

# Include Project

Information for  
HIV professionals



The  
Children's  
Society



supporting young carers  
in families with HIV

The Children's Society works through local and national partnerships to change children's lives for the better.

The Children's Society is an expert service provider that delivers outcomes to meet your priorities for families, children and young people in your area.

Close partnership working with our funders, added together with our local knowledge and expertise, we provide innovative solutions, which deliver outcomes that maximise the impact of your available funding.

We are passionate about our work. We work with you in a transparent and flexible way. We are fully committed to meeting agreed outcomes every time.

We have worked alongside service commissioners in local authorities and the wider public sector for over 125 years. We currently provide services to over 60 local authorities across the UK.

We have experience in a comprehensive range of services that are tailored to meet individual needs. Our work spans from prevention through to intensive targeted support services.

The Children's Society's Include Project offers information, training and support to both statutory and voluntary sectors who work with young carers and their families. More information and a range of information materials, resources including a Good Practice Guide for Practitioners are available at [www.youngcarer.com](http://www.youngcarer.com)

For a trusted service provider that will achieve your outcomes, provide value for money and deliver local solutions contact us on 0845 612 9402 or visit [www.childrenssociety.org.uk/services](http://www.childrenssociety.org.uk/services)

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# Who are young carers?

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**“Young carers are children and young persons under 18 who provide, or intend to provide, care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility, which would normally be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision”**

**(Becker 2000)**

While most children and young people help parents to some degree, some may be taking on caring responsibilities that are inappropriate for a child and that have a negative impact on their own well being.

The 2001 census found 175,000 young carers in the UK many of which will have significant unmet needs. This number is an underestimate, as it is unlikely to include those caring for parents with HIV, those with an alcohol or drug dependency and other stigmatised illnesses or impairments.

The number of HIV affected children (those living in families where one or more members is HIV infected) in the UK is unknown but has been estimated as between 15,000 to 20,000 (Conway 2006).

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## How can you help?

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HIV support services are likely to be the first people that 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.

*“We wouldn’t want to give up caring because we love them too much. If we gave up caring we would have to change our whole way of life, but we would like help and people to take notice of us.”*

**(Young carer)**

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# What tasks might young carers be carrying out?

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Some examples of the tasks young people caring for family members with HIV undertake are:

- **Household chores** – including cooking, cleaning and shopping, doing laundry, on behalf of the family.
- **Healthcare support** – such as responding to emergencies, accompanying the family member to hospital and to GP appointments, assisting with mobility and medication, including reminding family members to take their anti-retroviral medication at the right time.
- **Personal care** – washing, dressing, assisting with toilet requirements and encouraging and assisting to eat.
- **Emotional support** – listening, reassuring and ‘being there’ for the family member with HIV.
- **Childcare** – helping to care for younger siblings, including taking them to school and supervising them.
- **Other** – assisting with household administration, such as reminding parents about bills and appointments, acting as a translator for those whose first language is not English.

(Evans and Becker, 2009; Dearden and Becker, 2004)

*“I quite often go in with my mother when she goes to the doctor, but they still don’t recognise the fact that I’m a young carer and still don’t pay attention or give time to that matter.”*

(Young carer)

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# Why do young people take on caring responsibilities?

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There are many reasons why young people take on caring responsibilities. It may be because of:

- The structure of the family itself and lack of availability of other adults living in the household.
- The nature of the illness or disability and the person's requirements for care.
- A lack of effective support from outside the family. People living with HIV may not meet eligibility criteria or the services are not flexible and responsive to changing support needs.
- Stigma surrounding particular illnesses or disabilities, such as HIV and fear of seeking external support.
- Fear or mistrust of mainstream services because of a family's insecure immigration status.

Some families may not know about the services or support available to them. Some families may be reluctant to involve agencies in their family situation or be fearful of acknowledging their children's caring roles.

*“[Young carers affected by HIV] need to be helped like with everything, like to provide for their parents. And they need to form like a youth club or something with people who care for people, so people can see there's not only themselves that do that.”*

**(Young carer)**

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# What impact does this have on a young carer's life?

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Inappropriate levels of caring can impact on a child's own emotional and physical wellbeing as well as their educational achievement and life chances.

The following are examples of the effects on children and young people from providing inappropriate care:

- Problems concentrating at school due to tiredness or worry about a family member's illness, limited time to do homework, impacts on educational attainment and qualifications.
- Restricted time for play, sport or leisure activities with their peers.
- Worry and fears about their parent's illness.
- Conflict between the needs of the person they are helping and their own needs leading to feelings of guilt and resentment.

*“It's not just the caring that affects you.... What really gets you is the worry of it all. Having a parent who is ill and seeing them in such a state.”*

**(Young carer)**

- Feeling that there is nobody there for them, that professionals do not listen to them and are working only with the adult.
- Lack of recognition, praise or respect for their contribution.
- Feeling that they are different from other children and are unable to invite them to their home.
- Feeling that no one else understands their experience.
- Problems moving into adulthood, especially with finding work, their own home and establishing relationships.
- Some young carers experience being stigmatised or bullied by their peers. Some may have behavioural difficulties.

However there are also some positive outcomes for young carers who are well supported. For example, their caring role can lead to increased maturity, sense of responsibility and independence, can enable them to develop valuable life and social skills and can result in closer, supportive relationships within the family.

*“We wouldn’t want to give up caring because we love them too much. If we gave up caring we would have to change our whole way of life, but we would like help and people to take notice of us.”*

**(Young carer)**

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## Identifying young carers

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It should not be assumed that all children who are living with someone who is infected with HIV are automatically young carers. Problems arise when the level of responsibility taken on by the young person is inappropriate for their age and maturity and impacts upon their own well-being.

There is also a need to be aware of secondary health problems that may result in children taking on inappropriate caring responsibilities. This could be a physical impairment, a period of ill health or the impact HIV may have on a person's mental health.

Many children and young people affected by HIV may not be aware that their parent/relative or sibling is HIV positive, although they may still have significant caring responsibilities and worry about their parent/relative's illness. Young people's lack of knowledge about the nature of their parent/relative's illness should not lead to a lack of support, as services should be provided to support families with the impacts of secondary health problems and young people's caring role within the family.

Multi agency working is an extremely effective way to support children and families with additional needs.

*“I would like them (agencies) to learn more from talking to our family.”*

**(Young carer)**

More information about the extent of the impact of HIV upon the whole family may be gained by asking the following questions:

1. Who helps to care for the person at home?
2. What are the requirements for care of the person with HIV and how do these affect different family members?
3. Is there a child/young person in the family who helps to provide care?
4. How does this affect the child/young person in terms of their physical and emotional wellbeing, their education, their opportunities to socialise with their peers?
5. Is there any practical, emotional or peer support that would help to support the young person in their caring role?
6. Does the parent require support in their parenting role, in addition to any support they may require as a person living with HIV?
7. What can be offered to help the whole family?

*“It would be nice to get like regular checkups... just seeing how you’re coping and things like that. Because it can get quite hard and you just don’t know who to speak to or anything.”*

**(Young carer)**

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# How can you offer support once you have identified a need?

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**“Young carers and their families are the experts in their own lives and as such must be fully involved in the development and delivery of support services.”**

**(Frank *et al* 2008)**

When assessing the support required by a young carer it is important to take into account the needs of the whole family and how these needs impact on each other. The *Whole Family Pathway* (Leadbitter 2008) is a web based resource signposting practitioners to support for young carers and their families. Following the pathway helps to explain the assessments and support available for young carers.

HIV presents very specific needs concerning confidentiality and acknowledgement of, and sensitivity to, the real and perceived stigma HIV positive people face.

Many families living with HIV fear breaches in confidentiality, and may be reluctant to access support for young carers because of this. Young carers are entitled to assessments and support in recognition of their caring role and there may be a local Young Carer’s Project working in your area that can provide confidential support. Building strong working links with local young carers projects to establish a referral process and agree information sharing is the way forward. This partnership could also offer the opportunity for an exchange of training and sharing expertise.

Specific support for young carers may also be available within schools and young carers workers are able to provide individual support and opportunities for peer support with other young carers without disclosing the

nature of the parent's/family member's illness to school teachers. However, a direct referral from a HIV service to a school may present difficulties as this could lead to disclosure of information that the parent may not want to tell the school. If there is no young carers service in your area, it may be worth making enquires in your local Children's Services Department to talk through this issue and potential concerns regarding information sharing and confidentiality.

To find out more about referrals to other services including your local Young Carers Project see the *Whole Family Pathway* at [www.youngcarer.com](http://www.youngcarer.com).

You may wish to consider:

- Offering an initial assessment to the young carer following the Common Assessment Framework guidance.
- Referring the family member who has care needs for an assessment under the NHS and Community Care Act 1990. All young carers are entitled to a Carers Assessment under the 1995 Carer's (Recognition and Services) Act, when the person they are looking after is being assessed under NHS and Community Care Act 1990, S47
- Carers aged over 16 are also entitled to a Carers Assessment from Children's Services under the 2000 Carers and Disabled Children Act.
- Parents may value support to enable them to carry out their parenting role. Direct payments can be used for this purpose.

**If the young person's health or development is impaired or the young person is suffering or may suffer significant harm they should be identified as a child in need and referred to Children's Services for an assessment using the 1989 Children Act using the Framework for Assessment of Children in Need and their Families.**

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## Families with insecure immigration status

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Families with insecure immigration status are particularly vulnerable to social exclusion and isolation. They may be very worried about seeking support or services from outside the family due to a fear of deportation. All services should be integrated, inclusive and responsive to the needs of all families including those from a refugee and asylum seeking background. Specialist information and resources to support these families is available from a range of voluntary and statutory services. See [www.harpweb.org.uk](http://www.harpweb.org.uk) and [www.refugeecouncil.org.uk](http://www.refugeecouncil.org.uk).

It can be distressing for children to be asked to interpret inappropriate information for family members. Service providers must ensure that any need for professional interpreters is properly addressed (Department of Health, 1999). Families are entitled to interpreting services and multilingual appointment cards are available at [www.communicate-health.org.uk/card](http://www.communicate-health.org.uk/card) which can help to prevent children and young people taking on inappropriate translation roles for a family member with HIV.

*“It’s left to you to translate, interpret and figure out how the system works.”*

**(Young carer with refugee status)**

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## Providing information

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Many young carers have explained that although they may have significant, regular caring responsibilities, they are given minimal information about the health issues or disability affecting their parent/other family member. HIV presents additional complications as many parents/relatives feel they do not want to share the information about their HIV status with their children. Supporting parents/relatives towards disclosure will take time, but providing the young carer with comprehensive information about any secondary illnesses is a start. Again, good joint working relationships between the HIV organisation and the young carers service could offer the additional support the parent/relative feels their child needs to support disclosure. Recent research suggests that parental disclosure of HIV to their children helps children to understand why they are being asked to care for their parent/family member and often leads to more supportive caring relationships within families (Evans and Becker, 2009). Children may also provide more emotional support to their parent following parental disclosure.

*“I know they support children who have HIV and other things, but we also need support to get to know how to help the people who are ill who have that kind of disease.”*

**(Young carer with refugee status)**

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## Disclosure and confidentiality

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For those young people who are aware of their parents HIV status, feeling comfortable about when to disclose will differ between families, and should be agreed between the parent and the young person. They will know when they feel that discussing the HIV status is okay and when not to mention it. Consider the issue of disclosure when planning a referral to a young carers service and agree this with the young person in order to give them a level of control and security when accessing the service.

*“Remember young carers say they wish to be listened to, understood and believed. They also wish to be valued, consulted, respected.”*

**(Frank 2002)**

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## Action points

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- Remember that although your service user may be an adult, they may have children and HIV can impact on all family members.
- Find out if there is a local Young Carers Project or if support is offered in schools and provide accessible information about young carers and about potential sources of support for your staff and for parents/relatives living with HIV.
- Find a way of enabling your service to identify if a young person helps to care for the family member with HIV.
- Refer colleagues, including external support services, to the *Key Principles of Practice* and *Whole Family Pathway* for young carers: [www.youngcarer.com](http://www.youngcarer.com)
- Use the Whole Family Pathway to improve identification, referral and support of young carers.
- 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.)
- Promote liaison and collaboration between HIV professionals, young carers workers and other service professionals in a position to support young carers.
- Consider adding the young person's caring role to medical or other records about the person with HIV or family.
- Keep a list of useful websites/leaflets that contain age appropriate information about disability and illness.
- Remember that the needs of different family members change and therefore so can the extent and outcomes of young people's caring responsibilities.

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# Assessments

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The Framework for Assessment of Children in Need and their Families 2000

The Children Act 2004

The Common Assessment Framework 2005.

[www.everychildmatters.gov.uk/deliveringservices/caf/](http://www.everychildmatters.gov.uk/deliveringservices/caf/)

NHS and Community Care Act 1990, S47

Mental Health Act 1983

National Service Framework for Mental Health 1999

Fair Access to Care practice Guidance (DH 2002)

Disabled Persons (Services and Consultation and Representation) Act 1986, S8

Direct Payments Guidance 2003

[www.direct.gov.uk](http://www.direct.gov.uk)

Carers (Recognition and Services) Act 1995, S1

Carers and Disabled Children Act 2000

The Carers (Equal Opportunities) Act 2004

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## Resources and further information

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### The Children's Society

**[www.youngcarer.com](http://www.youngcarer.com)**

The Children's Society National Young Carers Initiative provides a national focus for people who work to support young carers and their families across England and have developed good practice information and resources for young carers, their families and those who work to support them including the *Key Principles of Practice* and *Whole Family Pathway*.

### The Princess Royal Trust for Carers

**[www.youngcarers.net](http://www.youngcarers.net)**

Offers useful information and support for all unpaid carers throughout the UK and has a website especially for young carers.

### NCB Children and Young People HIV Network

**[www.ncb.org.uk/](http://www.ncb.org.uk/)**

The Children and Young People HIV Network is a national network that brings together a wide range of organisations concerned with children and young people infected with and affected by HIV/AIDS

## Other useful websites

### **[www.tht.org.uk](http://www.tht.org.uk)**

Terrence Higgins Trust is the leading and largest HIV and sexual health charity in the UK.

### **[www.childrenfirst.nhs.uk](http://www.childrenfirst.nhs.uk)**

Age appropriate information on disease and illness which could be useful for secondary illness information.

### **[www.youngminds.org.uk](http://www.youngminds.org.uk)**

A national charity committed to improving the mental health of all children and young people.

Tel 0207 336 8445

### **[www.sibs.org.uk](http://www.sibs.org.uk)**

Information for children growing up with a sibling who has special needs a disability or chronic illness.

### **[www.DisabledParentsNetwork.org.uk](http://www.DisabledParentsNetwork.org.uk)**

A national organisation for disabled people who are parents.

### **[www.nacoa.org.uk](http://www.nacoa.org.uk)**

Information for children of alcoholics.

**[www.adfam.org.uk](http://www.adfam.org.uk)**

A national organisation working with families affected by drugs and alcohol.

**[www.parentsusingdrugs.org.uk](http://www.parentsusingdrugs.org.uk)**

Stars National Initiative, The Children's Society.  
Information for children with family members using drugs.

**[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)**

Provides health information in other languages

**[www.harpweb.org.uk](http://www.harpweb.org.uk)**

Online health information for health professionals and voluntary agencies working with minority communities.

**[www.communicate-health.org.uk/card](http://www.communicate-health.org.uk/card)**

Online multilingual and multicultural health resources.

**[www.refugeecouncil.org.uk](http://www.refugeecouncil.org.uk)**

Information and advice for individuals and organisations supporting refugees and asylum seekers.

*Please note these organisations and resources are listed for your information. The Children's Society does not necessarily endorse them.*

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# References

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Becker S (2000) 'Young Carers' in Davis M (ed). *The Blackwell Encyclopaedia of Social Work*. Blackwell Publishers Ltd, p 378

Conway M (2006) *Children, HIV, Asylum and Immigration: An overview of the current situation for children living with HIV and insecure immigration status*. NCB. Available from [www.ncb.org.uk](http://www.ncb.org.uk)

Dearden, C. and Becker, S. (2004) *Young Carers in the UK: The 2004 Report*, London: Carers UK

Evans, R. and Becker, S. (2009) *Children caring for parents with HIV and AIDS: Global Issues and Policy Responses*, The Policy Press: Bristol. [www.policypress.org.uk](http://www.policypress.org.uk)

Evans, R and Becker, S (2007) *Hidden Young Carers: The Experiences, Needs and Resilience of Children Caring for Parents and Relatives with HIV/AIDS in Tanzania and the UK: Stakeholder Report*, School of Sociology and Social Policy, University of Nottingham. Available from: [www.reading.ac.uk/nmsruntime/saveasdialog.asp?IID=14616&SID=63941](http://www.reading.ac.uk/nmsruntime/saveasdialog.asp?IID=14616&SID=63941)

Frank J (2002) *Making it Work. Good practice with young carers and their families*. The Children's Society with The Princess Royal Trust for Carers

Frank J and McLarnon J (2008) *Young Carers, Parents and their Families: Key Principles of Practice*. The Children's Society

Leadbitter H (2008) *Whole Family Pathway. A resource for practitioners*. The Children's Society. Available at <http://www.youngcarer.com>

# Key Principles of Practice for young carers and their families

- Children's welfare should be promoted and safeguarded by working towards the prevention of any child undertaking inappropriate levels of care and responsibility for any family member.
- The key to change is the development of a whole family approach and for all agencies to work together, including children's and adults' services, to offer co-ordinated assessments and services to the child and the whole family.
- Young carers and their families are the experts on their own lives and as such must be fully informed and involved in the development and delivery of support services.
- Young carers will have the same access to education and career choices as their peers.
- It is essential to continue to raise awareness of young carers and to support and influence change effectively. Work with young carers and their families must be monitored and evaluated regularly.
- Local young carers projects or other targeted services should be available to provide safe, quality support to those children who continue to be affected by any caring role within their family.

Taken from *Young carers, parents and their families: key principles of practice*, available from the Include Project.



The Children's Society's Include Project supports children and young people who care for parents or siblings who suffer from chronic illness or disability. We campaign for change and promote best practice with central and local government and work in partnership with social workers, teachers and health care professionals to deliver solutions that consider the needs of the whole family.

The Children's Society's Include Project offers information, training and support to both statutory and voluntary sectors who work with young carers and their families. More information and a range of resources, including a Good Practice Guide for Practitioners are available at [www.youngcarer.com](http://www.youngcarer.com)

## How to contact us

The Children's Society  
Include Project  
Unit 4, Calford House,  
Wessex Way,  
Wessex Business Park,  
SO21 1WP

Email: [include-project@childrenssociety.org.uk](mailto:include-project@childrenssociety.org.uk)

Telephone: 01962 711511

Fax: 01962 711512

This information is available in other formats.

