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# **HIV in Schools: a summary of the good practice guide to supporting children living with and affected by HIV**

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

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

## **A child living with HIV in a school:**

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

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

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

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

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## Key Facts:

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

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

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

## Stigma

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

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

## What schools have to do (the law)

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

**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)

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

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

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

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

## What schools want to do

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

## What schools should do when an HIV disclosure is made

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

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



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



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



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

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

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

### Checklist for developing an HIV Friendly School

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

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

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

For the full guidance on supporting the needs of children living with and affected by HIV in UK schools, please visit [www.chiva.org.uk/our-work/schools](http://www.chiva.org.uk/our-work/schools). For additional support contact either your local paediatric HIV team or the Children's HIV Association.