

Young carers affected by HIV

It should not be assumed that all children in families living with HIV are young carers. Problems can arise when the level of responsibility for care taken on by a young person becomes inappropriate, impacting on their own education, health and well-being:

- The number of children affected by HIV (those living in families where one or more members is living with HIV) in the UK is unknown, however it is estimated to be over **25,000**.¹
- In 2015 there were an estimated **101,200** people living with HIV in the UK, **69%** were men and **31%** were women.²
- People living with HIV in the UK represent a diverse group. Although rates remain highest among homosexual and bisexual men, and men who have sex with men, over half (**52%**) of all people diagnosed in 2015 were born in the UK.³
- HIV presents additional complications as many people may not want to disclose their HIV status to their children, even if their children are taking on significant caring roles.
- For those children that are aware of their parent's HIV status the associated stigma can lead to a high level of discomfort when disclosed to another support service, such as a young carers service. This should be a supported process that is done at an appropriate time for the whole family, and in a secure way.
- Young carers may be dealing with a high level of healthcare appointments as well as reminding relatives to take anti-retroviral medications.

Recommendations for practitioners:

Young people caring for a relative living with HIV have suggested the following good practice recommendations for supporting them:

- Remember that although your service user may be an adult they may have children, and HIV can impact on all family members. Think family.
- Find out if there is a local Young Carers Service in the area to seek advice and guidance and potentially refer the young person for support. Find your local young carers service: childrenssociety.org.uk/sites/default/files/whole-family-pathway-2018.pdf
- Find out if support is offered in schools and provide accessible information about young carers and about potential impacts of living with HIV. Advise your local schools about the Young Carers in Schools

A 'young carer' is defined in section 96 of the Children and Families Act 2014 as: '...a person under 18 who provides or intends to provide care for another person'.

This relates to care for any family member who is physically or mentally ill, frail elderly, disabled or misuses alcohol or substances.

The **key principle** is that: 'Children should not undertake inappropriate or excessive caring roles that may have an impact on their development. A young carer becomes vulnerable when their caring role risks impacting upon their emotional or physical well-being and their prospects in education and life.'

The **Children and Families Act 2014** amended the Children Act to make it easier for young carers to get an assessment of their needs and to introduce 'whole family' approaches to assessment and support. Local authorities must offer an assessment where it appears that a child is involved in providing care.

Children Act 1989: Section 17ZA 1(a) [inserted by section 96 Children and Families Act 2014] If any child or young person is identified as carrying out a caring role, this should result in an offer of a needs assessment for the adult requiring care and support, and the local authority must consider whether to undertake a young carer's needs assessment under the Children Act 1989. Refer to our 'Supporting Young Carers and their families' introductory booklet for more information.

HIV is a blood-borne virus that attacks the immune system, and weakens your ability to fight infections and disease.

¹ CHIVA (2015) Data on HIV affected children living in the UK, CHIVA, Bristol.

² Public Health (2016) HIV in the UK 2016 report

³ Public Health (2016) HIV in the UK 2016 report

Programme: youngcarersinschools.com

- Refer colleagues, including external support services, to the Whole Family Pathway for young carers at youngcarer.com. This tool will support services to create a 'no wrong door' approach to young carers to improve identification, referral and support.
- Train staff to identify young carers and raise awareness amongst all the staff in your service. Training and resources are available from The Children's Society at youngcarer.com
- Promote liaison and collaboration between HIV professionals, young carers workers and other service professionals in a position to support young carers.

HIV support services are likely to be the first people a family affected by HIV turn to for help. Whether you work in the statutory or voluntary sector, with adults or children, you may be the only person who is able to ask the right questions to find out if a child is taking on caring responsibilities. Timely intervention could prevent a child undertaking inappropriate levels of care and could offer much valued support for children in their caring roles.

HIV presents very specific needs concerning confidentiality and acknowledgement of (and sensitivity to) the real and perceived stigma faced by people living with HIV. Many families living with HIV fear breaches in confidentiality, and may be reluctant to access support for young carers because of this.

Good joint-working relationships between the HIV organisation and young carers services could offer the additional support the parent/relative feels their child needs to support disclosure. This should include established referral pathways and agreed information sharing procedures that support a family's need for confidentiality.

The Children's Society toolkit 'Supporting Families affected by HIV' provides information, resources and good practice guidance about supporting young carers affected by HIV. The toolkit also includes specialist information for a range of services, information about identification, stigma and disclosure.

childrenssociety.org.uk/youngcarer/families-affected-by-hiv

Specific support can also be provided within schools, such as:

- Providing young carers with access to appropriate information through the school-wide information sharing programme **HIV in Schools**: A good practice guide to supporting children living with and affected by HIV. chiva.org.uk/files/9114/4976/8872/HIV_in_Schools.pdf
- Schools can implement the **Young Carers in Schools** programme to make sure young carers are identified without a direct referral from a HIV service. youngcarersinschools.com
- Having access to young carers' support, such as drop-in services and peer mentoring, without having to disclose the nature of the caring role. See Step 6 (Young Carers in Schools) professionals.carers.org/step-by-step-guide-identify-assess-and-support-young-carers-schools

Support

The Children's Society Include Programmes introductory guide for professionals on supporting young carers and their families sets out key legislation and best practice guidance. Further resources are available from the Include Programme website youngcarer.com

HIV Aware: Run by the National AIDS Trust (NAT) to raise awareness, provide resources and information about HIV and to campaign for change. hivaware.org.uk

Terence Higgins Trust is the leading and largest HIV and sexual health charity in the UK. **Understanding HIV and AIDS** is a basic introductory guide to the subject and provides clear information in an easy-to-understand and accessible style. ttht.org.uk

Children's HIV Association (CHIVA) is a network for health care providers of children and young people living with HIV. CHIVA also works directly with young people living with HIV. chiva.org.uk

The Children and Young People HIV Network, led by NCB, is a national network for organisations and professionals concerned with children and young people who are living with or are affected by HIV, from conception to adulthood. ncb.org.uk/children-and-young-people-hiv-network

The Whole Family Pathway is a tool for all adults' and children's services, education, health and other agencies who have contact with young carers and their families. This resource will support practitioners to implement changes in legislation for young carers and their families, including effective responses to the needs of young carers and their families. childrenssociety.org.uk/sites/default/files/whole-family-pathway-2018.pdf