HIV in Schools

Good practice guide to supporting children infected or affected by HIV

Magda Conway

Children and Young People HIV Network

national children's bureau

National Children's Bureau
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Children and Young People HIV Network
The Children and Young People HIV Network is a national policy forum that brings together a wide range of organisations concerned with children, young people and HIV/AIDS. It is based at NCB 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.

Published by the National Children's Bureau
National Children's Bureau, 8 Wakley Street, London EC1V 7QE
Tel: 020 7843 6000
Website: www.ncb.org.uk
Registered charity number: 258825

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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Foreword

As chairman of the Children's HIV Association of the UK and Ireland, it is my privilege to endorse this clearly written and highly practical guide that will help schools support children infected or affected by HIV.

Schools face a complicated task of educating young people about HIV infection so that the uninfected majority can remain uninfected. This means giving an accurate picture of how the virus is transmitted, and the damage it can cause to an infected individual's immune system. The message necessarily needs to ensure young people understand that this is a very serious infection, there is no easy cure, and prevention is the best solution.

Increasingly, however, in our schools there will be children and young people already living with the virus – perhaps they or a family member are HIV positive. The school community has a duty of care to these children also, which requires teachers to discuss HIV in a non-judgemental and well-informed fashion. No health education about HIV should be reinforcing myths or increasing prejudice against those living with HIV. If teachers become aware that a child in the school is infected, they need to understand that this poses no risk to the other pupils and they must ensure that confidentiality is respected and maintained.

Through a variety of quotations and case histories, this publication imparts a great deal of insight into and accurate information about the lives of children in the school system living with HIV. Teachers who have read this will be in a far better position to understand and support the children in their classes who are infected or affected by HIV, whether or not the diagnosis has been disclosed to them.

Gareth Tudor-Williams
Chairman, Children's HIV Association for
the UK and Ireland (CHIVA)

Acknowledgements

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
- Mark Jennett, Health Development Agency.

We would like to thank everyone who generously gave help and support in the production of this guidance. Special thanks go to:

- Betty Layward Primary School
- 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, CHIVA Executive Committee member
- Dr Linda Lazarus, EAGA Secretariat
- Laycock Primary School
- Christine Lenehan, Council for Disabled Children
- Juliet Ramage, manager, Health Through Action
- Dr Andrew Riordan, paediatric consultant, CHIVA Executive Committee member
- 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.

Introduction 1

This guide provides schools and local education authorities (LEAs) with practical information and suggestions on ways of supporting children and young people 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 infected and affected children. This is addressed as part of the pastoral support that schools already provide, which includes all pupils with health needs.

The guide is written for LEAs and schools (for example, maintained nursery, primary, secondary and special schools, and pupil referral units), the staff who work in them – including LEA personnel, governors and headteachers – and external bodies who have regular contact with schools. It will also be of use to those operating in other educational settings (non-maintained schools) and 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 and young people living with HIV.

> 'At school I found it difficult knowing that I have HIV and that I couldn't talk to anyone … Talking to a teacher about your situation was too risky; you hear about young people who have told one teacher in confidence and soon every teacher in the school knew about it. Because of this lack of good judgement, confidentiality and trust, many young people like myself have to live a life based on secrets due to the fact that we are in a situation that is surrounded by ignorance and prejudice.'
>
> **HIV-positive young person speaking at Children's Rights & HIV conference (June 2004)**

Terminology

Throughout this guide the following terms are used:

Infected refers to children and young people who are infected by the HIV virus.

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

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

Child refers to any child or young person in full-time education or nursery care settings.

School denotes all educational settings for school-age children and local education authorities.

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.

Why should schools support infected and affected children?

Schools are an important part of a child's life and provide a supportive, caring environment for children. In some instances, the reaction of staff, parents or pupils to a child who is infected or affected by HIV has led to the child leaving the school. Such prejudice is caused by a lack of knowledge about how HIV is transmitted and stereotypes of those who are infected.

Creating a supportive and inclusive environment through policy and practice will make a real difference to the lives

A starting point

To develop policies for supporting affected and infected children, 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 affected or infected with the virus?
- Is HIV awareness part of your school development plan?
- Does the entire school community have an understanding of the issues raised by HIV, including stigma?

of infected and affected children. It will prevent exclusion and bullying, and it will encourage educational development, thus improving infected and affected children's health, well-being and opportunities.

HIV in schools

- In 2005, there are just over 1,000 HIV-positive children under the age of 19 living in the United Kingdom.
- The number of affected children is not known, but can be estimated at over 10,000.
- There is no known reported case of HIV transmission occurring in a UK school.
- HIV is a non-notifiable disease, which means that parents or children who are affected or infected may choose to not inform the school. This is because the infected pupil poses no risk to others.

- Due to many people's reactions, confidentiality is essential in regard to knowing an individual's HIV status. Even today, the stigma attached to HIV is so extreme that, if discovered, many HIV-positive people have had to leave their homes, work and communities, and, in the case of children, their school.

Routes of HIV transmission and schools 2

HIV has been known about for over 20 years and in this time the only routes of transmission in the United Kingdom have been through blood, breast milk, and seminal and vaginal fluids. Screening is in place to make blood and organs safe. Transmission of the HIV virus is only possible if there is a sufficient quantity of the virus entering the bloodstream directly.

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

Having an infected child 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. No case has ever been recorded of HIV transmission from child to child by biting, fighting, playing or any other normal childhood interaction.

Children being injured by or playing with injecting equipment is a major concern for the transmission of some blood-borne viruses, but not in the case of HIV. Due to the success of needle exchange schemes, HIV prevalence is low in intravenous drug users (Health Protection Agency and others, 2004). Additionally, HIV cannot sustain

‘We have two identities just to try to fit in with our friends and peer groups and even if it means that *we* have the correct views and knowledge about HIV and AIDS we have to keep quiet. Having two identities makes life a lot difficult and fearful too because you have to be attentive and vigilant.’

HIV-positive young person speaking at Children’s Rights & HIV conference (June 2004)

exposure to oxygen and can therefore only survive outside of the body for a few minutes.

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 unsafe sex.

Living with HIV 3

Virtually all infected children are completely healthy for the majority of their school career. With regular clinical check-ups and advances in medical science and medication, the majority of infected children in the United Kingdom are reaching adulthood. They take medication at home once or twice a day and will appear as normal, healthy children. If a school does agree to manage a pupil's medication, perhaps due to a school trip, as with any medication, a robust system should be in place to manage it safely and confidentially (DfEE and DoH 1996).

Stigma and discrimination

Infected and affected children and adults face stigma, discrimination and social exclusion. An infected child is at risk of isolation, discrimination and bullying from his or her peer group and other members of the school and wider community.

A large proportion of infected and affected children do not know about their own, or their family members', infection. Often, children take medication, attend hospital appointments and have periods of ill health, but are not told the actual reason why until it is felt they will be able to process the information and maintain a level of confidentiality. This illustrates the depth of fear infected and affected people face about the reactions of others. It also adds a complex dynamic to working with infected and affected children.

> 'Being a teenager who is infected or affected by HIV and AIDS, you try to live as normal life as possible like any other teenager, by taking each day as it comes because your life revolves around HIV, medication and going into hospital. You become more cautious in attitude and actions and you are aware of what is happening in your life.'
>
> **HIV-positive young person speaking at Children's Rights & HIV conference (June 2004)**

For the majority of families affected by HIV, the fear of discrimination leads them to decide against telling the school (Lewis 2001). If a school wants to support an infected or affected pupil, they need to first provide parents with the reassurance that information will be kept confidential and only discussed on a need-to-know basis with the parents' consent. Parents need to be aware of, and have access to, the school's policies – and these should include the need for confidentiality and the actions that will be taken if it is breached.

There have been many examples of school communities reacting inappropriately to the disclosure of a child's or parent'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 may be needed in order to reach his or her academic potential.

The harm to a child caused by inappropriate reactions underlines the importance of schools having policies and practice in place to reassure the child and parents. These will protect the child from negative reactions, enabling him or her to receive the care and support needed to thrive and achieve academic potential.

A whole-school approach to being HIV-friendly will challenge the attitudes and misconceptions of the entire

> "We work with these two sisters; both are HIV positive, both have children. They live roads apart and see each other all the time. But they haven't told each other. That is how scared people are about others' reactions, they won't even confide with their nearest and dearest."
>
> **Social Worker, Sheffield 2004**

school community. As 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.

Supporting infected and affected children in schools

The number of HIV infections in the United Kingdom is rising and it is estimated that almost a third of those infected with HIV are unaware of their positive HIV status. Schools may not know whether an individual child is infected or affected by HIV, but having a supportive approach to HIV can benefit all pupils and the school.

An infected child is at no greater health risk in an educational setting than any other child, but he or she may need additional emotional and educational support. Compared with non-affected children, infected and affected children are more likely to be marginalised and fall behind with their work due to periods of ill health, hospital appointments or caring responsibilities for relatives.

Access to education 4

Right to education

Infected and affected children have the same right of admission to a school, and access to education and associated services, as all other children. Where a school is aware that a child is infected with HIV, it should treat such information in the strictest confidence and consider what additional support may be necessary.

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); and through health education (such as PSHE).

Disability Discrimination Act

The Disability Discrimination Act (DDA) 1995 protects people with disabilities, including those with HIV or AIDS, from being discriminated against. At present, the DDA applies to HIV at symptomatic stage and AIDS at diagnosis; but from December 2005, these protections will apply to HIV from the moment of diagnosis.

The Special Educational Needs and Disability Act 2001 amends the DDA 1995 Part 4 to prevent discrimination against disabled people in their access to education. It extended new duties to cover every aspect of education. The principle behind this legislation is that, wherever possible, disabled people should have the same opportunities as non-disabled people in their access to education. The duties make it unlawful to discriminate, without justification, against disabled pupils and prospective pupils in any aspect of school life (Disability Rights Commission 2002).

> ‘I want them to treat him as normal. I want him to have as normal a childhood as possible.’
>
> **Parent of an HIV-positive child quoted in Lewis (2001)**

Part 4 of the DDA, as amended, continues by stating that it is unlawful to discriminate against a disabled child in relation to school admissions, education and associated services, or excluding a pupil (paragraph 6.1). This applies to all schools and local education authorities in England, Northern Ireland, Wales and Scotland. *The Code of Practice for Schools* (Disability Rights Commission 2002) gives practical guidance on how to avoid discrimination against prospective disabled pupils and disabled pupils during their time in school, and describes the duties of the bodies responsible for this provision.

Inclusion agenda

Some infected and affected children may have behavioural problems that relate directly to coping with their own or a family member’s HIV infection, and this can put them at risk of social exclusion. DfES Circular 10/99 *Social Inclusion: Pupil Support* offers guidance on pupil attendance, behaviour, exclusion and re-integration. It describes the law and good practice for educational institutions on reducing the risk of disaffection, putting the emphasis on early intervention and prevention through multi-agency working and through partnership with parents (Department for Education and Skills 1999).

Healthy Schools

The National Healthy School Standard provides a framework that enables schools to address health-related activities through a whole-school approach. Amongst other

things, a healthy school understands the importance of investing in health to assist in the process of raising levels of pupil achievement and improving standards. It also recognises the need to provide both a physical and social environment that is conducive to learning. Local programmes can provide access to support for a variety of areas, including staff professional development, pupil support and policy development. This can help to promote a school culture and environment that is HIV friendly. All areas have a healthy schools coordinator who would be able to support a school in this.

Working towards an HIV-friendly school

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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 so that HIV is considered in the same light as other medical conditions. This is preferable to schools developing a separate HIV policy that pulls these elements together.

Schools should have standard policies, procedures and practices that apply to all children. This will lead to the health and medical needs of all children being addressed with sensitivity and respect. Planning for and management of individual medical needs require agreement with the child, parents and, where appropriate, health professionals.

Referring to HIV by name alongside other illnesses and disabilities in school policies will help destigmatise it. 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 infected or affected child. Below are suggestions and examples of some school policies where HIV could be mentioned. There may be other, equally appropriate policies not mentioned here.

First aid

The Health and Safety (First Aid) Regulations 1981 requires 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 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 commonsense measures to protect against such infection. Ideally, as many staff as possible should be trained in basic first aid and use universal first aid practice at all times with the entire school community.

General policy

If the school has a general school policy, it could include a specific statement on the impact of HIV and other chronic illnesses on the family and how the school wishes to support these pupils. For example:

> [Name of school] acknowledges that chronic illness such as diabetes, HIV and hepatitis can impact on the child and their family in varying degrees, mainly on attendance, behaviour and educational attainment. [Name of school] aims to create a supportive environment and recognises that a child living with or affected by a chronic illness has the right to access education and that support will be provided to the child and their family.

> ‘I’m not telling the school, it’s all about the fear of my children getting all this negative response and stuff from the school. No. I don’t want to. As long as she is not a danger to anyone; in any case she is more vulnerable, there is no medication she needs to take at school time.’
>
> **Parent of HIV positive child quoted in Lewis (2001)**

Both affected and infected pupils may at times in their school career have pastoral care needs; and these can only be met if the school is informed. A general statement in the schools pastoral care policy that highlights confidentiality can encourage disclosure. For example:

> [Name of school] acknowledges that if a family discloses any information about illness or disability affecting the child or members of his/her family, any sharing of that information will be done on a need-to-know basis and only with the consent of the pupil and/or parent, unless there is a child protection issue.

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

SRE policy

DfES Sex and Relationship Education (SRE) Guidance (DfES 0116/2000) requires that pupils: clarify their knowledge of HIV, AIDS and sexually transmitted infections; are taught assertiveness skills for negotiating relationships; and 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, and they should have a policy that covers these aspects and promotes a climate that counters stigma, discrimination and social isolation.

Medical needs policy

Local education authorities or individual schools 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; and that this should be reflected in the wording of this policy.

The school prospectus

To encourage disclosure, parents 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 portrayed negatively.

In order to promote acceptance and support for infected and affected pupils, it would be helpful if the school prospectus and mission statement includes a statement on supporting pupils with medical needs. For example:

> [Name of school] will seek to support, as far as is practical, any child that has a medical or health condition to ensure his or her health and 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 that it 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 parents 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 and, where appropriate, the pupil.

Disclosure and confidentiality

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

The headteacher and staff should treat this medical information confidentially. The headteacher should agree with the parent and pupil (where appropriate) who else should have access to records and other information about a pupil (DfEE/DoH 1996).

It is paramount 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, to 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 the primary care trust lead in HIV and sexual health.

Realistically, no more than two staff need to know if a pupil is affected or infected by HIV. One would normally be the headteacher and the other a designated staff member, ideally chosen by the pupil and parent, who can oversee the child's education and pastoral care. As stated previously, the majority of infected children spend their school career healthy, but they may need time off for medical appointments or to care for family members, or may occasionally have periods in hospital.

The role of the headteacher will be to support the designated staff member, to discuss any issues with him or her and to instigate any discussion between parents and the school on issues that arise concerning the pupil's education or well-being.

Quick reference to disclosure

If a child tells you about his or her own or his or her parent's HIV status

Step 1: Reassure the child that this information will be kept confidential.
Step 2: Explain that the school wants to support the pupil and has simple systems to do this.
Step 3: Suggest that the child tells his or her parents about the information you have been told, and arrange for the parents to come to meet you.

If a parent tells you about his or her own, or his or her child's, HIV infection or the parent is informed that the child has disclosed

Step 1: Reassure the parent that this information will be kept confidential.
Step 2: Explain that the school wants to support all its pupils and that there is a simple system for supporting infected and affected children.
Step 3: Explain the system and the different roles staff have in these systems. Ask consent to arrange a meeting with other appropriate members of staff, the parent and child (where appropriate). It may be that the parent requests the school nurse is involved, or additional staff. That is his or her choice.
Step 4: Organise the meeting with appropriate staff, parent and child (where appropriate). At this meeting the following issues can be discussed and agreed:

- 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 of the meetings in regards to this.

> ‘It’s like all the teachers know, and it’s like they always come up to me when I’m around my friends and say things like ‘How are you, how’s your Mum?’ And friends look at me and wonder ‘How come they ask?’ – and I don’t really like it if you know what I’m saying.’
>
> **Affected child quoted in Lewis (2001)**

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 or periods of lateness due to any side-effects of the child’s medication.

The school may feel that in the case of an infected pupil, they would like the school nurse to be involved. It may be that the pupil or parent chooses to disclose to the nurse initially, as he or she works under professional confidentiality and information-sharing protocols. Therefore, 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 moves between all those involved in meeting the child’s medical, educational and support needs.

The above roles should be discussed and agreed with the parent and child concerned. Depending on the child’s health needs, an optional health plan may be drawn up (DfEE and DH 1996). Alternatively, the school may decide that their protocols will include a ‘care plan’: one that establishes the support 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 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 school's protocols. Again, reassurance needs to be given to the parent and child that no one will have access to these records without their consent.

At the point of disclosure, it is important to reassure both parent and child that confidentiality will be upheld throughout and that no information on the individual's HIV status will be passed on without his or her consent. Families will not have taken the decision to disclose lightly and will need both acceptance and reassurance.

Information about individual or family HIV status should not normally be added to a pupil's record. Families sometimes complain that, following disclosure to one school, the information is passed to subsequent schools without consent. If the school feels that it is essential to include this information on the child's record, parents 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 it can guarantee this information remains confidential if it is included in the school records system.

Additional issues to consider

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Being infected or affected by HIV is not a child protection issue. But, as with any medical condition that either a child or a member of their family has, it may impact on the well-being of the child.

In the light of the Children Act 2004, establishing protocols for sharing information with health, social care and education professionals will become routine practice. 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 parents are involved in these decisions.

If a pupil spends time in hospital, it may be appropriate for a reintegration officer, or person in an equivalent post, to become involved. It is essential that parents are informed and involved throughout and that any health, social care or education professional that does become involved understands the need for confidentiality and abides by the established protocols to protect information.

Effective assessment and management of risk is a necessary part of school life. A school can define itself as a community that supports diversity or one that acts to limit it. Encouraging a diverse and accepting ethos and culture in school will not only benefit infected and affected children, but the whole school community.

> ‘Sometimes I miss school because Mum’s ill. And in the morning I’m late, like most mornings, because I have to make sure Mum takes her medication, because obviously if she doesn’t take it we know what will happen. So I like to make sure that she takes her medication.’
>
> **Affected child quoted in Lewis (2001)**

APPENDIX 1

Case studies

For the purpose of this guide all names have been changed to protect the identities of those involved. These case studies were provided by The African Child, Health Through Action, St. Georges Paediatric HIV Team and Positively Women. They all took place in the last two years.

Paul

Paul has been HIV positive from birth. He regularly attended school, although school staff were unaware of his HIV status. At the age of 14, Paul became very ill and was away from school for four months. The school was very supportive and ensured that Paul was regularly provided with work so that he did not fall behind too much. Due to the nature of his ill health over this time, Paul became a wheelchair user.

It took a further two months to negotiate and plan Paul's return to school because of his wheelchair use. A week before Paul was due to return to school, after all arrangements had been agreed, his education welfare officer revealed at a planning meeting with the school and without Paul or his parents' consent, that Paul was HIV positive.

The school withdrew their agreement for Paul to return, claiming this was on the grounds that they could not accommodate a wheelchair user, as it would breach their health and safety regulations. Examples they cited were that the toilets were too far from where Paul would be located and that Paul would feel isolated at school as he would not be able to have all his lessons with his peers. They also suggested that the school was geographically difficult for the family to access and that they should consider other schools.

Subsequent attempts to negotiate Paul's return to this school failed. Paul was out of full-time education for nearly two years,

and has only now returned at the age of 16 because he can attend a further education college.

This case highlights how the reaction of individuals and institutions towards HIV can be different to their reaction to other chronic illnesses. Until disclosure, the school was supportive and working towards Paul's reintegration into school life as a wheelchair user. The school's reaction not only deprived Paul of his right to education, but also his need for peer interaction, self-esteem and well-being.

Additionally, there was no reason for Paul's welfare officer to disclose information about his HIV status. The meeting was to finalise arrangements in regard to Paul's additional needs as a wheelchair user, not as an HIV-positive pupil. In such breaches of confidentiality, complaints should be made against the individual(s) involved.

Jonah

Jonah and his family came to the United Kingdom from Zimbabwe when he was nine years old. They were fleeing persecution. Jonah is one of three children, and he and his parents are HIV positive. The National Asylum Support System (NASS) placed the family in a seaside town where there were no other black African families.

Jonah started at the local school. At that time, Jonah had to take medication during the school day and so the parents met with the school nurse and asked for her support in administering this medication. The school nurse agreed.

The school nurse was talking to the school receptionist and mentioned how the new boy was HIV positive. Over the following days, the information regarding Jonah's HIV status was spread throughout the school. Jonah himself was not aware of his HIV

status and came home saying that children had started to say he had AIDS.

The parents visited the school and were told that other parents were now threatening to withdraw their children if Jonah and his HIV-negative siblings were not withdrawn from the school.

The family had started to receive abuse and discrimination outside of the school setting as they were easily identified. The family had to withdraw their children from the school and then make a request to NASS to be relocated.

Jonah's and his family's experiences highlight the absolute need for confidentiality and the impact breaking this can have on the child and family. This case is extreme, but it is not isolated. The school nurse was obviously in breach of her own medical codes of practice in regards to sharing patient information. This aside, if the school had some policy and guidance for staff in place, it may have prevented this information from reaching the entire community.

Alexia

Alexia is 13 and lives with her mother. Both Alexia and her mother are HIV positive. Alexia had a period of ill health where she missed a lot of school. Staff at the school were persistent in wanting to know why Alexia's attendance was so poor, and her mother decided that they would tell the school.

Alexia and her mother met with Alexia's form tutor and explained the reason why Alexia was often away from school. The form tutor disclosed this information in a staff meeting, and the staff team were shocked. The headteacher said that they had to seek further information, but until then nothing should be done. One teacher was adamant that all parents should be notified, as it was their right to know if their children were at risk.

The headteacher consulted with Alexia's nurse, who presented the school with information and reassured them that there was no risk to the school community. The headteacher agreed that it was inappropriate and unnecessary to notify all parents and informed the particular member of staff that if this decision was not accepted then disciplinary action would follow.

The mother was then asked to attend a meeting with Alexia and her form tutor to discuss her support and educational needs. Alexia attends school when she is well, and work is sent home for her when she is not. She does wish that the whole staff team did not know, and she and her mother still worry about what will happen if one day someone does decide to tell other members of the school community.

This case highlights how if protocols were in place, the staff member would have known exactly what action to undertake. Instead, the teacher reacted, believing this to be an issue for the staff as a whole.

It also shows why confidentiality is so crucial. Even when medical facts and research are presented, some individuals still believe that every parent needs to know if there is an HIV-positive child in their child's school. The consequences of this information being shared were demonstrated in Jonah's case.

Latisha

Latisha is 15 years old and lives with her mother. They are both HIV positive. Her father died from an AIDS-related illness when Latisha was five.

When Latisha moved to secondary school, her mother decided that she wanted to share the information about Latisha's HIV status. She met with the headteacher of the lower school, and

they agreed that at that time it was not necessary for any other staff to be informed.

During a prolonged period of ill health and additional external events, Latisha's mother feared her family's HIV status would become public knowledge. She decided that Latisha may need to be protected from bullying and that the best way to counter this was for the staff team to be informed.

Latisha's mother met with the headteacher of the lower school and they agreed that the information would be shared with the staff team and that an inset day would be arranged to ensure all staff's knowledge on HIV was up to date and to address any additional issues that arose. Latisha's nurse and a social worker from Barnardo's were invited to speak to the staff team about the medical, emotional and support needs of HIV-positive children.

Latisha's mother believes that sharing this information was both in Latisha's and the school's best interests. She feels that this has led to a better understanding of her family's situation and has meant her daughter's needs have been addressed in school. It has minimised pressures put upon Latisha to explain associated issues such as taking medications, tiredness or illness, and absences from school through illness or appointments. Both Latisha and her mother have been satisfied with the response of the school and its management of the ongoing situation.

Latisha's case demonstrates how a school and parent can work together. It shows how the calm approach taken by the headteacher of the lower school enabled the parent and school to work together. It also shows how understanding, access to information and involving medical and support experts made disclosure a positive experience for this family. Unfortunately in the present climate, cases such as Latisha's are rare.

APPENDIX 2

Further information

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

1 General

The African HIV Policy Network (AHPN): an umbrella organisation that represents African community groups addressing HIV/AIDS and sexual health throughout the UK.

AVERT: a charity providing information on HIV/AIDS, including information and quizzes for young people, and news and statistics about HIV and other sexually transmitted infections. Visit www.avert.org or write to AVERT, 4 Brighton Road, Horsham, West Sussex RH13 5BA.

Centre for HIV & Sexual Health: provides training, resources and information. Visit www.sexualhealthsheffield.co.uk or write to Centre for HIV & Sexual Health, 22 Collegiate Crescent, Sheffield S10 2BA.

Crusaid: a charity that exists to relieve poverty and illness caused by HIV. It undertakes extensive fundraising and produces campaigns and educational materials. Visit www.crusaid.org.uk.

National AIDS Trust: the United Kingdom's leading HIV and AIDS policy development and advocacy organisation. Visit www.nat.org.uk or www.worldaidsday.org, or write to NAT, New City Cloisters, 196 Old Street, London EC1V 9FR.

NHS specialists: include local and regional genito-urinary medicine (GUM) clinics, health promotion and HIV services. To contact these professionals, visit www.nhs.uk or call your local primary care trust (PCT).

Positively Women: a national charity that offers support and information for HIV positive women and their families. Visit www.positivelywomen.org.uk.

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 or write to Terrence Higgins Trust, 52–54 Grays Inn Road, London WC1X 8JU.

UK Coalition for People Living with HIV and AIDS: a charity that provides information, policy development and campaigning for and by those living with HIV and AIDS. Visit www.ukcoalition.org.

2 Children, young people and HIV

Body and Soul: a charity supporting children, teenagers, women, heterosexual men and their families who are living with, or are closely affected by, HIV and AIDS. Visit www.bodyandsoul.demon.co.uk.

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 or write to The Children and Young People HIV Network, 8 Wakley Street, London EC1V 7QE.

Children with Aids Charity (CWAC): a national charity that aims to help the youngest of those affected or infected by HIV and AIDS and work towards a future without prejudice for these children and their families. To view information and resources visit www.cwac.org.

Health Initiatives: a charity supporting young people living with HIV and AIDS and developing sexual health programmes. Visit www.healthinitiatives.org.

3 Education resources

Stand up for us: a resource that aims to help schools to challenge homophobia in the context of developing an inclusive, safer and more successful school environment for all. Visit www.wiredforhealth.gov.uk.

Teaching and Learning about HIV: A teaching resource for Key Stages 1 to 4. Blake, S and Power, P (2003). National Children's Bureau. To view in full visit www.ncb.org.uk or order copies from NCB Book Sales, 8 Wakley Street, London EC1V 7QE.

Teachernet: a DfES website for teachers and school managers, which includes resources, lesson plans and case studies. Visit www.teachernet.gov.uk.

Wired for Health: a series of websites managed by the Health Development Agency to support the National Healthy School Standard. There are sections for teachers, health professionals, and children and young people. You can also locate your local Healthy Schools coordinator on this site. Visit www.wiredforhealth.gov.uk.

4 Useful guidance

Blood-borne Viruses in the Workplace: Guidance for employers and employees. Health and Safety Executive (2003). To view visit www.hse.gov.uk or to order a copy from HSE Books visit www.hsebooks.com or telephone 01787 881165.

Code of Practice for Schools. Disability Rights Commission (2002). To view in full visit www.legislation.hmso.gov.uk.

Employers Resource Pack to Prevent HIV-related Discrimination. National AIDS Trust (2005). To view visit www.nat.org.uk or write to NAT, New City Cloisters, 196 Old Street, London EC1V 9FR.

Guidance on First Aid for Schools: A good practice guide. DfEE (1996). To view visit www.teachernet.gov.uk or to order a copy call DfES Publications (PROLOG) on 0845 6022260.

Guidance on Infection Control in Schools and Nurseries. Department of Health (1999). This is a poster that presents useful information. To view visit www.wiredforhealth.gov.uk.

Social Inclusion: Pupil support. DfES (1999). Supplementary Circular 11/99 gives statutory and administrative guidance on issues relating to social inclusion and pupil support that are primarily the responsibility of LEAs, rather than schools. To view visit www.dfes.gov.uk.

Supporting Pupils with Medical Needs: A good practice guide. DfEE/DoH (1996). To view in full visit www.teachernet.gov.uk or to order a copy call DfES Publications (PROLOG) on 0845 6022260.

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