websites provide useful information about HIV.

1. HIV organisations

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

Body and Soul: charity in London providing family focussed support including around HIV. <http://bodyandsoulcharity.org>.

CHIVA: national charity working to ensure children and young people living with HIV have the treatment and care, knowledge, understanding, skills and wider support needed to live well. www.chiva.org.uk.

National AIDS Trust: UK's HIV rights charity. www.nat.org.uk.

Positively UK: charity providing peer lead support, advocacy and information for people living with HIV. <http://positivelyuk.org/>.

Terrence Higgins Trust: HIV and sexual health charity, offers advice and help to those living with HIV, and works to reduce HIV transmissions. They can provide speakers for schools. www.tht.org.uk.

2. Further resources

Empower Students: End HIV Stigma – Education Toolkit (CHIVA)
CHIVA.org.uk/education

Life Growing Up short film, (CHIVA): CHIVA.org.uk/lifegrowingup

Learning materials (National AIDS Trust)
<https://www.nat.org.uk/our-work/training-and-learning>

HIV Schools Pack (National AIDS Trust)
https://www.nat.org.uk/sites/default/files/teachers-resources/NAT_HIV_Schools_Pack.pdf

Student Life: Going to University or College (NCB)
https://www.chiva.org.uk/files/9014/5330/4829/student_life.pdf

Supporting young carers in families affected by HIV (The Children's Society)
<https://www.childrenssociety.org.uk/information/professionals/young-carers/families-affected-by-HIV>

3. Useful guidance

Advice on statutory policies for schools (Department for Education 2019)
<https://www.gov.uk/government/publications/statutory-policies-for-schools>

Blood-borne Viruses in the Workplace: Guidance for employers and employees (Health and Safety Executive 2001)
<https://www.hse.gov.uk/pubns/indg342.pdf>

Disabled Children and The Equality Act 2010 for Schools (Council for Disabled Children 2015)
<https://councilfordisabledchildren.org.uk/resources/all-resources/filter/statutory-guidance/disabled-children-and-equality-act-2010-schools>

First aid in schools, early years and colleges. Department for Education (2020 – updated 2022) <https://www.gov.uk/government/publications/first-aid-in-schools>

Health Conditions in School Alliance: Includes sample policies and healthcare plans, plus an explanation of the legal requirements for schools.
<http://www.medicalconditionsatschool.org.uk/>

PSHE Association Curriculum guidance & FAQs (PSHE)
<https://pshe-association.org.uk/guidance/ks1-5/planning/long-term-planning>

Special educational needs and disability code of practice: 0-25 years. (Department for Education, 2020)
<https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

Special educational needs and disabilities: Education, health and care (EHC) plans (Gov.uk) <https://www.gov.uk/children-with-special-educational-needs/extra-SEN-help>

Statutory Guidance: Supporting pupils at school with medical conditions (Department for Education, 2015)
<https://www.gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions--3>

Statutory guidance on relationships education, relationships and sex education (RSE) and health education (Department for Education, 2019)
<https://www.gov.uk/government/publications/relationships-education-relationships-and-sex-education-rse-and-health-education>

UK annual HIV data tables (UK Health Security Agency)
<https://www.gov.uk/government/statistics/hiv-annual-data-tables>

Appendix 2: References

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

https://www.chiva.org.uk/files/9714/4762/0030/CHIVA_Paediatric_Nurses_Schools_Audit.pdf

Ely, A (2012) Open and honest practice when working with children. CHIVA. Bristol.

<https://www.chiva.org.uk/infoprofessionals/support/chiva-position-statement/>

Ipsos Healthcare poll of 500 teachers (2014) HIV in schools: Uncovering the unmet needs in management of children affected by HIV.

https://www.chiva.org.uk/files/8614/3808/7012/14-060786-01_HIV_in_Schools_23Jul15_revisions_2.pdf

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

<http://dev.ncb.org.uk/resources-publications/talking-children-young-people-and-families-about-chronic-illness-and-living>

National AIDS Trust. (2021) HIV Public Knowledge & Attitudes.

<https://www.nat.org.uk/publication/hiv-public-knowledge-and-attitudes>

UKHSA (2021) HIV testing, new HIV diagnoses, outcomes and quality of care for people accessing HIV services: 2021 report. UK Health Security Agency

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1037215/hiv-2021-report.pdf

WHO (2011) Guideline on HIV disclosure counselling for children up to 12 years of age. World Health Organisation <https://apps.who.int/iris/handle/10665/44777>

